Hand in Hand:
A Training Series for Nursing Homes
Orientation Guide
This page intentionally left blank.
Overview of Hand in Hand: A Training Series for Nursing Homes

Background

Section 6121 of the Affordable Care Act of 2010 requires Centers for Medicare & Medicaid Services (CMS) to ensure that nurse aides receive regular training on caring for residents with dementia and on abuse prevention. CMS, supported by a team of training developers and subject matters experts, created this training to address the need for nurse aides’ annual in-service training on these important topics.

Mission

The mission of the Hand in Hand training is to provide nursing homes with a high-quality training program that emphasizes person-centered care for persons with dementia and abuse prevention.
Introduction to Hand in Hand Training

Before using the Hand in Hand training, watch “Hand in Hand: A Training Series for Nursing Homes, An Introduction for Facilitators and Administrators” to get a better understanding of the purpose of the training and the many ways it can benefit your nursing home and the residents in your care.

This introduction contains three short segments:

- A welcome from Karen Tritz, Director, CMS, Division of Nursing Homes.
- Person-centered approach to care of persons with dementia by Dr. Allen Power, geriatrician.
- Hand in Hand in action, a video showing some elements of the training being delivered.

Training Description

The Hand in Hand training materials consist of this orientation guide and five one-hour video-based modules with an accompanying instructor guide. The modules are:

- Module 1: Understanding the World of Dementia: The Person and the Disease
- Module 2: Being with a Person with Dementia: Listening and Speaking
The modules, and the lessons within each module, are designed to be presented in order from Module 1 through Module 5. Module 1 is designed to establish a foundation in providing person-centered care for persons with dementia. Modules 2 through 5 build upon that foundation. We strongly suggest that you follow the recommended sequence of the modules and lessons.
About the Videos

The Hand in Hand training allows participants to watch and discuss scenarios that depict realistic interactions with persons with dementia and situations where abuse has or might have occurred. The video clips are designed to be the focal point of the training; they are impactful and memorable. Thought-provoking questions provided in the instructor guide and on the discussion screens that follow the video clips help participants to understand the learning points and to apply them to their own work experience.

It is important to effective facilitation and to participants’ positive training experience that you note the following points about the video clips in this training:

- Most of the clips focus on a particular learning point to meet the module objectives. Many other issues or concerns will likely come to mind as you watch a clip, but it is important to keep the discussion focused on the intended learning point.

- Several clips are used more than once, but the discussions that follow these clips highlight different learning points. Participants are asked to look at the clip with a different learning point in mind.

- Some of the clips, especially those in Module 5: Preventing and Responding to Abuse, portray graphic abuse situations
and may be disturbing to some participants. Please be sensitive to this fact and inform participants ahead of time.

If you or the participants would like to watch a clip, or if you would like to show a single clip during a staff meeting or in a 10-minute training, you can easily access all the clips in each module from the last screen in the module.

**Learning Objectives and Key Points**

The learning objectives and key points in each module are outlined below.

**Module 1: Understanding the World of Dementia: The Person and the Disease**

This module is a foundational overview of dementia. By the end of this module, participants will be able to:

- Define dementia.
- Identify the symptoms of dementia.
- Identify irreversible types of dementia.
- Identify conditions that may present with dementia-like symptoms.
- Recognize that dementia affects people differently.
- Develop empathy for persons with dementia by better understanding their condition.
- Understand that we must meet persons with dementia in their world.
Some key points in this module are:

- Dementia is not a specific disease. It is a term that describes a group of symptoms related to loss of memory, judgment, language, complex motor skills, and other intellectual function, caused by the permanent damage or death of the brain’s nerve cells, or neurons.

- Symptoms of dementia include challenges with memory, concentration, orientation, language, judgment, visuospatial skills, and sequencing. The actions and reactions of persons with dementia are related to one or more of these challenges.

- There are several irreversible causes of dementia, including Alzheimer’s disease, mixed dementia, Parkinson’s disease, Dementia with Lewy body, vascular dementia, frontotemporal dementia, and others. The most common irreversible cause of dementia is Alzheimer’s disease.

- Other conditions can also cause dementia or dementia-like symptoms (including, e.g., reactions to medications, metabolic problems and endocrine abnormalities, nutritional deficiencies, and heart and lung problems). If these conditions are treated, the dementia symptoms may decrease or go away. Persons with dementia who have these conditions might also have changes or increases in their dementia symptoms.

- Many residents have common conditions that cause discomfort and can make dementia symptoms worse, including constipation, acute or chronic pain, lack of sleep, and others.

- Delirium caused by a new or worsening medical problem may cause increased confusion or problems with thinking and
functioning, especially in residents with dementia. It is very important to notify the nurses so that they can assess the resident further.

- Changes in the brains of persons with dementia cause them to experience the world differently. We must try to understand their experience by being with them in their world. Seeing things from their perspective helps us to understand the frustrations and confusion they experience. It also helps us to recognize that we must adjust the way we act, and interact, to meet their needs.

**Module 2: Being with a Person with Dementia: Listening and Speaking**

This module is about communicating with persons with dementia. By the end of this module, participants will be able to:

- Explain why persons with dementia have unique communication needs.
- Identify strategies for communicating with persons with dementia.
- Recognize the impact of their interactions with persons with dementia.
- Understand how to look for meaning in the verbal and non-verbal communication of persons with dementia.
Key points in this module include:

- Being with persons with dementia means understanding their world by trying to see it from their perspective—by being with them where they are.

- Communication involves sending and receiving information—listening and speaking. Persons with dementia have challenges in both areas, so we must learn to look for the meaning in their verbal and non-verbal communication.

- The brain changes that cause dementia symptoms, including challenges with memory, concentration, orientation, language, judgment, visuospatial skills, and sequencing impact a person with dementia’s ability to communicate. Persons with dementia want and need to express themselves and connect with others, and they communicate this in different ways.

- Effective strategies for communicating with persons with dementia include:
  - Always identify yourself.
  - Call the person by his or her preferred name.
  - Be at his or her eye level.
  - Make eye contact.
  - Sit down with him or her, if possible.
  - Really listen to the person.
  - Pay attention to your body language.
  - Use visual and verbal cues.
• Pay attention to the body language of the person with dementia.

• Speak slowly.

• Speak in short, simple sentences.

• Be patient.

• Give the person enough time.

• Be specific.

• Ask one question at a time.

• Give one direction at a time.

• Repeat questions or instructions.

• Ask how you can help.

• Tell the person what you are doing.

• Reassure with words and touch.

• Look for the feelings behind the words or actions.

• Connect through laughing.

• Avoid using no, don’t, and other negative words.

• Don’t argue with a person with dementia.

• Just as staff experience frustration trying to understand what persons with dementia are communicating, persons with
dementia experience frustration with their communication challenges.

- Communicating with persons with dementia encompasses more than words. It involves understanding the meaning and feelings behind what they are saying, so that we can respond to their emotions and meet their needs.

- When we take the time to communicate effectively, we save time and reduce stress in our work environment.

**Module 3: Being with a Person with Dementia: Actions and Reactions**

This module is about understanding the actions and reactions of persons with dementia as forms of communication. By the end of this module, participants will be able to:

- Understand behaviors of a person with dementia as actions and reactions that are forms of communication.

- Evaluate possible reasons behind the actions and reactions of a person with dementia.

- Identify ways to prepare for, prevent, or respond to actions and reactions of a person with dementia.

Key points in this module are:

- Being with a person with dementia means understanding his or her world by trying to see it from his or her perspective—by being with the person where he or she is.
• When we think about behaviors of persons with dementia, we may often think of them as negative, bad, or challenging. When we reframe behaviors as actions and reactions, it helps us understand that behaviors are a form of communication. It forces us to dig deeper to understand why the person is expressing distress.

• There are many reasons why persons with dementia might express or indicate distress. These reasons might be related to health conditions, medications, communication, the environment, the task itself, unmet needs, a resident’s life story, and your interactions with that person.

• When we understand the meaning of the actions and reactions of persons with dementia, we are better able to respond to them and meet their needs.

• Each person with dementia is an individual. Being with a person means seeing things from his or her unique perspective and responding to that person as an individual.

• To identify ways to respond to a person with dementia, ask yourself the “three Ps”: (1) How can I prepare?; (2) How can I prevent?; and (3) How can I be present? Preparing includes understanding and anticipating actions or reactions of persons with dementia and thinking about how you or someone else should respond. Some actions and reactions of persons with dementia might be prevented, relieved, and accommodated by redirecting, using a different approach, or identifying triggers. Being present means responding to a person’s actions and reactions as they are happening.

• Sometimes the best response to persons with dementia is to be with them, reassure them, and let them know you are there for them.

• There is no one-size-fits-all way to respond to persons with dementia. Different persons have different reasons for their actions and require different responses. Sometimes responses work one day, but not the next. Some responses work well for one caregiver, but not another.

• The actions of some persons with dementia might result in their being medicated when it is not clinically indicated. When we understand the reasons behind the actions of persons with dementia, we can step into their world and identify a way to respond that both meets their needs and avoids unnecessary medication.
• All behavior has meaning. It is up to us to understand the meaning so that we know how to respond to and support persons with dementia.

Module 4: Being with a Person with Dementia: Making a Difference

This module is about being with persons with dementia where they are in their experience of dementia. It is about the difference you make in their lives every day. By the end of this module, participants will be able to:

• Explain what it means to meet persons with dementia where they are.
• Recognize the importance of focusing on the strengths and abilities of persons with dementia.
• Identify ways to connect with persons with dementia where they are.
• Recognize their role in making a difference in the lives of persons with dementia.
Key points in this module are:

- Meeting persons with dementia where they are means understanding and accepting their reality, knowing who they are as individuals, knowing where they are in their dementia, and recognizing and honoring their strengths. Dementia symptoms tend to worsen with time, and over time persons with dementia will be in “different places” and have different needs.

- Meeting persons with dementia where they are requires good communication. We must pay attention not only to the words persons with dementia tell us, but also to their non-verbal communication and behavior.

- Persons with dementia are whole individuals who have strengths and abilities, as well as weaknesses and incapacities. Recognizing their strengths helps us to see persons with dementia beyond their diagnosis—not as problems to be solved or as tasks that need to be accomplished, but as individuals with human needs that we can help meet.

- Persons with dementia are “still there” and every interaction with a person with dementia is an opportunity to connect with him or her. Every human being, including persons with dementia, has basic needs for comfort, attachment, inclusion, occupation, and identity. Even when helping a person with dementia with everyday tasks such as bathing, eating, or dressing, we can find ways to connect and fulfill their emotional needs.¹

- As a person’s dementia progresses, he or she might have difficulty communicating with words. We can continue to connect wherever they are in their progression, through the five senses of touch, sound, smell, sight, and taste.

- Each person who lives and works in a nursing home makes a difference in the lives of everyone around him or her, staff as well as residents. You have the opportunity to improve someone’s quality of life with even a small act of kindness.

---

Module 5: Preventing and Responding to Abuse

This module is about preventing and responding to abuse of nursing home residents. By the end of this module, participants will be able to:

- Understand CMS’s definition of abuse.
- Identify types and signs of abuse.
- Evaluate how a series of actions and reactions might lead to abuse.
- Recognize how abuse might be prevented.
- Respond to abuse if they see it happening.
- Report abuse and suspicion of crime.
Key points in this module include:

- It is a violation of State and Federal laws to neglect or abuse a resident.

- Federal regulations define “abuse” as the willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain, or mental anguish. Abuse also includes the deprivation by an individual, including a caretaker, of goods or services that are necessary to attain or maintain physical, mental, and psychosocial well-being. Instances of abuse of all residents, irrespective of any mental or physical condition, cause physical harm, pain, or mental anguish. It includes verbal abuse, sexual abuse, physical abuse, and mental abuse including abuse facilitated or enabled through the use of technology.

- Types of abuse include verbal, mental, physical, sexual, and the deprivation of goods or services.

- Other areas related to abuse include neglect, involuntary seclusion, misappropriation of resident property, and exploitation.

- Important definitions related to abuse include:
  - Mental abuse is the use of verbal or non-verbal conduct that causes or has the potential to cause the resident to experience humiliation, intimidation, fear, shame, agitation, or degradation.
  - Verbal abuse includes the use of oral, written, or gestured communication, or sounds, to residents within hearing distance, regardless of age, ability to comprehend, or disability.
  - Physical abuse includes, but is not limited to, hitting, slapping, punching, biting, and corporal punishment.
  - Sexual abuse is non-consensual sexual contact of any type with a resident.
  - Neglect is the failure of the facility, its employees, or service providers to provide goods and services to residents that are necessary to avoid physical harm, pain, mental anguish, or emotional distress.
  - Involuntary seclusion means separation of a resident from other residents or from his or her room, or confinement
to his or her room (with or without roommates) against the resident’s will, or the will of the resident representative.

- Misappropriation of resident property means the deliberate misplacement; exploitation; or wrongful, temporary, or permanent use of a resident’s belongings or money without the resident’s consent.

- Exploitation means taking advantage of a resident for personal gain, through the use of manipulation, intimidation, threats, or coercion.

- Many times we will not actually witness abuse as it occurs, but might observe signs that abuse has occurred. It is through really knowing residents that we can recognize changes that indicate something is wrong. All changes in a resident need to be reported to a supervisor.

- Examples of injuries that could indicate abuse include, but are not limited to, injuries that are non-accidental or unexplained; fractures; sprains; dislocations; burns, blisters, or scalds on the hands or torso; bite marks, scratches, skin tears, and lacerations with or without bleeding, including those that are in locations that would unlikely result from an accident; bruises, including those found in unusual locations such as the head, neck, lateral locations on the arms, or posterior torso and trunk, or bruises in shapes (e.g., finger imprints); and facial injuries, including but not limited to, broken or missing teeth, facial fractures, black eye(s), bruising, bleeding, or swelling of the mouth or cheeks.

- Abuse situations are sometimes the result of a series of actions and reactions that escalate. This chain of events is often preventable.

- There are many reasons residents might act the way they do. Understanding why helps us to better understand what they are experiencing and what they need—even if we never know exactly why. Then we can better understand how to respond. Understanding why will help us to find a better approach to a situation and prevent the series of events that might lead to abuse.

- We can prevent abuse by putting ourselves in the shoes of our residents, looking at our own actions, knowing residents well, and knowing ourselves (and our limits).

- Different ways to respond to a resident include trying later, stepping into their world, tagging out, and taking a breath. If a resident does not want to do something at that moment, try to approach him or her at a later time. Step into the
world of the resident by accepting his or her reality. When you are at your limit with a resident, see if a coworker can help you. Take a breath and find ways to calm yourself.

- In some cases you might witness abuse happening and might need to intervene at that moment. The SAFE acronym helps you remember to try to safely STOP the abuse, be ALERT and alert others, be a FRIEND to anyone involved in the situation by remaining calm and reassuring, and call 911 if there is an EMERGENCY.

- All staff are required to report all suspected abuse.

- Abuse must be reported immediately to the nursing home administrator.

- A suspicion of a crime must be reported to both the State Agency and local law enforcement immediately, but not later than 2 hours if there is serious bodily injury and not later than 24 hours for all others.

- Basic elements to include in an abuse report are who, what, where, and when. Reports should be as detailed as possible and include facts rather than interpretation.

- Anybody can be a part of the “circle of abuse,” including the resident, the perpetrator, the person who witnessed the abuse, the person who heard about the abuse, and the person who notices signs of abuse. We all have a role in identifying, reporting, and preventing abuse.

- Abuse can be the result of escalated situations between staff and residents.
Person-Centered Care

The Hand in Hand training series is based on person-centered care. Person-centered care means focusing on the resident as the locus of control and supporting the residents in making their own choices and having control over their daily lives. It involves a continuing process of listening, trying new approaches, seeing how they work, and changing routines and organizational approaches to individualize and de-institutionalize the care environment.

Person-centered care is part of the culture change movement in long-term care, a paradigm shift in the way we care for people. It is about changing a medical and institutional culture to one that focuses on the individual, honors the choices and unique needs of residents, and creates true homes in which residents can thrive and live meaningfully. Culture change also means changing the work environment in long-term care, so that we honor and respect those working closest to residents, especially...
nurse aides. Culture change means making deep system changes in the way nursing homes operate so that nurse aides are empowered to make decisions and have the tools they need to care for residents in the best way possible. This includes changing from a “facility-based” culture to a culture of home and community. Person-centered care is how we make this change.

Person-centered care values choice, dignity, respect, self-determination, and purposeful living. Person-centered care honors an individual’s goals and preferences. Specifically, with dementia, this approach looks past the diagnosis to the person, emphasizing communication and relationships between residents and caregivers.

Person-centered care is not about more things to do. It is how we do things. It becomes what we do every day. It is about finding a decent and kind way to serve residents that makes their lives and the lives of their caregivers more meaningful—a commonsense approach to bringing care back into caregiving and enriching the lives of those who live and work there.

Other values of a person-centered care approach are:²

- Know each person.
- Put the person before the task.
- Risk taking is a normal part of life.
- Promote the growth and development of all.
- Respond to spirit, as well as mind and body.
- Each person can and does make a difference.
- Community is the antidote to institutionalization.

² Pioneer Network Values and Principles
• Do unto others as you would have them do unto you.

• Everyone is entitled to self-determination wherever they live.

• Relationship is the fundamental building block of a transformed culture.

• Shape and use the potential of the environment in all its aspects: physical, organizational, and psycho/social/spiritual.

• Recognize that culture change and transformation are not destinations, but a journey—always a work in progress.

Person-Centered Care and Dementia

The *Being with a Person with Dementia* modules are based on person-centered dementia care. In person-centered dementia care, we regard the person, not just his or her symptoms or medical diagnosis. Rather than focus only on the person’s losses, and incapacities, we focus on the person’s strengths and abilities and on his or her value as an individual.
Person-centered dementia care is based on the work of Dr. Tom Kitwood, a British gerontologist. Dr. Kitwood believed that the personhood of persons with dementia could be upheld through their positive interactions with others. Personhood refers to a person’s sense of self, which is often developed in relationship to how others see or treat us. This is why, in person-centered care, there is a strong emphasis on creating positive relationships with persons with dementia, knowing them as individuals, and taking every opportunity to create a positive moment or interaction. Sometimes just being with a person with dementia is the best support we can give.

Throughout this training, we refer to people who have dementia as persons with dementia. This is intentionally different from terms such as dementia patient, dementia resident, or dementia victim. These terms, although not intended to be hurtful, can diminish a person to just his or her disease. In person-centered care, persons with dementia are persons first. They have personalities, emotions, interests, life stories, and strengths—and they also have dementia. When we say person with dementia, it reminds us to think of the person first and to look at the whole person. Dementia is just one part of the person.

**Person-Centered Care and Prevention of Abuse**

According to the National Association of State Units on Aging and the National Center on Elder Abuse, “Employees must be able to recognize the signs and symptoms of abuse and believe that they can report allegations to management without suffering negative consequences themselves.”

Training is essential to abuse prevention. The Hand in Hand training helps participants recognize the signs and symptoms of abuse and teaches them how to respond to and report abuse. It also emphasizes that person-centered care principles can play a role in preventing abuse by helping caregivers put themselves in the shoes of residents, look at their own actions, know themselves and their limits, and know their residents as individuals.

---

4 National Center on Elder Abuse and National Association of State Units on Aging, *Nursing Home Abuse Risk Prevention: Profile and Checklist* (National Center on Elder Abuse, 2005) 7.
Summary

Person-centered care approaches are transforming how we think about caregiving in nursing homes. The Hand in Hand training series embeds person-centered principles seamlessly throughout, for you and your participants to get a better sense of how these principles are applied and the positive results they will yield.

Seeing these principles in action will help you evaluate your current practices, adjust them, and apply person-centered principles to enhance the lives of those you care for, as well as your own.

For more information on person-centered care see the Resources section at the end of this toolkit.
Preparing to Facilitate Hand in Hand

The materials accompanying Hand in Hand: A Training Series for Nursing Homes have been designed to be as easy and intuitive to use as possible. However, it is vital for all facilitators to familiarize themselves with the instructor guides, the ISO file, videos, and activities before presenting the modules. Practice will enhance everyone’s experience.

It is especially important to rehearse using the ISO file and associated video clips to get used to the ISO navigation and to make sure that the videos play and display correctly on your system.

Again, be sure to review the materials and practice with the ISO presentation until you feel comfortable. Then, your delivery will reflect your confidence and mastery of the content.

The following section of the orientation guide will show you how to use each component.
How to Use the Instructor Guide

The Instructor Guide (IG) will guide you, the instructor, through the training process. The guide includes instructional materials and instructor guidance. Each element is designed to help you deliver the training effectively.

Sample IG Page
Clock/Time

Each lesson has an estimated time to help you stay on track. You’ll see the time inside the clock in the top right corner of each lesson’s title page. For example, the Warm-up Exercise: Human Scavenger Hunt in Module 1 should take no more than 5 minutes.

ISO and Instructor Guide Page Numbering

All ISO presentation slides have a lesson reference number in the lower right corner. For example, if you are presenting a lesson with 10 slides and you are on the third slide, your ISO presentation will show “3 of 10” in the lower right-hand corner of the slide. All pages in the IG have corresponding slide references that match the number on the ISO presentation slides.
Instructor Guide Supports the Presentation

Each slide is supported by two types of pages in the IG: instructor guidance (top page) and instructor action (bottom page). This design allows you to present the material effectively and thoroughly with a minimum of preparation time. However, it is highly recommended that you read each page carefully and take notes in the space provided, as well as practice with the videos before presenting the material to your participants. Watching the video clips and knowing the recommended teaching points for each group discussion will help to create a better learning experience.
Instructor Guidance

Instructor guidance pages provide goals and objectives, background information, instructional or facilitation tips, suggested answers, and other information that will help you deliver the lesson in a smooth and efficient manner.

Notice that the instructor guidance page corresponds to the presentation screen and provides suggested answers to the questions you are prompted to ask on the instructor action page. Notice, too, that icons on this page help you find information quickly. You may want to use the notes column to add examples or information you want to cover with participants.

Be aware that not every topic has additional instructor guidance. Those pages will say “No instructor guidance for this slide.”
Instructor Action

The bottom pages relay instructor actions in the form of DO, SAY, or ASK prompts. While you should not read verbatim from the IG, the scripts provided for SAY and ASK steps will guide you through the lesson. DO instructions provide guidance for various exercises and actions, such as moving forward to the next video clip.

Notice that, in this example, you will ask two questions about the clip. Those two questions also appear on the presentation slide. The questions are designed to stimulate discussion about the video clips that participants have just seen and to support specific teaching points. For those questions that support specific teaching points, you will find suggested answers on the accompanying instructor guidance page.
Instructional Icons

Throughout the IG, the icons in the chart below prompt you to perform instructional activities.

Instructor Guidance Icons

<table>
<thead>
<tr>
<th>Icon</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="Image" alt="Instructor Note" /></td>
<td><strong>Instructor Note</strong>—Indicates a note for the instructor. These notes are extra information that you may or may not decide to share with the class during the lesson.</td>
</tr>
<tr>
<td><img src="Image" alt="Easel Chart" /></td>
<td><strong>Easel Chart</strong>—Indicates easel chart should be used. You may want to ask a participant to assist you. This involves the participants and gives you more ability to interact with the class.</td>
</tr>
<tr>
<td><img src="Image" alt="Handouts" /></td>
<td><strong>Handouts</strong>—Indicates information sheets or worksheets used to enhance information or complete exercises in the lesson, or for participants to use outside the classroom or on the job.</td>
</tr>
<tr>
<td><img src="Image" alt="More Information" /></td>
<td><strong>More Information</strong>—Indicates that more information or additional discussion questions are provided for reference, background, or use in the lesson.</td>
</tr>
<tr>
<td><img src="Image" alt="Person Centered" /></td>
<td><strong>Person Centered</strong>—Indicates that the instructional material provides information on a person-centered approach to care or the person-centered philosophy.</td>
</tr>
<tr>
<td><img src="Image" alt="Question" /></td>
<td><strong>Question</strong>—Indicates a discussion question.</td>
</tr>
<tr>
<td><img src="Image" alt="Answer Key" /></td>
<td><strong>Answer Key</strong>—Provides suggested answers for review questions and group exercises.</td>
</tr>
</tbody>
</table>
### Instructor Action Icons

<table>
<thead>
<tr>
<th>Icon</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Play Icon" /></td>
<td><strong>Play</strong>—Advancing to the next screen will play the video clip.</td>
</tr>
<tr>
<td><img src="image" alt="Stop Icon" /></td>
<td><strong>Stop</strong>—Stop the video clip.</td>
</tr>
<tr>
<td><img src="image" alt="Discussion Icon" /></td>
<td><strong>Discussion</strong>—Indicates classroom discussion.</td>
</tr>
<tr>
<td><img src="image" alt="Exercise Icon" /></td>
<td><strong>Exercise</strong>—Represents a group exercise, paired activity, or an icebreaker.</td>
</tr>
<tr>
<td><img src="image" alt="Review Icon" /></td>
<td><strong>Review</strong>—Indicates a lesson review.</td>
</tr>
<tr>
<td><img src="image" alt="Key Point Icon" /></td>
<td><strong>Key Point</strong>—Indicates a point that you must emphasize to participants.</td>
</tr>
</tbody>
</table>
How to Use the ISO File

The presentations that you will use during the training include the slides and video clips that accompany the IG.

Module Menu

The lessons in each module are designed to be presented in the order listed on the module menu. To begin a lesson, simply click the lesson title on the menu.

When you have completed all the screens in a lesson, the presentation will return you to the module menu. Select the next lesson title—which will be highlighted—until you have presented all lessons in the module.

Clicking the forward button from the module menu will take you to the video review option.
Video Review Option

The final screen of each module is an index that lists all the video clips contained in that module. This screen provides quick access to any clips you want to show again or review with your participants.
Video Clips

Each video clip is preceded by a screen that informs you that a clip will play when you select the forward arrow. Once you select the forward arrow, the video will play and automatically advance to the next screen, which displays discussion questions for that clip. After the discussion screen, you will need to click the forward button to move to the next screen.

Equipment

This training can be played on a computer.

Handouts

Copies of all handouts for each module are included in the appendix of that module. Directions for using the exercise handouts and distributing other handouts appear in the appropriate places in the IG.
Closed Captions

If you have participants who require subtitles and captioning for the video clips, be sure to turn on that option for them.

Mounting an ISO File

Note: Depending on the software present on your computer, the directions for mounting an ISO will differ. Please consult with your IT professional if you have any difficulties using the ISO files.

ISO files require DVD software to be installed on your computer. If you need DVD software, consider downloading Kodi for free at: https://kodi.tv/download.

You may download the ISO files at: https://surveyortraining.cms.hhs.gov/pubs/ClassInformation.aspx?cid=0CMSHANDINHAND.
Module 1:
Understanding the World of Dementia:
The Person and the Disease
This page intentionally left blank.
Methodology

This module uses lecture, interactive discussion, and exercises.

(Total Time: 60 minutes)

<table>
<thead>
<tr>
<th>Estimated Time</th>
<th>Lecture and Discussion</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 minute</td>
<td>Welcome</td>
<td>4</td>
</tr>
<tr>
<td>5 minutes</td>
<td>Warm-Up Exercise: Human Scavenger Hunt</td>
<td>6</td>
</tr>
<tr>
<td>1 minute</td>
<td>Module Objectives</td>
<td>10</td>
</tr>
<tr>
<td>20 minutes</td>
<td>What Is Dementia?</td>
<td>16</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Types of Dementia</td>
<td>55</td>
</tr>
<tr>
<td>13 minutes</td>
<td>Understanding Persons with Dementia</td>
<td>87</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Conclusion</td>
<td>109</td>
</tr>
</tbody>
</table>

Appendix

Training Follow-Up Activities .......................................................... A-2
Handout: Human Scavenger Hunt .......................................................... A-3
Handout: Brain Coloring Exercise ......................................................... A-7

Training Resources

- Computer capable of playing an .ISO file.
- Downloaded .ISO file for Module 1.
- Module 1 Instructor Guide.
- Easel chart with markers.
- Pens, pencils, and crayons.
- Prizes (optional).
- Writing tablets.

Instructor Preparation

- Review the Instructor Guide and .ISO. Practice exercise delivery. Rehearse with .ISO. Print copies of the handouts.
I. Welcome

Welcome to Module 1: Understanding the World of Dementia: The Person and the Disease—Slide 1 of 5

Instructor Guidance:

If the participants do not know one another, have each participant state his or her name, position, and where he or she works in the nursing home.

So that you can have some flexibility in introducing this module, there isn’t a specific script for the welcome. Instead, you will find a DO action that outlines the topics to cover on the welcome screen. You will want to ensure that students are comfortable, that they know who you are, and that they understand that Module 1: Understanding the World of Dementia: The Person and the Disease will take approximately one hour to complete.

Be sure to pass out a sign-in sheet to track attendance.
Welcome to Module 1: Understanding the World of Dementia: The Person and the Disease

DO

- Greet participants.
- Welcome participants to the training.
- Have participants introduce themselves (if they don’t know one another).
II. Warm-Up Exercise: Human Scavenger Hunt

Warm-Up Exercise—Slide 2 of 5

Instructor Guidance:

Instructor Goals

- To encourage participants to become comfortable talking to one another.
- To help participants get to know one another better.

Materials Needed:

- Human scavenger hunt worksheet.
- Prizes.

The human scavenger hunt worksheet is found in the Appendix, page A-3. You will need to make one copy for each participant.

You might want to give an example about yourself. This opens you up to sharing personal information and allows participants to get to know you better.
Warm-Up Exercise

SAY

This exercise is called the human scavenger hunt. It will help you get to know one another.

DO

Pass out the human scavenger hunt worksheets, placing them face down.
SAY

The human scavenger hunt worksheet lists six things that you can find out about your coworkers. In a moment you will be instructed to move around the room and talk to others in the class. The goal is to find someone who fits each description listed on your sheet and write his or her name down. For example, find someone who likes soda in the morning instead of coffee or tea and write that person’s name in the blank.

Remember, you are trying to fill in all the blanks with names. The person who completes his or her sheet first will win a prize. Any questions? Great, let’s begin.

DO

Read the winning participant’s responses to the class.
This page intentionally left blank.
III. Module Objectives

Module Objectives—Slide 3 of 5

Instructor Guidance:

It’s important to set participant expectations by stating the module objectives. It is not necessary to explain the objectives on this screen; you are only introducing the anticipated instructional outcomes. Remember, this screen should take only about one minute.
Module Objectives

SAY

Dementia is not a specific disease. It is a term that describes a group of symptoms related to loss of memory, judgment, language, complex motor skills, and other intellectual function, caused by the permanent damage or death of the brain's nerve cells, or neurons. In this training, we are going to talk specifically about dementia among nursing home residents.

By the end of this module, you will be able to:

- Define dementia.
- Identify the symptoms of dementia.
- Identify the irreversible types of dementia.
- Identify other conditions that might present with symptoms that
can that can look like dementia.

- Recognize that dementia affects people differently.
- Develop empathy for persons with dementia by better understanding their condition.
- Understand that we must meet persons with dementia in their world.
This page intentionally left blank.
Module 1 Menu

Module 1 Menu—Slide 4 of 5

Instructor Guidance:

The menu screen allows you to easily navigate through the module by selecting the lesson you want to present. At the end of the module, you can click the forward arrow at the bottom of the screen to Module 1 Video Clips. These are the same video clips used in the lessons; they are available to you for review and discussion once all lessons have been covered.

Notes:
Module 1 Menu

SAY

Let's get started with the first lesson, What Is Dementia?

DO

On the menu, click the first lesson, What Is Dementia?
IV. What Is Dementia?

What Is Dementia?: Goals—Slide 1 of 11

Instructor Guidance:
The goal of sharing this information is for the participants to understand the term *dementia* and the symptoms commonly associated with dementia.
What Is Dementia?: Goals

SAY

The goals of this lesson are to help you understand the term *dementia* and the symptoms commonly associated with dementia.
What Is Dementia? —Slide 2 of 11

Instructor Guidance:

The most common question at most trainings about dementia is, What is the difference between Alzheimer’s and dementia?

If you are comfortable that the participants have an idea of the difference, begin by asking:

What is dementia?

You can then follow up with:

Do you know the difference between dementia and Alzheimer’s disease?

- Dementia is an umbrella term and Alzheimer’s disease is one of the types of dementia under the umbrella of dementia.

The Alzheimer’s Association defines dementia as “a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain.”

---

What Is Dementia?

SAY

Today’s lesson is about understanding dementia and the world of residents who have dementia.

Dementia isn’t a specific disease. Instead, think of dementia as a broad umbrella term that covers a group of symptoms related to loss of memory, judgment, language, complex motor skills, and other intellectual function, caused by the permanent damage or death of the brain’s nerve cells, or neurons.
Who Gets Dementia? —Slide 3 of 11

Instructor Guidance:

It is important that participants understand that dementia is not a normal part of aging.

Dementia symptoms tend to develop late in life, mostly impacting older people. However, people in their 30s, 40s, or 50s can also have dementia. At age 65, about 5–8 percent of people have some form of dementia, and this number doubles every five years above that age. Two-thirds of people with dementia are women, but this is partly because women live longer and the risk of developing dementia increases with age. It is estimated that as many as half of people 85 or older have dementia.²

Who Gets Dementia?

SAY

Most people with dementia are older, but it is important to remember that not all older people get dementia. Dementia is not a normal part of aging. Dementia can happen to anyone, but it is more common after the age of 65. However, people in their 30s, 40s, or 50s can also have dementia.
Symptoms of Dementia—Slide 4 of 11

Instructor Guidance:

The importance of discussing each of the symptoms of dementia is to help participants understand that the actions and reactions of the residents are a result of the dementia, not something they are doing intentionally.

Each time you click the forward arrow, a new symptom will appear on the umbrella. Explain each one to the participants, using the guidance provided.
Symptoms of Dementia

SAY

Think of dementia as an umbrella, covering several different symptoms.

DO

Click the forward arrow to advance to the first symptom.
**Instructor Guidance:**

The American Heritage Stedman’s Medical Dictionary defines memory as “the mental faculty of retaining and recalling past experiences based on the mental processes of learning, retention, recall, and recognition.”

The hippocampus in our brain is shaped like a seahorse. This is the area of the brain that helps to decide if a short-term memory will become a long-term memory. Scientists believe that this is the first area that is affected by Alzheimer’s disease, the most common form of dementia. Sometimes people with dementia will not be able to remember things that just happened (such as what they ate at their most recent meal, or whether their daughter visited yesterday). However, those same residents may remember things from many years ago if they were important memories (such as major family or life events).

You may want to ask participants whether they have any experience with residents with memory loss.

---

Symptoms of Dementia: Memory

SAY

Memory. This is the number one symptom that we’ve all seen. Each of us can identify residents who have memory loss.

ASK

Do you have any personal experiences dealing with residents with memory loss?

DO

Click the forward arrow to advance to the next symptom.
Instructor Guidance:

Concentration is the ability to focus one’s attention.

As their symptoms progress, persons with dementia will avoid activities that require concentration. Imagine reading a book. It is very difficult to enjoy a mystery if you can’t focus on the characters and remember what you just read four pages ago.
Symptoms of Dementia: Concentration

SAY

Concentration. Mr. B used to enjoy sitting in the living room area and watching detective shows, but he doesn’t seem to have much interest anymore. Now when you turn to his show, he sits for a bit and then gets up and goes to his room. Mr. B may be having trouble concentrating on the plot. His memory loss and lack of concentration make it almost impossible for him to follow the storyline and to understand what’s happening.

DO

Click the forward arrow to advance to the next symptom.
Instructor Guidance:

We typically think of orientation as “orientation to time, place, and person”—this means a person’s awareness of who and where he or she is, what time and date it is, and who other people are.
Symptoms of Dementia: Orientation

SAY

Orientation to who, when, and where. Residents may not be able to understand where they are, who they are, the date or day, or even what time it is. A resident may come out of her room at 9:00 p.m. fully dressed and looking for breakfast, thinking that it is morning instead of evening. She may think it’s the year 1944. She may be looking for her mother or her children. This is her world.

DO

Click the forward arrow to advance to the next symptom.
Symptoms of Dementia: Language—Slide 4 of 11

Instructor Guidance:

Dictionary.com defines language as “any system of formalized symbols, signs, sounds, gestures, or the like used or conceived as a means of communicating thought, emotion, etc.”

Think about how frustrating it is when you can’t find the word you want to say—especially when someone finishes your sentence for you and it is not what you were trying to say.

Add a personal story, if you have one, about someone who had a challenge with language. Ask the participants if they have any personal stories.

Notes:

---

Symptoms of Dementia: Language

SAY

Language. Have you noticed any of our residents having difficulty with their speech? Trying to find a word and it just isn’t there? Saying cat when they are pointing to a chair? You will notice that their ability to understand what you are saying and to communicate what they are trying to say gets worse with time.

ASK

Do you have any personal stories or experiences with residents who have had a challenge with language?

SAY

Remember, not everyone who experiences a problem with language and expressing himself or herself has dementia. Isolated language problems can occur with certain diseases affecting the brain, such as a stroke that just affects the language center.
DO

Click the forward arrow to advance to the next symptom.
This page intentionally left blank.
Symptoms of Dementia: Judgment—Slide 4 of 11

Instructor Guidance:

Dictionary.com defines judgment as “the ability to judge, make a decision, or form an opinion objectively, authoritatively, and wisely, especially in matters affecting action; good sense; discretion.”

If possible, use examples of residents from your own nursing home who exhibit these symptoms of dementia. Real-world examples will help make the training more relevant and meaningful for participants.

Notes:

---

Symptoms of Dementia: Judgment

SAY

Judgment. We know not to touch a cookie tray when it has just come out of the oven. We know to put on shoes when we’re going out in the snow. A person with dementia, though, may not be able to make these simple decisions. The judgment skills of a person with dementia will get increasingly worse as his or her condition worsens.

DO

Click the forward arrow to advance to the next symptom.
Instructor Guidance:

Visuospatial ability refers to the mental process of how we make sense of what we see and how objects relate to one another.

It is not important that participants know the word visuospatial. It is important, however, for them to be able to recognize that a resident is having these challenges. The resident may see a step where there isn’t one or may be afraid to walk on a shiny floor, thinking it is wet. He or she may avoid a stain on a carpet, seeing it as a hole or a muddy puddle.

The point is to be ready to assist those residents that participants know have challenges. A person who can walk just fine can fall very easily if he or she is trying to jump over a black hole.

If possible, use examples of residents from your own nursing home who exhibit these symptoms of dementia. Real-world examples will help make the training more relevant and meaningful for participants.
Symptoms of Dementia: Visuospatial Skills

SAY

Visuospatial skills help us figure out how objects relate to one another; in other words, they help “make sense of what you see.” Those skills decline in persons with dementia.

We are going to learn more about these two last symptoms by looking at some video clips.
Play Video Clip: Visuospatial Skills—Slide 5 of 11

Instructor Guidance:

This lesson uses two video clips to portray dementia symptoms.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen.

Use the discussion questions to help participants process what they saw.
Play Video Clip: Visuospatial Skills

SAY

This video shows a resident who is experiencing a decline in visuospatial skills.

DO

Click the forward arrow to play the clip.
Discussion—Slide 6 of 11

Instructor Guidance:

Using the characters’ names from the video makes them more human and real to the participants.

What did you see happening in that clip?

- Mrs. Caputo was afraid to step on the black squares.

What was Lynne’s reaction?

- She didn’t get upset and she didn’t make Mrs. Caputo feel foolish. Instead, she helped her around the black squares.

If the participants don’t recognize that Mrs. Caputo thought the black squares were a hole or a wet area, consider asking a follow-up question such as:

- Does anyone know why Mrs. Caputo might not want to step on the black squares?
You want the participants to realize that Mrs. Caputo is having trouble understanding what she sees. She may be seeing the black squares as holes in the ground. Another person with dementia may see them as wet and slippery. Explain to participants that they may also see residents stop at the end of one type of carpet and not want to continue. Flooring can make a big difference to persons with dementia.

You also want the participants to think about the aide’s behavior in the video. It will help them to start thinking about their own behavior. We will discuss behavior in more depth in later modules.
Discussion

ASK

• What did you see happening in that clip?
• What was Lynne’s reaction?
Symptoms of Dementia: Sequencing—Slide 7 of 11

Instructor Guidance:

The American Heritage Stedman’s Medical Dictionary defines sequencing as “following one thing after another, succession.”

Notes:

Symptoms of Dementia: Sequencing

SAY

Sequencing. Sequencing means being able to do things in a certain logical order. There are many things we do every day without even thinking about them—they are natural for us. For a person with dementia, even the sequence for performing a basic activity can become confusing and complicated.

Let’s look at a video clip about sequencing.
Instructor Guidance:

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen.

After the clip, ask the discussion questions to help participants process what they saw.
Play Video Clip: Sequencing

SAY

This video clip shows a resident who is experiencing a decline in sequencing skills.

DO

Click the forward arrow to play the clip.
Discussion—Slide 9 of 11

Instructor Guidance:

What did you see happening in that clip?

- Mrs. Caputo knew that she needed to put on all the clothes on the bed, but she couldn’t determine the sequence for putting them on.

What was Heather’s reaction?

- She didn’t get upset. She was calm and didn’t make Mrs. Caputo feel foolish.

Some people with dementia will put on underwear outside their clothes or put on a sweater first and then a blouse. They know which clothes they need to put on, but they can no longer figure out the correct order.
It is acceptable for you to coach the participants to the correct answers. Ultimately, you want to make sure that either you or the participants acknowledge the following:

Mrs. Caputo has the ability to dress herself if the clothes are laid out and the instructions are clear. Her increasing dementia symptoms may be making it more and more difficult for her to get dressed without assistance.
Discussion

ASK

• What did you see happening in that clip?
• What was Heather’s reaction?

SAY

One thing I want to point out to you is that the aide, Heather, let Mrs. Caputo get dressed on her own. When Heather came in, she saw that Mrs. Caputo was trying to put her sock on over her shoe. She calmly removed the sock, handed it to Mrs. Caputo, and then helped her with her shoe. She let Mrs. Caputo put her sock on herself. This is an example of giving the resident just the right amount of assistance—not too much, not too little.
Symptoms of Dementia: Review—Slide 10 of 11

Instructor Guidance:
Ask the participants if they have any questions about any of the symptoms of dementia.
Symptoms of Dementia: Review

SAY

Here we see all of the symptoms of dementia that we discussed.

ASK

Do you have questions about any of them?
What Is Dementia?: Summary—Slide 11 of 11

Instructor Guidance:

It is important to ensure that all of your participants understand the definition of dementia and the symptoms of dementia before moving on.

Based on what we’ve learned about the symptoms of dementia, why might it be difficult for a person with dementia to get dressed in the morning?

- Memory—She can’t remember what the aide said or what to wear.
- Concentration—She can get her pants on but can’t get her top on because she has lost her concentration on the task.
- Orientation—She may think it is night instead of morning.
- Language—She may not have understood the aide’s instructions.
- Judgment—She may want to wear clothes that are not appropriate for the season or may try to wear her roommate’s clothes.
- Visuospatial skills—The clothes may look like they blend in with the bedspread and she cannot see them.
- Sequencing—Remember the video.
What Is Dementia?: Summary

SAY

In this lesson we have learned that dementia is an umbrella term that covers a group of disorders with symptoms that make normal life increasingly difficult for our residents. We have learned that we need to be there for our residents, to assist them as their dementia symptoms worsen.

ASK

Based on what we’ve learned about the symptoms of dementia, why might it be difficult for a person with dementia to get dressed in the morning?
V. Types of Dementia

**Instructor Guidance:**

The goal of this lesson is to understand the irreversible types of dementia and conditions that may present with dementia-like symptoms.
Types of Dementia: Goal

SAY

The goal of this lesson is for you to understand the irreversible types of dementia and conditions that may present with dementia-like symptoms.
Types of Irreversible Dementia—Slide 2 of 9

Instructor Guidance:

There are many types of irreversible dementia. Alzheimer’s is the most common. Vascular dementia, mixed dementia (which is typically a combination of Alzheimer’s and vascular dementia), Parkinson’s disease, and Lewy body are other types of irreversible dementia.
Types of Irreversible Dementia

SAY

There are several types of irreversible dementia; they are progressive and will continue to get worse. While medications can slow the progression of these types of dementia, they are not a cure.

We can think of these different types of dementia as being under the umbrella of dementia.

DO

Click the forward arrow to see the first type of irreversible dementia.
Instructor Guidance:

Alzheimer’s is the most common type of dementia, accounting for 60—80 percent of cases. Alzheimer’s disease causes brain changes that gradually get worse. In Alzheimer’s disease, brain cells degenerate and die, causing a steady decline in memory and mental function. Plaques and tangles in the brain are a part of Alzheimer’s.
Types of Irreversible Dementia

SAY

Alzheimer’s disease is the most common type of irreversible dementia, accounting for 60–80% of dementia cases.

DO

Click the forward arrow to see the next type of irreversible dementia.
Instructor Guidance:

Vascular dementia is caused by brain damage from impaired blood flow to the brain. A person can develop vascular dementia after a stroke blocks an artery in the brain, but it can also result from other conditions that damage blood vessels and reduce circulation, depriving the brain of vital oxygen and nutrients.
Types of Irreversible Dementia

SAY

A person can develop vascular dementia after a stroke blocks an artery in the brain, but strokes don’t always cause vascular dementia.

Factors that increase the risk of stroke—including high blood pressure, high cholesterol, and smoking—also raise the risk of vascular dementia.

DO

Click the forward arrow to see the next type of irreversible dementia.
Instructor Guidance:

Lewy body dementia causes a progressive decline in mental abilities. It may also cause visual hallucinations, and, like Parkinson's disease, Lewy body dementia can result in rigid muscles, slowed movement, and tremors.
Types of Irreversible Dementia

SAY

Persons with Lewy body dementia are commonly misdiagnosed with Alzheimer’s due to the loss of memory, or with Parkinson’s disease because of the appearance of tremors. However, people with Lewy body dementia may also have visual hallucinations and moments of confusion interspersed with complete clarity.

DO

Click the forward arrow to see the next type of irreversible dementia.
Persons with mixed dementia have symptoms of more than one type of dementia—for example, they may have brain changes associated with both Alzheimer’s and vascular dementia.
Types of Irreversible Dementia

SAY

Persons with mixed dementia have symptoms of more than one type of dementia—for example, they may have brain changes associated with both Alzheimer’s and vascular dementia. This type of dementia may be more common than previously thought.

DO

Click the forward arrow to see the next type of irreversible dementia.
Instructor Guidance:

Parkinson’s disease is a progressive disorder of the nervous system that affects movement. It develops gradually, often starting with a barely noticeable tremor in just one hand. But while tremors may be the most well-known sign of Parkinson’s disease, the disorder also commonly causes a slowing or freezing of movement. You may notice that the faces of persons with Parkinson’s show little or no expression and their arms don’t swing when they walk. Speech often becomes soft and mumbling. About half of persons with Parkinson’s disease may develop dementia as their disease progresses, either related to the Parkinson’s disease or because they also develop Alzheimer’s disease.

Can anyone name a famous person with Parkinson’s?

- Michael J. Fox
Types of Irreversible Dementia

SAY

Have you ever seen anyone with hand tremors? That is one common physical sign of Parkinson’s disease.

Can anyone name a famous person with Parkinson’s?

DO

Click the forward arrow to see more types of irreversible dementia.
Instructor Guidance:

There are a number of less-common types of irreversible dementia. They include:

- Frontotemporal dementia which primarily affects the frontal and temporal lobes of the brain—the areas generally associated with personality, behavior, and language.

- Huntington’s disease which, in addition to dementia, includes symptoms such as behavioral changes, abnormal movements in the face and extremities, difficulty swallowing, and speech impairment.

- Wernicke-Korsakoff syndrome, a degenerative brain disorder caused by a lack of vitamin B-1. This syndrome can result from alcohol abuse, dietary deficiencies, prolonged vomiting, eating disorders, or the effects of chemotherapy.

- Creutzfeldt-Jakob disease (CJD), a rare, degenerative, invariably fatal brain disorder. It is very difficult to diagnose, occurring in only one in one million people. CJD symptoms progress quickly and lead to death.

- AIDS-related dementia. Symptoms include the inability to concentrate, impaired short-term memory, motor dysfunction, and behavioral changes.
Note: More information about these types of dementia can be found in the glossary at the end of this toolkit.
Types of Irreversible Dementia

SAY

There are a number of less-common types of irreversible dementia. They include frontotemporal dementia, Huntington’s disease, Wernicke-Korsakoff syndrome, Creutzfeldt-Jakob disease, and AIDS-related dementia.
Other Conditions That May Have Dementia-Like Symptoms—Slide 3 of 9

Instructor Guidance:

There are a number of medical conditions that might result in dementia-like symptoms.
Other Conditions That May Have Dementia-Like Symptoms

**SAY**

Irreversible dementia is progressive and does not get better. There are reversible conditions, though, that might result in dementia-like symptoms, including B-12 deficiency, medication side effects, depression, thyroid or endocrine problems, infections, electrolyte problems, dehydration, and others.
Conditions That May Worsen Symptoms of Dementia—Slide 4 of 9

Instructor Guidance:

There are also common conditions that might result in dementia-like symptoms.
Many residents also have common conditions—including constipation, acute or chronic pain, lack of sleep, and others—that cause discomfort and can make dementia symptoms worse. These conditions may be confused with irreversible dementia symptoms, but they can often be treated, and, in most cases, the symptoms of dementia lessen or go away. They must be recognized and taken care of to prevent them from getting worse.

If a person with dementia also has any of these conditions, you may see a worsening in his or her usual dementia symptoms, including increased difficulty with communication and a change in behavior. It’s important for you to be the eyes and ears in noticing changes in a resident, particularly if a resident suddenly has dementia-like symptoms or the symptoms get worse. For example, you are caring for Mrs. Caputo. She can usually dress herself as we saw in the video clip, but you notice increased confusion. You leave her
clothes out and when you return to her room, she is still sitting in the same spot—not dressed—and looking confused. Something else may be going on with her.
Instructor Guidance:

Delirium is always due to a new or worsening medical problem; it is very important that nurse aides notify the nurses so that they can assess the resident further. Delirium usually improves once the medical problem is diagnosed and treated.
Delirium

**SAY**

Any sudden change in a resident’s medical condition or a new medication can cause increased confusion or problems with thinking and functioning, especially in persons with dementia who become ill. When a new, underlying medical problem such as dehydration, pneumonia, or a urinary tract infection (UTI) is causing the symptoms, this is often called delirium. People with delirium may seem very alert one moment, but very sleepy within a short time. They are more confused and may have more trouble than usual paying attention to things.

This is why it is so important that caregivers really know each resident. Most often, it is the nurse aide or family who will notice a change in a person with dementia, and that change could be delirium. Delirium is always due to a new or worsening medical problem; it is very important to notify the nurses so that they can assess the person further. Delirium usually improves once the medical problem is diagnosed and treated.
Example 1: Lack of Sleep—Slide 6 of 9

Instructor Guidance:

This example is used to help participants understand how a common condition, such as lack of sleep, can mimic a symptom of dementia.

You may want to use an example from your experience.
Example 1: Lack of Sleep

SAY

Those of you who have—or have had—a young child know what the lack of sleep can do. It can cause you to lose your memory. You feel as if you can’t concentrate; you may have no idea what day it is; and you may have lost your ability to speak with adults. You can’t find words when speaking and your whole mind feels “fuzzy.”
Example 2: Dehydration—Slide 7 of 9

Instructor Guidance:

This example is used to help participants understand how a common condition, such as dehydration, can mimic a symptom of dementia. You may want to use a personal example.

Changes in the resident’s behavior could also be a result of a UTI, constipation, or hypothyroidism.

You may also see a change in behavior or communication caused by a new medication or change in medication dosage. Does the resident have diabetes as well as Alzheimer’s disease? She may have high or low blood sugar.
Example 2: Dehydration

SAY

Maybe a resident is suddenly acting differently or having problems performing activities she could do before. Could it be that she is dehydrated?

Have you ever seen a movie where people are wandering in the desert without food or water? Often in these movies, the characters rush to an oasis filled with cool, fresh water, only to find it is a mirage. This type of hallucination is an example of dementia symptoms caused by dehydration.

As you can see, the fact that a resident has an irreversible disease that causes dementia doesn’t mean that other conditions won’t cause new symptoms or aggravate his or her existing dementia symptoms.
**Instructor Guidance:**

It is important that participants understand that they may be the only voice a resident has. If they notice anything that is not “normal” for that resident, it is their responsibility to let the nurse know.
Be Their Voice

SAY

If you see any change in ability, communication, or behavior from what is usual for that resident, tell the nurse. You are the person who needs to let the nurse know about the change. Be the advocate for your residents. Be their voice.
Instructor Guidance:

An important point of this lesson is that participants should tell a nurse when they see a change from what is “normal” for any of their residents.
Types of Dementia: Summary

SAY

In this lesson you’ve learned that there are several different types of irreversible dementia. You’ve learned that if you see a change in any of your residents from what is “normal” for them, you need to tell a nurse what is happening.
VI. Understanding Persons with Dementia

Understanding Persons with Dementia: Goals—Slide 1 of 10

Instructor Guidance:

The goals of this lesson are: (1) to understand that a resident’s actions and reactions are directly related to how the brain is being affected; (2) to understand the frustrations that persons with dementia have; and (3) to understand why we must meet persons with dementia in their world.

This lesson includes an exercise and two video clips.

Notes:
Understanding Persons with Dementia: Goals

SAY

The goals of this lesson are: (1) to understand that dementia is a brain disorder and that a resident’s actions and reactions are directly related to how the brain is being affected; (2) to know what it feels like to have dementia and understand the frustrations that persons with dementia have; and (3) to understand why we must meet persons with dementia in their world.

In this lesson you will participate in a short exercise and watch two videos to help you better understand the world of a person with dementia.
Exercise: Brain Coloring—Slide 2 of 10

Instructor Guidance:

You will need to make a copy of the brain coloring worksheet found in the Appendix, page A-7 for each participant. Also have available a variety of crayon colors.

Demonstrate the first few instructions on your own worksheet. Write your name above the brain on the left. Write the name Auguste above the brain on the right.

Be sure to give the participants enough time to complete the directions.

When most participants have finished coloring, go around the room and collect three or four very different looking examples from participants. Tape the completed worksheets up on a wall or bulletin board or on your easel chart. When you see that most participants have finished, you can continue.

There is no simple map or exact pattern of how a degenerative cognitive disease will affect a specific person. Everyone is an individual. We all need to approach each person with that in mind.
Exercise: Brain Coloring

DO

Hand out the brain coloring worksheet.

SAY

This brain coloring exercise will help us embrace one another’s differences.

First, everyone picks some crayons. Write your name above the brain on the left side of the paper. Then, above the brain on the right side of the paper, write the name Auguste (A-u-g-u-s-t-e).

Now I would like you to color the brain on the left side of your worksheet two-thirds full. You can color it any way you wish, as long as it is two-thirds full.

DO

Wait a few minutes until you see that most participants have finished.
SAY

Now color the brain on the right side only one-third full. Once again, you may color it any way you wish.

DO

Wait a few minutes. When most participants have finished coloring, go around the room and collect three or four very different looking examples from participants. Tape the completed worksheets up on a wall or bulletin board or on your easel chart. When you see that most participants have finished, you can continue.

SAY

Alzheimer’s disease was named for Dr. Alois Alzheimer. He first documented the presence of tangles and plaques in the brain after the autopsy of Auguste D, a patient with dementia that Dr. Alzheimer had followed for several years. Both tangles and plaques are involved in killing brain cells. The tangles happen within neurons, and plaques build up between brain cells.

Let’s say that, on a good day, a person with Alzheimer’s disease has the ability to use one-third of his or her brain. Let’s say each of you has the ability to use two-thirds of your brain.

Look around at one another’s drawings and the ones that I displayed. None of your brains are the same. Even if two of you colored your brains in the same way, you used different colors. This is a simple, yet important point.
• Each person who works here is an individual.

• Each person who lives here is an individual.

• Alzheimer’s disease affects each person in a different way.

• You may have two residents who both have diabetes, Alzheimer’s disease, and high blood pressure, but they will act and react in totally different ways. That’s because each has a different life story as his or her foundation.

• There is no simple map or exact pattern of how a degenerative cognitive disease will affect a specific person.

• Everyone is an individual. We all need to approach each person with that in mind.
Brain Graphics—Slide 3 of 10

Instructor Guidance:

The graphics used in this lesson will help participants understand the difference between the brain of a person without dementia and the brain of a person who has Alzheimer’s.

Can anyone tell me one difference between these two brain graphics?

- The brain of the person with Alzheimer’s has shrunk.
- The grooves have gotten bigger in the brain of the person with Alzheimer’s.
Brain Graphics

SAY

Here is a graphic illustration of the brain of a person without Alzheimer’s and the brain of a person with Alzheimer’s.

ASK

Can anyone tell me one difference between these two brain graphics?
Brain Photographs—Slide 4 of 10

Instructor Guidance:

These are actual photographs of two brains. Once again, the difference is distinct.
Brain Photographs

SAY

These are photographs of two real brains. Once again, you can see distinct differences between the two brains.
Instructor Guidance:

A positron emission tomography (PET) scan measures body functions such as blood flow and oxygen use. The purpose of the scan shown on the slide was to evaluate brain abnormalities.
Brain PET Scans

SAY

This graphic shows PET scans of the brains of three living people. A PET scan is like an x-ray that shows areas of activity.

As you can see, the brain on the left shows no cognitive impairment.

The brain in the middle shows mild cognitive impairment. This PET scan could belong to your bus driver, your neighbor, or the cashier at the local grocery store. This is the brain of people you run into almost every day. They are having some difficulties but can still manage typical daily life.

The scan on the right shows much more damage from the progression of Alzheimer’s disease. This individual would have dementia symptoms of advanced brain disease. This person needs those around him or her to be patient, kind, and gentle.
Understanding Their World: Video Clip 1—Slide 6 of 10

Instructor Guidance:

Participants will have the chance to look into the world of a person with dementia through this video clip.

After the clip, lead a brief discussion with the participants.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen.
Have you ever heard the expression “walk a mile in their shoes”? Well, this next clip might help all of us understand that concept a little better.

Click the forward arrow to play the clip.
Discussion—Slide 7 of 10

Instructor Guidance:

What did you think of that clip?

Some questions for a more guided discussion are:

- What would it feel like to be a resident?
- How do you normally wake up? Would you like to wake up like Mr. O’Sullivan did?
- Was the aide listening to the resident?
- Did you notice any instances when Mr. O’Sullivan was trying to communicate, but the aide wasn’t listening to him?
Discussion

ASK
What did you think about that clip?

SAY

We have all done what we just saw in that clip at one time or another—we are in a rush, we have other residents we have to take care of. The next time you find yourself in that situation, stop, take a breath, and think about what it would be like if you were in the resident’s shoes.
Understanding Their World: Video Clip 2—Slide 8 of 10

Instructor Guidance:

The second clip gives participants another look into the world of a person with dementia.

After the clip, lead a brief discussion with the participants.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen.
Understanding Their World: Video Clip 2

SAY

This clip gives you another look into the world of a person with dementia.

DO

Click the forward arrow to play the clip.
Discussion—Slide 9 of 10

**Instructor Guidance:**

What do you think about that clip?

How can we meet a person with dementia in his or her world?

Have you ever talked to a resident who believes that her adult children are still young? How can we meet her in her world while still being honest with her?

Encourage the participants to take part in this discussion. Facilitate their realization of the importance of understanding persons with dementia and meeting them where they are.
Discussion

ASK

What did you think about that clip?
Understanding Persons with Dementia: Summary—Slide 10 of 10

Instructor Guidance:

It is important to ensure that all of your participants understand that dementia affects people differently. You want them to think about how it feels to be an adult with dementia.
Understanding Persons with Dementia: Summary

SAY

In this lesson we have learned that each person with dementia, especially Alzheimer’s disease, is affected individually. We understand that it must be very hard and confusing to have dementia and to be unable to remember. We also recognize that we need to meet the person with dementia in his or her world.
VII. Conclusion

Discussion—Slide 1 of 2

Instructor Guidance:

No instructor guidance for this slide.
Discussion

ASK

What is one thing that you’ll take away from this training?
Congratulations!—Slide 2 of 2

Instructor Guidance:

No instructor guidance for this slide.
Congratulations!

SAY

In the last hour, we have discussed symptoms of dementia, types of dementia, and understanding persons with dementia.

ASK

Do you have any final questions?
Module 1 Video Clips—Slide 5 of 5

Instructor Guidance:

From this slide you can easily access any of the video clips in this module for review or additional discussion.

- Video Clip 1—Visuospatial Skills.
- Video Clip 2—Sequencing.
- Video Clip 3—Understanding the Resident’s Point of View.
- Video Clip 4—Understanding Memory Loss.
Module 1 Video Clips

What Is Dementia?
- Video Clip 1
- Video Clip 2

Understanding Persons with Dementia
- Video Clip 3
- Video Clip 4

Select a video clip above

Module 1—Understanding the World of Dementia

Notes:
Appendix

Training Follow-Up Activities ................................................................. A-2
Handout: Human Scavenger Hunt ............................................................ A-3
Handout: Brain Coloring Exercise ............................................................ A-7
Training Follow-Up Activities

Instructor Guidance:
We know to make any training topic stick you must find ways to reinforce and apply the key points from the lesson. You may assign any of these optional exercises for participants to complete after the training.

Make a scavenger hunt for your participants or use the one provided on page A-5. Hand out the worksheet at the end of class and ask participants to complete it within a week. They can turn them in to your mailbox or a file box on the door or near your classroom. Be sure to give a clear due date and remind them to include their name on the worksheet.

Create a bulletin board in a common area where you can post information, ideas, or interactive tools.

You can also collect the brain coloring worksheets the participants completed in the training and post them on a bulletin board below the following statement:

*Be Patient. Be Kind. Be Gentle.*
Human Scavenger Hunt

Write the first name of the person or persons that fit the description. If there is no one to whom the question applies, write N/A.

1. Who was born in the same month as you? ________________________________

2. Who was born the farthest away from here? ______________________________

3. Who has the same color eyes as you? ________________________________

4. Who is the youngest in his or her family? ______________________________

5. Who has a cat and a dog? ________________________________

6. Who is left-handed? ________________________________
This page intentionally left blank.
Human Scavenger Hunt—Resident

Write the name of the resident or residents that fit the description. If there is no one to whom the question applies, write N/A.

1. Who was born in the same month as you? ________________________________

2. Who was born the farthest away from here? ________________________________

3. Who has the same color eyes as you? ________________________________

4. Who is the youngest in his or her family? ________________________________

5. Who was named after a family member? ________________________________

6. Who is left-handed? ________________________________

7. Who smiles when you look in his or her eyes? ________________________________

8. Who loves to cook? ________________________________

9. Who is a veteran? ________________________________

10. Who reminds you of one of your grandparents? ________________________________
This page intentionally left blank.
Brain Coloring Exercise
Module 2:
Being with a Person with Dementia:
Listening and Speaking
Methodology

This module uses lecture, interactive discussion, and exercises.

(Total Time: 57 minutes)

<table>
<thead>
<tr>
<th>Estimated Time</th>
<th>Lecture and Discussion</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 minutes</td>
<td>Welcome</td>
<td>4</td>
</tr>
<tr>
<td>5 minutes</td>
<td>Module Objectives</td>
<td>12</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Why Dementia Causes Changes in Communication</td>
<td>20</td>
</tr>
<tr>
<td>20 minutes</td>
<td>Communicating with Persons with Dementia</td>
<td>50</td>
</tr>
<tr>
<td>15 minutes</td>
<td>More Than Words</td>
<td>80</td>
</tr>
<tr>
<td>5 minutes</td>
<td>Conclusion</td>
<td>100</td>
</tr>
</tbody>
</table>

Appendix

Training Follow-Up Activity .................................................................................................................. A-2
Handout: Good Morning Clip 2 .................................................................................................................. A-3
Handout: Exercise: More Than Words ........................................................................................................ A-5

Training Resources

- Computer capable of playing an .ISO file.
- Downloaded .ISO file for Module 2.
- Module 2 Instructor Guide.
- Pens, pencils, and writing tablets.
- Handouts.
- Easel chart and markers.
- Post-it® Note.

Instructor Preparation

- Review the Instructor Guide and .ISO. Practice exercise delivery. Rehearse with .ISO. Print copies of the handouts.
I. Welcome

Welcome to Module 2: Being with a Person with Dementia: Listening and Speaking—Slide 1 of 6

Instructor Guidance:

If the participants do not know one another, have each participant state his or her name, position, and where he or she works in the nursing home.

You will want to ensure that participants are comfortable, that they know who you are and that they understand that Module 2: Being with a Person with Dementia: Listening and Speaking will take approximately an hour to complete. When you introduce the module, be sure to cover the points in the SAY section.

Be sure to pass out a sign-in sheet to track attendance.

Notes:
Welcome to Module 2: Being with a Person with Dementia: Listening and Speaking

**DO**

- Greet participants.
- Welcome participants to the training.
- Have participants introduce themselves (if they don’t know one another).

**SAY**

This module is about “being with” a person with dementia, listening to and speaking with him or her. Being with a resident, rather than “doing for” or “doing to” reminds us to know the person with dementia, to see him or her as a unique individual, and to recognize the relationship you have with that
person. Being with persons with dementia reminds us to see things from their perspective and to try to understand what they are communicating to us.

Listening is more than hearing the words someone is saying—it is about understanding the message he or she is sending through both words and actions. Speaking, too, is more than words. It is about the message you send to people with your words, tone, and body language.

Finally, communication is not just about sending and receiving messages. It is about making someone feel heard. It is about treating one another with dignity and respect, which are fundamental human needs.
Instructor Guidance

Four of the modules in this Hand in Hand training series are about caring for persons with dementia. Three of the titles share a common introduction: Being with a Person with Dementia. This means understanding his or her world by trying to see it from his or her perspective—trying to be with the person where he or she is. Being with a person with dementia is different from doing for. It recognizes them as whole individuals, who have strengths as well as weaknesses, unique needs, preferences, and histories. By building on strengths and knowing who they are as individuals, we support persons with dementia to do as much as they can and to live meaningfully.

Here is a list of the topics in the Being with a Person with Dementia series:

Module 1: Understanding the World of Dementia: The Person and the Disease

Module 2: Being with a Person with Dementia: Listening and Speaking

Module 3: Being with a Person with Dementia: Actions and Reactions

Module 4: Being with a Person with Dementia: Making a Difference

Notes:
This module is one of four modules on dementia. They cover different topics, but the titles of three modules all begin with *Being with a Person with Dementia*. This means:

- Understanding the world of persons with dementia by trying to understand things from their perspective.
- Being “where they are.” This means meeting them in their world, in their understanding of what is happening around them, and in what they are able to do and what they need help with.
- Recognizing persons with dementia as whole individuals who have strengths as well as weaknesses, unique needs, preferences, and histories.
• Building on strengths and knowing who they are as individuals.
• Supporting persons with dementia to do as much as they can and to live meaningfully.
• Connecting with persons with dementia through communication, laughter, touch, and so on to validate them as human beings and as equals.
• Recognizing that sometimes the best way we can support persons with dementia is to just be with them, to sit with them, and to listen to them.
II. Module Objectives

Instructor Guidance:

It is important to set participant outcomes by stating the module objectives. It is not necessary to explain the objectives on this screen; you are only introducing the anticipated instructional outcomes.
SAY

In order to communicate with persons with dementia, it helps to understand why they communicate differently. We will talk about the unique communication needs of persons with dementia and strategies for communicating more effectively with them. We will see how our communication directly impacts their reactions to us, our ability to meet their needs, and our relationship with them.

Because communication can be difficult for persons with dementia, we have to learn to look for the meaning in their verbal and nonverbal communication.
What Is Dementia? —Slide 4 of 6

Instructor Guidance:

It might be helpful to review the explanation of dementia in Module 1: Understanding the World of Dementia: The Person and the Disease. (Note: It’s recommended that participants complete module 1 before the other dementia modules.)

Dementia is an umbrella term that describes a wide range of disorders and symptoms that affect a person’s cognitive, physical, and social abilities severely enough to interfere with the person’s daily life. They include challenges with memory, concentration, orientation, language, judgment, visuospatial skills, and sequencing.

- Memory refers to the processes used to acquire, store, retain, and retrieve information.
- Concentration is the ability to focus one’s attention.
- Orientation refers to a person’s awareness of who and where he or she is, what time and date it is, and who other people are.
- Language refers to the communication of thoughts. It includes both spoken and written words, as well as nonverbal methods of communication.
- Judgment refers to the mental processes of making decisions.
- Visuospatial ability refers to the mental processes of how we make sense of what we see and how objects relate to each other.
- Sequencing means doing something in a logical order.

Notes:
The Alzheimer’s Association identifies Alzheimer’s disease as the most common cause of dementia, accounting for 60–80 percent of all cases of dementia.
This page intentionally left blank.
What Is Dementia?

SAY

Let’s take a step back and revisit what dementia is. Dementia is not a specific disease. It is an umbrella term that describes groups of symptoms, including challenges with memory, concentration, orientation, language, judgment, visuospatial skills, and sequencing.

These dementia symptoms can be caused by many different illnesses and conditions—some are reversible and some are irreversible. The most common irreversible cause of dementia is Alzheimer’s disease.
Module 2 Menu

Module 2 Menu—Slide 5 of 6

Instructor Guidance:

The menu screen allows you to easily navigate through the module by selecting the lesson you want to present. It is intended for the class to go through all the lessons in order so that they can build upon what they learn.

At the end of the module, if you want to look at the clips again or use them for additional training, you can click the forward arrow at the bottom of the screen to Module 2 Video Clips (slide 2 of 2). These are the same video clips used in the lessons; they are available to you for review and additional discussion.
Module 2 Menu

SAY

Let’s get started with the first lesson, Why Dementia Causes Changes in Communication.

DO

On the menu, click the first lesson, Why Dementia Causes Changes in Communication.
III. Why Dementia Causes Changes in Communication

Instructor Guidance:

The goal of this lesson is to describe the changes in the brain of a person with dementia that cause communication changes that we see and hear.

It is important for participants to understand that the brain changes that cause dementia symptoms impact the ability to communicate. The communication challenges of persons with dementia are not about their “not trying hard enough” or “trying to irritate us.” Persons with dementia want and need to express themselves and connect with others and they communicate this in different ways.
Why Dementia Causes Changes in Communication: Goal

SAY

The goal of this lesson is to describe the changes in the brain of a person with dementia that causes communication changes that we see and hear.

Communication involves sending and receiving information—listening and speaking. Persons with dementia have challenges in both areas, so we sometimes have to dig deeper to understand what they are trying to communicate. Because they might not be able to find the words, we have to pay close attention to other signals such as their facial expressions and body language.
Brain PET Scans—Slide 2 of 8

**Instructor Guidance:**

The intent of comparing the three brains side by side is to show the deterioration that occurs in the brain of someone with Alzheimer’s type dementia, in contrast to brains that have no deterioration (normal) or little deterioration (mild cognitive impairment).

Note: A positron emission tomography (PET) scan measures body functions such as blood flow and oxygen use.

What do you notice about these three brains?

Participants might say:

- The brain with Alzheimer’s has deteriorated.
- There are lots of spaces in the brains of people with mild cognitive impairment (MCI) and Alzheimer’s disease.
- Whole parts of the brain with Alzheimer’s are missing, are no longer there, or are lost.
According to the Alzheimer’s Association, MCI is a condition in which a person has problems with memory, language, or another mental function severe enough to be noticeable to other people and to show up on tests, but not serious enough to interfere with daily life. It is often seen as a step before Alzheimer’s disease, although not all people with MCI develop Alzheimer’s disease.

If participants ask about the brain with Alzheimer’s and the difference between Alzheimer’s and dementia, remind them that dementia is a term used to refer to the group of symptoms. Alzheimer’s disease is the most common cause of dementia.
Brain PET Scans

SAY

These images show three brains. On the left is a “normal” brain of someone who has no impairment. The middle image is the brain of a person with MCI, a condition in which people have cognitive difficulties, but not dementia. Sometimes the condition progresses to dementia. The image on the right is the brain of someone with dementia, specifically Alzheimer’s disease.

ASK

What do you notice about these three brains?
SAY

This slide shows that the brains of these three people are actually different. Changes in the brain cause symptoms of dementia. These changes also cause problems with communication because the parts of the brain that are responsible for communication deteriorate.

Let’s look at the abilities that this person with Alzheimer’s disease has lost.
This page intentionally left blank.
Memory—Slide 3 of 8

Instructor Guidance:

The purpose of slides 3 through 6 is to show participants how deterioration in the brain results in specific dementia symptoms that are directly related to communication.

It is important to note that the mapping of symptoms on these brain scans is for illustrative purposes only. It should not be interpreted for diagnostic purposes or as pathologically precise.

This slide concerns the dementia symptom of memory. A number of areas in the brain are involved in memory; three of those areas are the frontal lobe, hypothalamus, and temporal lobe. This slide shows that all three of those areas have deteriorated in the brain of a person with Alzheimer’s. It is not important that nurse aides remember these brain structures. Rather, the point to make is that areas in the brain involved in memory have deteriorated.

How would memory loss affect how a person with dementia communicates?

Persons with dementia might:

- Forget what they said.
- Say the same thing or ask the same question again and again, because they forgot saying it.

Notes:

Persons with dementia might:

- Forget what they said.
- Say the same thing or ask the same question again and again, because they forgot saying it.
• Forget who you are and not understand their relationship with you. In other words, they might not remember that you are a caregiver who is helping them get dressed, bathe, or go to the bathroom. So, when you ask them about these things, they are confused.

• Not remember how to do things they have always done. As a result, they might need simple and detailed instructions on how to do things.

• Forget information you tell them. For example, a person might not remember that you told her that lunch is at noon or that her daughter is coming to visit today.

• Forget things they do, even if they do the same things every day. For example, a person might forget that her daughter always visits at 5 p.m.
Memory

SAY

The symptom of memory loss is required for the diagnosis of dementia. Many parts of the brain have to do with memory; three of those parts are the frontal lobe, hypothalamus, and temporal lobe. In this slide you can see that these three areas have deteriorated in the brain of a person with Alzheimer’s disease. This is why persons with dementia have trouble with memory.

ASK

How would memory loss affect how a person with dementia communicates?

SAY (after discussion)

So, as you can see, areas in the brain involved with memory have deteriorated. Loss of the ability to remember affects both the listening and speaking aspects of how persons with dementia communicate.
Language—Slide 4 of 8

Instructor Guidance:
A number of areas in the brain are involved in language; two of those areas are the frontal and temporal lobes. This slide shows the deterioration of the frontal and temporal lobes in the brain of a person with Alzheimer’s.

It is not important that nurse aides remember these brain structures. Rather, the point to make is that the places in the brain involved in language have deteriorated.

How would challenges with language affect the way a person with dementia communicates?

Persons with dementia might:

- Not be able to find the right words.
- Use inappropriate words to explain what they mean.
- Not understand the words you are using.
- Need to express what they are trying to say in other ways (gesturing, yelling, making sounds, facial expressions, and so on) because the words are not there.
- Be frustrated that they cannot find the right words and might not talk at all.
Another symptom of dementia is language changes. Many parts of the brain have to do with language; two parts involved with language and speech are the frontal and temporal lobes. In this slide you can see that these areas have deteriorated in the brain of a person with Alzheimer’s disease.

How would challenges with language affect the way a person with dementia communicates?

Clearly, challenges with language, such as understanding and finding words, make communication difficult.
Concentration, Orientation, and Visuospatial Abilities—Slide 5 of 8

**Instructor Guidance:**

This slide shows the deterioration in the areas of the brain responsible for concentration, orientation, and visuospatial abilities.

Concentration is the ability to focus one’s attention.

We typically think of orientation as “orientation to time, place, and person”—this means a person’s awareness of who and where he or she is, what time and date it is, and who other people are.

Visuospatial ability refers to the mental process of how we make sense of what we see, and how objects relate to each other.

A number of places in the brain are involved in concentration, orientation, and visuospatial abilities. A main area in the brain that is involved in concentration and orientation is the frontal lobe. The parietal and occipital lobes play roles in visuospatial abilities. This slide shows that these areas have deteriorated in the brain of a person with Alzheimer’s. It is not important that nurse aides remember these brain structures. Rather, the point to make is that the places in the brain involved in concentration, orientation, and visuospatial abilities have deteriorated.

How would challenges with concentration affect how a person with dementia communicates?
Persons with dementia might:

- Be unable to maintain attention and forget what they were talking about.
- Get off track when talking.
- Be distracted easily and have trouble finishing what they started.
- Have difficulty answering questions.
- Be overwhelmed by too many choices.
- Become frustrated if asked too many questions.

How would challenges with orientation affect how a person with dementia communicates?

Persons with dementia might:

- Frequently ask where they are or say that they need to go somewhere else.
- Not know who you are as a caregiver and ask who you are, or not understand that you are trying to help them.
- Not know what time it is or what day it is and frequently ask what time it is, what day it is, when lunch is, and what they should be doing at what time.

How would challenges with visuospatial abilities affect how a person with dementia communicates?
Persons with dementia might:

- Have visuospatial challenges that confuse them, causing them to say or do things that do not make sense to us.
- Ask questions that do not make sense to us because they are based on what the person with dementia sees. For example, a person who asks if she can “go over it” when she sees a dark area on the ground may be afraid to walk on it for fear of falling or slipping.
Concentration, Orientation, and Visuospatial Abilities

SAY

Challenges with concentration, orientation, and visuospatial abilities are other symptoms of dementia. Concentration means “focusing one’s attention.” When we think of orientation we typically think of orientation to time, place and person—this means a person’s awareness of who and where he or she is, what date and time it is, and who other people are. Visuospatial refers to the mental processes of how we make sense of what we see and how objects relate to each other.

Multiple areas of the brain are involved in these abilities. The frontal lobe is involved in concentration and orientation. The parietal and occipital lobes play roles in visuospatial abilities. In this slide you can see that these areas have deteriorated in the brain of a person with Alzheimer’s disease.
ASK

- How would challenges with concentration affect how a person with dementia communicates?

- How would challenges with orientation affect how a person with dementia communicates?

- How would challenges with visuospatial abilities affect how a person with dementia communicates?

SAY (after discussion)

So, as you can see, areas in the brain involved in concentration, orientation, and visuospatial abilities have deteriorated. The loss of these abilities affects how persons with dementia communicate.
This page intentionally left blank.
Judgment and Sequencing—Slide 6 of 8

Instructor Guidance:

This slide shows deterioration in the areas of the brain responsible for judgment and sequencing.

Judgment refers to the mental process of making decisions.

Sequencing means doing something in a logical order.

A number of places in the brain are involved in judgment and sequencing. A main area in the brain that is involved in judgment and is affected by Alzheimer’s is the frontal lobe. The cerebellum is involved in sequencing. This slide shows that these areas have deteriorated in the brain of a person with Alzheimer’s. It is not important that nurse aides remember these brain structures. Rather, the point to make is that the places in the brain involved in judgment and sequencing have deteriorated.

How would challenges with judgment affect how a person with dementia communicates?

Persons with dementia might:

- Have difficulty answering questions, perhaps because they do not know the “right” answer or have difficulty making decisions.
- Be overwhelmed by too many choices.
- Become frustrated if they are asked too many questions.
How would challenges with sequencing affect how a person with dementia communicates?

Persons with dementia might:

- Have difficulty answering questions, perhaps because they are confused about the “right” order of things.
- Say things or do things in the wrong order.
- Need simple, detailed instructions and cueing about how to do things in the correct order.
This page intentionally left blank.
Judgment and Sequencing

SAY

Challenges in judgment and sequencing are other symptoms of dementia. Judgment refers to the mental process of making decisions. Sequencing means doing something in a logical order.

There are multiple parts of the brain that have to do with judgment and sequencing. The frontal lobe of the brain is involved in judgment and the cerebellum is involved in sequencing. In this slide you can see that these areas have deteriorated in the brain of a person with Alzheimer’s disease.

ASK

How would challenges with judgment and sequencing affect how a person with dementia communicates?
SAY (after discussion)

So, as you can see, places in the brain involved in judgment and sequencing have deteriorated. The loss of these abilities affects how persons with dementia communicate.
This page intentionally left blank.
Dementia Affects Communication—Slide 7 of 8

Instructor Guidance:

Emphasize that the communication challenges that persons with dementia experience are the result of the brain changes we have seen in the last four slides. Because persons with dementia cannot change their ways of communicating, we have to change ours.
Dementia Affects Communication

SAY

We need to remember that persons with dementia have experienced changes in their brains. The way they communicate, act, and react is not their fault; it is the result of a disorder that will keep getting worse and keep changing the way they communicate. Although dementia is progressive, we can focus on the abilities of persons with dementia—what they can do and how we can meet them where they are.

We are the ones who can and must change and adapt how we communicate with them.
Why Dementia Causes Changes in Communication: Summary—Slide 8 of 8

Instructor Guidance:

It is important to ensure that participants understand the brain changes that result in communication changes in persons with dementia.

What three things have you learned or relearned in this lesson?
Why Dementia Causes Changes in Communication: Summary

ASK

What three things have you learned or relearned in this lesson?
IV. Communicating with Persons with Dementia

Communicating with Persons with Dementia: Goals—Slide 1 of 11

Instructor Guidance:

The goal of this lesson is for participants to learn strategies to enhance communication with persons with dementia.

We have learned that changes in the brain that occur with dementia cause changes in communication. We as caregivers have to adapt to these changes and find effective ways of communicating with persons with dementia.
Communicating with Persons with Dementia: Goals

SAY

Communication involves sending and receiving messages, listening, and speaking. In any exchange, we have to consider the perspectives of both the person sending the message and the person receiving it. Communication includes not only the words people say, but also their nonverbal communication—gestures, body language, facial expressions, tone, and so on.

Listening to persons with dementia means not just listening to the words, but also trying to understand what they are communicating through their actions. In this lesson we will watch several video clips and take a closer look at how both residents with dementia and nurse aides are sending and receiving messages.
Play Video Clip: Good Morning: Video Clip 1—Slide 2 of 11

Instructor Guidance:

In this lesson, participants will see two video clips. When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen. Use the discussion questions to help participants process what they saw.

The first clip shows an interaction between Mrs. Caputo, a resident with dementia, and an aide, Jane. The clip shows “bad” or ineffective communication approaches. Do not introduce the clip as “bad”—let the class determine this on their own.

After they’ve seen the clip, ask the class what they observed about the communication between Mrs. Caputo and Jane.

You may want to write their observations on the easel chart.
Play Video Clip: Good Morning: Video Clip 1

SAY

We are going to look at a clip of Mrs. Caputo’s morning. You will see Mrs. Caputo and an aide, Jane.

Pay close attention to how they are communicating, both verbally and nonverbally. How do you see Mrs. Caputo communicating, acting, and reacting to Jane? How is Jane communicating and responding to Mrs. Caputo?

After the clip we’ll discuss what you noticed.

DO

Click the forward arrow to play the video clip.
Discussion—Slide 3 of 11

Instructor Guidance:

In your discussion of the clips in this lesson, stress to the participants that each person in the interaction is sending and receiving messages by listening and speaking, using, and observing body language and expressions. Break down what each person in the clip is trying to communicate and how the other person is receiving and reacting to that message.

What did you notice about Mrs. Caputo’s communication? How was she communicating?

- She wasn’t using the “right” words.
- She said the same thing many times.
- She forgot what she was saying.
- Her body language showed that she was confused and frustrated and that she did not understand the aide.

What did you notice about how Jane communicated with Mrs. Caputo? How well did she listen to what Mrs. Caputo was trying to say?

- She talked too fast.
- She didn’t get to Mrs. Caputo’s eye level.
- She didn’t make eye contact.
- Her body language and facial expressions did not match her words.
- Her body language showed she wasn't interested.
• Her body language showed a bad attitude.
• She approached the resident from behind.
• She became impatient.
• She gave several instructions at once.
• She used abstract terms and pronouns.

How did Mrs. Caputo react to Jane?

• She became more frustrated with her.
• She seemed upset.
• She appeared confused.

What happened as a result?

• Mrs. Caputo became more confused and frustrated.
• Mrs. Caputo went back to bed.
This page intentionally left blank.
Discussion

SAY

Each person in this interaction is sending and receiving messages. Let’s break down what each person is communicating.

ASK

- What did you notice about Mrs. Caputo’s communication? How was she communicating?
- What did you notice about Jane’s communication? How well did she listen to what Mrs. Caputo was trying to say? How did she respond?
- How did Mrs. Caputo react to Jane?
- What happened as a result?
Play Video Clip: Good Morning: Video Clip 2—Slide 4 of 11

Instructor Guidance:

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen.

The second clip is a different version of Mrs. Caputo’s morning. It shows an interaction between Mrs. Caputo and another aide, Heather.

This clip shows “good” or effective ways to communicate with a person with dementia. Do not present this clip as “good”—let the participants point out the effective communication style.

Before they watch the clip, distribute the handout titled Good Morning Clip 2, on page A-3. Tell the participants that, after they view the clip, they will use the handout to check off communication strategies they saw in the clip.

Ask participants to share and discuss their answers.
Play Video Clip: Good Morning: Video Clip 2

SAY

Now, we’re going to watch a second clip of Mrs. Caputo’s morning. You’ll see Mrs. Caputo and an aide, Heather.

Again, pay close attention to how they are communicating, both verbally and nonverbally. How do you see Mrs. Caputo communicating, acting, and reacting to Heather? How is Heather communicating with and responding to Mrs. Caputo?

I’m giving you a handout with a checklist. After the clip, I’ll give you a few minutes to check off the things you noticed in the clip. Then we’ll discuss the clip as a class.

DO

Click the forward arrow to play the video clip.
Discussion—Slide 5 of 11

Instructor Guidance:

What did you notice about Mrs. Caputo’s communication? How was she communicating?

- She wasn’t using the “right” words.
- She said the same thing many times.
- She forgot what she was saying.
- Her body language showed that she was confused and frustrated and that she did not understand Heather.

What did you notice about how Heather was communicating with Mrs. Caputo? How did she listen to what Mrs. Caputo was trying to say? How did she respond?

- She got to Mrs. Caputo’s eye level and made eye contact when speaking with her.
- She spoke more slowly.
- She spoke in shorter, simpler sentences.
- She reassured Mrs. Caputo through her words, tone, and touch.
How did Mrs. Caputo react to the aide?

- She seemed relieved.
- She smiled.
- She allowed Heather to help her.

What happened as a result?

- Heather was able to help Mrs. Caputo.
- Mrs. Caputo seemed to feel listened to.

What was the difference between the two clips?

In the second clip:

- Heather was more patient.
- Heather had better communication skills.
- Mrs. Caputo seemed happier.
- Heather was able to help Mrs. Caputo.
This page intentionally left blank.
Discussion

SAY

Take a few minutes to check off the things you saw in the clip.

ASK

- First, what did you notice about Mrs. Caputo’s communication? How was she communicating?
- Looking at your checklist, what did you notice the aide, Heather, doing?
- How did Mrs. Caputo react to Heather?
- What happened as a result?
- What was the difference between the two clips?
Play Video Clip: Good Morning: Video Clip 2 Replay—Slide 6 of 11

Instructor Guidance:

Have the class watch Good Morning: Clip 2 again. They will just watch; they won’t use their checklist. This will allow participants to see the positive communication strategies without the distraction of the handout.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the next screen.
Play Video Clip: Good Morning: Video Clip 2 Replay

SAY

You’ve done a great job observing what happened in the last clip. Let’s take one more look at it. Don’t worry about your checklist this time. Just watch the clip.

DO

Click the forward arrow to play the video clip.
### Strategies for Communicating with a Person with Dementia—Slides 7 and 8 of 11

**Instructor Guidance:**

After watching the clip a second time, review strategies for communicating effectively with a person with dementia:

- Always identify yourself.
- Call the person by the name he or she prefers.
- Keep in mind that, depending on that person's progression of dementia, they might not respond to certain names. For example, if a person thinks she is in a time before she was married, she might not think of herself as Mrs.____.
- Be at his or her eye level.
- Make eye contact.
- Sit down with him or her if possible.
- Really listen to the person. Give him or her your complete attention.
- Pay attention to your body language—it shows you are present with that person.
- Use visual and verbal cues to get your message across.
- Look at the body language of the person with dementia to see what he or she might be trying to communicate.
- Speak slowly.
- Speak in short, simple sentences.
- Be patient.
- Give the person enough time to talk or to respond.
• Be specific.
• Ask one question at a time.
• Give one direction at a time.
• Repeat questions or instructions if needed.
• Ask how you can help.
• Tell the person what you are doing or going to do.
• Reassure with words and touch.
• Look for the feelings behind the words or actions.
• Laughing with someone is a universal way to connect.

Review some things to avoid:

• Using no, don’t, or other negative words.
• Arguing with someone with dementia, even when you know that what he or she says is wrong. It might be right to him or her!

Underscore the importance of taking the extra time to communicate well with residents. Although staff might be very busy and feel that they have to rush residents to get their work done, rushing residents often results in their getting upset, which ultimately takes more staff time. Communicating well helps staff get their jobs done better and can even save time in the long run.
Strategies for Communicating with a Person with Dementia

SAY

Now that you have seen that clip again, let’s review.
DO
Go over the strategies on the slides.

ASK
Is there anything else you would add?

SAY
Perhaps you’re thinking that these communication strategies take too much time. However, keep in mind that it often takes more time to calm residents who are upset because they feel ignored or rushed. Think about Mrs. Caputo in the first video we saw—she didn’t understand what she needed to do, became frustrated with the aide, and went back to sleep. So, the aide did not accomplish what she needed to, and Mrs. Caputo didn’t get the help she needed. Taking time and communicating well can actually make your job easier!
This page intentionally left blank.
Play Video Clip—Slide 9 of 11

**Instructor Guidance:**

In the next clip, Dr. Al Power, a geriatrician who works in a nursing home in New York, shares some ideas about the importance of how we communicate in making meaningful connections with residents.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen. Use the discussion questions to help participants process what they saw.
In this clip, you’ll see Dr. Al Power, a geriatrician who works in a nursing home in Rochester, New York. Let’s listen to what he says about communication.
Discussion—Slide 10 of 11

Instructor Guidance:

What do you think it means to be present?

This is an opportunity for participants to express what they think, so there are no wrong answers. If participants have difficulty answering the question, you can stimulate discussion by offering this explanation of what being present means.

Being present means giving someone your complete attention, trying to understand what he or she needs at that moment. Being present for persons with dementia might mean looking them in the eye when you talk to them, taking a moment to touch them on the arm or give them a hug, or even sitting with them and just being with them.

In thinking about how to be present, it might be helpful to understand what it means not to be present. You can ask the class what not being present means. Here are some examples of not being present:

- Talking to other nurse aides and not talking to the resident while you are helping him or her eat.
- Not talking to a resident while you are bathing him or her.
- Coming into a resident’s room, helping him or her with something, and then abruptly leaving without saying anything.
• Interrupting a resident who is trying to say something, finishing sentences for a resident, correcting or arguing with a resident.

In what ways have you tried to be present for your residents?

• Participants might share examples of how they have given their undivided attention to residents, spent a few minutes with residents even when they were very busy, or genuinely tried to listen to what someone was saying.

In what ways have you given control to your residents?

Participants might share examples such as:

• Asking residents what they would like or how they would like something.
• Treating residents with respect.
• Calling residents by their preferred names.
Discussion

ASK

Dr. Power talked about being present for someone. What does it mean to be present?

In what ways have you tried to be present for your residents?

Dr. Power also talked about giving people control, especially in situations where they might have lost a lot of control. In what ways have you given control to your residents?
Communicating with Persons with Dementia: Summary—Slide 11 of 11

Instructor Guidance:

It is important to ensure that your participants understand successful ways of communicating with persons with dementia before you move on.

What are three things you learned in this lesson?
Communicating with Persons with Dementia: Summary

ASK

What are three things you learned in this lesson?
V. More Than Words

More Than Words: Opening Exercise—Slide 1 of 6

Instructor Guidance:

In this opening exercise, participants will hear a narrated introduction to this lesson. Although it is about the goals of this lesson and instructions for this exercise, the narration is intentionally garbled and incomprehensible. The instructor will act as if there is nothing wrong with the narration.

The purpose of this exercise is for participants to experience trying to understand what someone is saying when the language is unfamiliar and garbled. Liken the frustration they experience to the frustration persons with dementia might feel when trying to understand what we are saying, as well as the frustration participants might experience as caregivers when trying to understand what a person with dementia is communicating.

Persons with dementia have challenges in listening and speaking. Words might be unfamiliar, and it might feel to them as if they are communicating in a different language. Because persons with dementia might use words that are not familiar to us and they might not understand the words we are using, we have to learn to look beyond the words for meaning in what they are communicating. When we try to understand the feelings behind what persons with dementia are saying, we can respond to their emotions and meet their needs.
More Than Words: Opening Exercise

SAY

To introduce this lesson and give us instructions on what we are going to do next, we are going to listen to a short recording.

DO

To listen to the recording, click the forward button on the slide.
Discussion: More Than Words: Opening Exercise—Slide 2 of 6

Instructor Guidance:

Facilitate a discussion with the class about what it felt like to listen to the recording.

How did you feel listening to the recording?

For a more guided discussion, ask, did you understand that? What was it like to try to understand that message?

Participants might say:

- I couldn’t understand anything.
- It was very frustrating.
- I was worried I was missing something.

Point out that this experience might help us understand what it is like to be a person with dementia communicating with us. What we are saying to them—and what they are saying to us—might sound like the recording we just heard. Communication must be more than words in order for us to understand everything persons with dementia are telling us. This includes looking for meaning in the feelings they are expressing.
Discussion: More Than Words Opening Exercise

**SAY**
So, everyone understands what to do next? Okay, maybe that wasn’t so clear!

**ASK**
How did that feel?

**SAY**
Maybe this is what persons with dementia feel like sometimes. When we speak to them, we assume that what we are saying is clear to them. But what if what they are hearing is more like what you just heard, can you imagine the frustration they must experience?

When persons with dementia communicate with us, they might not be able to find the words. It might sound to us like what you just heard.
Communicating with persons with dementia is about more than words. It is about trying to find meaning behind the words, trying to understand the feelings behind what people are saying.
More Than Words: Goal—Slide 3 of 6

Instructor Guidance:

We can now clearly state the goal of this lesson.

The goal of this lesson is to practice looking for the meaning behind the words when communicating with persons with dementia.
Here is the goal of this lesson presented more clearly! We are going to practice looking for the meaning behind the words when communicating with persons with dementia.
Exercise: More Than Words—Slide 4 of 6

Instructor Guidance:

In this exercise, participants are asked to interpret what someone is communicating, using more than words, and looking for the feelings behind the words.

Before the activity, print the handout on A-5 and cut out the slips so that you have one slip for each pair of participants. There are three different scenarios, so determine how many slips of each you need for your class.

Have the class work in pairs. Ask each pair to designate one member of the pair as A and one member as B.

Hand out one of the slips of paper to each A (so that pairs have different scenarios). Tell them to read and follow the instructions for sending the message on the slip. Tell Bs to try to interpret the message. Clarify that this is not a game of charades. Partners will allow A’s enough time to communicate the message and then give their interpretation. Give the participants two or three minutes. After the pairs are finished, use the questions on the next slide to discuss their experiences.

Scenario 1

Instructions: You may use only facial expressions and body language. You may not use words or noises.

Message you want to send: I have finished eating. I want to go lie down for a nap.
Scenario 2
Instructions: You must use only gibberish. You may **not** use understandable words. You may **not** use gestures or body language.

You say: Ebby bopo shoogy ma-kaa-daaaa.

Message you want to send: I need to go to the bathroom.

Scenario 3
Instructions: You may use gestures, facial expressions, and noises. You may **not** use words.

Message you want to send: Please help me. I feel alone.
This page intentionally left blank.
Exercise: More Than Words

**SAY**

We are going to do an exercise to practice understanding what someone with dementia might be saying to us.

**DO**

Have the class work in pairs. Ask each pair to designate one member as A and one member as B.

Hand out one of the instruction slips to each A (so that pairs have different scenarios).
SAY

In this exercise, the As will read the slip of paper and try to communicate the message to their partners using the instructions given. Pay careful attention to the instructions because they will tell you what you can and cannot do in trying to send these messages. The Bs will try to understand what their partners are saying. After a few minutes, we will come back together as a group and talk about what happened.
This page intentionally left blank.
Discussion: More Than Words—Slide 5 of 6

Instructor Guidance:

Once the pairs have completed the exercise, have the class go back to their seats.

Use these questions to discuss participants’ experiences.

First, ask the As to share their experiences.

• When you could not use words, did you still have something you were trying to communicate?

• How did you feel trying to get your message across?

Discussion might include:

• Participants still had a message to communicate, even though they could not use words.

• They had to rely on nonverbal communication to try to get their messages across.

• It was very frustrating to be limited in how they could communicate the message.

• Participants became angry because their partners could not understand. They might have also been angry with themselves because they couldn’t get their messages across.
• Some of the messages were urgent so it was very stressful to get the message across in the limited time.

Then ask the Bs to share their experiences.

• What do you think your partner was trying to tell you?
• What feelings did he or she try to communicate?
• How did you try to understand what your partner was saying?
• How did you feel trying to interpret your partner’s message?

Discussion might include:

• Although they could not clearly understand what their partners were trying to communicate, they had a sense of how they felt.
• They observed their partners’ nonverbal communication to try to understand.
• It was very frustrating to try to understand what their partners were saying.
• They wished they could have understood their partners better.
• They found themselves getting impatient with themselves and their partners.

Ask everyone:

How might we respond to persons with dementia when we don’t understand what they are saying but are trying to understand their feelings?
Answers might include:

- Say something to let them know you are listening and trying to understand. For example, “okay,” “I’m listening,” or “I’m here for you.”
- Let them know you are trying to help them.
- Walk with them.
- Make eye contact.
- Touch their arm to let them know you are present and listening.
Discussion: More Than Words

ASK

First, ask the As to share their experiences.

- When you could not use words, did you still have something you were trying to communicate?
- How did you feel trying to get your message across?

Then ask the Bs to share their experiences.

- What do you think your partner was trying to tell you?
- What feelings did he or she try to communicate?
- How did you try to understand what your partner was saying?
- How did you feel trying to interpret your partner’s message?
More Than Words: Summary—Slide 6 of 6

Instructor Guidance:

In this lesson participants explored understanding and practicing communication as more than words.
More Than Words: Summary

SAY

In this lesson we practiced looking for the meaning behind the words. Persons with dementia have challenges with listening and speaking. It is up to us to try to interpret what they are communicating by looking at the feelings behind the words.
VI. Conclusion

Congratulations!—Slide 1 of 2

Instructor Guidance:

This slide summarizes the topics covered in this module.
Conclusion

In this module, we have discussed being with a person with dementia—listening to and speaking with him or her. We started with understanding the brain changes that happen with dementia that result in communication challenges. When we understand how dementia affects someone and try to see things from his or her perspective—to step into his or her world—we can be better communicators.

Communication is not just about listening and speaking or sending and receiving messages. Listening is more than hearing what someone is saying; it is about understanding what that person is trying to say through both words and actions. Speaking is more than words. It is about the message you send to people with tone and body language.
Communication is about making someone feel *heard* and being present to him or her. It is about treating each other with dignity and respect, which are fundamental human needs.

**ASK**

What is one thing you learned or relearned from this module?
This page intentionally left blank.
Module 2 Video Clips—Slide 2 of 2

Instructor Guidance:

From this slide you can easily access any of the video clips in this module for review or additional discussion.

- Video Clip 1—Good Morning—Jane.
- Video Clip 2—Good Morning—Heather.
- Video Clip 3—Dr. Power.
This page intentionally left blank.
Appendix

Training Follow-Up Activity ................................................................. A-2
Handout: Good Morning Clip 2 ................................................................. A-3
Handout: Exercise: More Than Words .................................................... A-5
Training Follow-Up Activity

Instructor Guidance:

On a Post-it® Note, write down an area discussed in this module that you would like to improve upon and stick the note on the wall (or bulletin board) as an example for the participants. Ask participants to write down one area they want to improve upon and stick their notes on the wall or board as well.

Examples of good communication with persons with dementia:

- Talk slowly.
- Speak to them at eye level.
- Make eye contact.
- Ensure that body language and expressions match words.
- Do not approach from behind.
- Be patient.
- Maintain a positive attitude.
- Give instructions one at a time.
- Use clear, descriptive terms when speaking.
Good Morning Clip 2

Below are strategies that we can use to communicate more effectively with persons with dementia. Which of these did you see in the video clip? Check off the strategies you noticed the aide using with Mrs. Caputo.

___ Always identify yourself.
___ Call her by the name she prefers.
___ Keep in mind that, depending on the progression of the disease, she might not respond to certain names. For example, if she thinks she is in a time before she was married, she might not think of herself as “Mrs. ___.”
___ Be at her eye level.
___ Make eye contact with her.
___ Sit down with her if possible.
___ Really listen to her. Give her your complete attention.
___ Pay attention to your body language. It’s showing you are present to that person.
___ Use visual and verbal cues to get your message across.
___ Look at the body language of the person with dementia to see what she might be trying to communicate.
___ Give her enough time to talk or to respond.
___ Speak slowly.
___ Speak in short, simple sentences.
___ Be patient.
___ Be specific.
___ Ask one question at a time.
___ Give one direction at a time.
___ Repeat questions or instructions if needed.
___ Ask how you can help.
___ Tell her what you are doing or going to do.
___ Reassure her with words and touch.
___ Look for the feelings behind the words or actions.
___ Laughing with someone is a universal way to connect.
## Exercise: More Than Words

### Scenario 1

| Instructions: | You may use only facial expressions and body language.  
|               | You may **not** use words or noises. |
| Message you want to send: | I have finished eating. I want to go lie down for a nap. |

### Scenario 2

| Instructions: | You must use only gibberish. You may **not** use understandable words.  
|               | You may **not** use gestures or body language. |
| You say: | Ebby bopo shoogy ma-kaa-daaaa. |
| Message you want to send: | I need to go to the bathroom. |
### Scenario 3

<table>
<thead>
<tr>
<th>Instructions:</th>
<th>You may use gestures, facial expressions, and noises. You may <strong>not</strong> use words.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Message you want to send:</td>
<td>Please help me. I feel alone.</td>
</tr>
</tbody>
</table>
Module 3:
Being with a Person with Dementia:
Actions and Reactions
This page intentionally left blank.
Methodology

This module uses lecture, interactive discussion, and exercises.

(Total Time: 60 minutes)

<table>
<thead>
<tr>
<th>Estimated Time</th>
<th>Lecture and Discussion</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 minute</td>
<td>Opening Exercise</td>
<td>4</td>
</tr>
<tr>
<td>1 minute</td>
<td>Welcome</td>
<td>8</td>
</tr>
<tr>
<td>1 minute</td>
<td>Module Objectives</td>
<td>18</td>
</tr>
<tr>
<td>2 minutes</td>
<td>Actions and Reactions: Introduction</td>
<td>20</td>
</tr>
<tr>
<td>10 minutes</td>
<td>I Want to Go Home</td>
<td>28</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Actions and Reactions: Why?</td>
<td>42</td>
</tr>
<tr>
<td>15 minutes</td>
<td>Actions and Reactions: Ways to Respond</td>
<td>82</td>
</tr>
<tr>
<td>15 minutes</td>
<td>Brainstorming</td>
<td>128</td>
</tr>
<tr>
<td>5 minutes</td>
<td>Conclusion</td>
<td>162</td>
</tr>
</tbody>
</table>

Appendix

Handout: Brainstorming Worksheet ........................................................................................................ A-3

Training Resources

- Computer capable of playing an .ISO file.
- Downloaded .ISO file for Module 3.
- Module 3 Instructor Guide.
- Pens, pencils, and writing tablets.
- Handout.
- Easel chart.
- Post-it® Notes and markers.

Instructor Preparation

I. Opening Exercise

Opening Exercise—Slide 1 of 7

Instructor Guidance:

As participants enter the classroom, hand each one three Post-it® Notes and a marker. Once they are seated, ask them to write down three behaviors of persons with dementia, one on each Post-it® Note. Then ask them to post their notes on an easel chart or wall at the front of the room.

If participants need clarification, try asking these questions:

- What behaviors do you see in people living with dementia?
- What are common behaviors of people living with Alzheimer’s or dementia?

Note to instructor: The purpose of this exercise is to have participants identify behaviors of persons with dementia. Likely answers will include yelling, hitting, kicking, wandering, hoarding, exit seeking, and so on. Later in the module, the point will be made that the term behavior suggests mostly negative things. In this opening exercise, there are no wrong answers. Participants might also identify positive behaviors, like hugging, and these should be included.
Once everyone has finished, read aloud some of the responses, especially if they are not visible to the entire group. Do not label behaviors as negative or positive at this point—just read them from the list.

You will come back to the responses on the Post-it® Notes later in the training.

Materials Needed:

- Post-it® Notes and markers.
Opening Exercise

DO

As participants enter the classroom, hand each one three Post-it® Notes and a marker. Once they are seated, ask them to write down three behaviors of persons with dementia, one on each Post-it® Note. Then ask them to post their notes on an easel chart or wall at the front of the room.
II. Welcome

Welcome to Module 3: Being with a Person with Dementia: Actions and Reactions—Slide 2 of 7

Instructor Guidance:

If the participants do not know one another, have each participant state his or her name, position, and where he or she works in the nursing home. Be sure to pass out a sign-in sheet to track attendance.

You will want to ensure that participants are comfortable and that they know who you are. When you introduce the module, be sure to cover the points in the SAY section.

Note: Module 3 may take longer than one hour, especially if the video clips and exercises generate in-depth discussion or questions. If you have only one hour and cannot complete the entire module in that time, you may choose to conclude the presentation after the third lesson, Actions and Reactions: Ways to Respond, and to complete the final lesson, Brainstorming, in a separate training session. You will want to complete that lesson as soon as possible; it allows participants to practice what they have learned and then summarizes the module’s learning objectives in a video. Providing adequate time to practice the brainstorming skills is important.
Module 2 provides an overview of communicating with persons with dementia. It is suggested that students complete Module 2 before Module 3. If this is not possible, you might find it helpful to review Module 2. A summary review of all five modules is found in the Orientation Guide.
Welcome to Module 3: Being with a Person with Dementia: Actions and Reactions

**DO**

- Greet participants.
- Welcome participants to the training.
- Have participants introduce themselves (if they don’t know one another).

**SAY**

This module is about understanding the behaviors of persons with dementia. Behavior, or how a person acts, is a form of communication. It is important to look at all the possible reasons behind a person with dementia’s actions to understand what the person might be trying to tell us.
Throughout this training you will notice that we use the term *person with dementia* rather than dementia patient or Alzheimer’s patient. The term person with dementia reminds us to put the person first and to look beyond the diagnosis.
This page intentionally left blank.
Being with Persons with Dementia Overview—Slide 3 of 7

Instructor Guidance:

Four of the modules in this Hand in Hand training series are about caring for persons with dementia. Three of the titles share a common introduction: Being with a Person with Dementia.

Being with a person with dementia means understanding his or her world by trying to see it from his or her perspective—trying to be with the person where he or she is. Being with a person with dementia is different from doing for. Being with persons with dementia recognizes them as whole individuals, who have strengths as well as weaknesses, unique needs, preferences, and histories. By building on strengths and knowing who they are as individuals, we support persons with dementia to do as much as they can and to live meaningfully.

Here are the titles in the Being with a Person with Dementia series:

Module 1: Understanding the World of Dementia: The Person and the Disease
Module 2: Being with a Person with Dementia: Listening and Speaking
Module 3: Being with a Person with Dementia: Actions and Reactions
Module 4: Being with a Person with Dementia: Making a Difference
SAY

This module is one of four modules on dementia. Three of the module titles begin with *Being with a Person with Dementia*. Being with a person with dementia means:

- Understanding the world of persons with dementia by trying to understand things from their perspective.
- Being with persons with dementia “where they are.” This means meeting them in their world, in their understanding of what is happening around them, and in what they are able to do and what they need help with.
- Recognizing persons with dementia as whole individuals, who have strengths as well as weaknesses, unique needs, preferences, and histories.
• Building on strengths and knowing who they are as individuals.
• Supporting persons with dementia to do as much as they can and to live meaningfully.
• Connecting with persons with dementia through communication, laughter, touch, and so on to validate them as human beings and as equals.
• Recognizing that sometimes the best way we can support persons with dementia is to just be with them, to sit with them, and to listen to them.
This page intentionally left blank.
III. Module Objectives

Instructor Guidance:

It is important to set participant outcomes by stating the module objectives. It is not necessary to explain the objectives on this screen; you are only introducing the anticipated instructional outcomes. Remember, this screen should take only one minute.
Module Objectives

SAY

We will be looking at behaviors a little differently in this training. At the end of this training, you will be able to:

- Understand behaviors of a person with dementia as actions and reactions that are forms of communication.
- Evaluate possible reasons behind the actions and reactions of a person with dementia.
- Identify ways to prepare for, prevent, or respond to actions and reactions of a person with dementia.
IV. Actions and Reactions: Introduction

Instructor Guidance:

This slide is the framework for our discussion of behaviors throughout this training. It is important to make the point that when we think of behaviors of persons with dementia, we typically think of negative or problematic ones.

In this training we will look at behaviors differently; we will look at them in terms of actions and reactions—the way we act and the way we respond to others and react to situations. When we reframe behaviors as actions and reactions, it helps us to see them not just as problematic or negative. It also reminds us to look for the meaning behind the actions.

Traditionally, certain behaviors have been associated with persons with dementia. Refer to the Post-it® Notes written during the opening exercise and point out that many of the behaviors identified are considered “problems.” Behaviors that are considered problematic might include:

- Wandering.
- Yelling.
- Agitation.
- Repeating questions.
• Saying the same thing repeatedly.
• Forgetting words.
• Aggressive behavior (hitting, kicking, biting).
• Sundowning.
• Hoarding.
• Exit-seeking.
• Repetitive actions.
• Paranoia and suspiciousness.
• Refusing care (refusing to bathe, dress, etc.).
• Hallucinating.
• Anxiety.
• Trouble sleeping.

If participants identified behaviors that are clearly positive (for example, hugging, singing, dancing, smiling), point these out and emphasize that we know behaviors can be positive as well.

In person-centered care, behaviors are seen as a form of communication. Understanding what a behavior means helps us meet the needs of persons with dementia.

Notes:
This page intentionally left blank.
Actions and Reactions: Introduction

SAY

What do we think of when we think about behaviors of persons with dementia? Let’s look at the behaviors you identified earlier.

DO

Refer to the Post-it® Notes from the opening exercise. Read out loud the behaviors that participants identified.

SAY

When we think about behaviors of persons with dementia, we almost always think of them as negative, bad, or challenging.

When we think about the way we behave, we don’t think of behaviors in the same way. In fact, we don’t usually think of them as behaviors—they are just the way we’re acting.
So, let’s think about behaviors of persons with dementia in a different way. Let’s think of them as the person’s actions and reactions to the world around him or her.

We all have actions and reactions. An action is something you do. A reaction is how you respond to what someone else has done or to a situation.

When we think of behaviors as actions and reactions it helps us understand that behaviors are a form of communication. It also helps us understand that the behaviors we see in persons with dementia may well be reactions. It forces us to dig deeper to try to understand why a person is acting that way.
Module 3 Menu

Module 3 Menu—Slide 6 of 7

Instructor Guidance:

The menu screen allows you to easily navigate through the module lessons. It is intended for the class to go through all the lessons in order so that participants can build upon what they learn. However, you can easily return to any of the lessons or video clips for a refresher. At the end of the module, you can click the forward arrow at the bottom of the screen to go to Module 3 Video Clips. These are the same video clips used in the lessons; they are available to you for review and discussion once all lessons have been covered.

Notes:
Module 3 Menu

SAY

Let’s start with “I Want to Go Home.”

DO

On the menu, click the first lesson, “I Want to Go Home.”
V. I Want to Go Home

I Want to Go Home: Goal—Slide 1 of 6

Instructor Guidance:

The goal of this lesson is to begin to understand the meaning behind the actions of persons with dementia by looking at an example of a specific action. Saying “I want to go home” is a common action of persons with dementia.

Asking the participants whether they have observed this action is not intended to start a lengthy discussion, but to validate that this is an action they have experienced.

If the participants have never experienced this action, tell them they will see an example in this lesson.
I Want to Go Home: Goal

SAY

We regularly see certain actions in persons with dementia. One common action is a resident saying, “I want to go home.”

ASK

Have any of you heard that from one of your residents with dementia?
Exercise—Slide 2 of 6

Instructor Guidance:

In this exercise, the class will brainstorm what home means to them. The purpose of this exercise is to show the participants that home means many things to people.

When a resident with dementia says “I want to go home,” she may be trying to communicate many things about what home means to her. Understanding what home might mean to a resident with dementia will help participants know how to respond to this action.

Materials Needed:

- Easel chart.
- Markers.

Ask, What do you think of when you see or hear the word home? What does home mean to you?

(Note: To get the discussion started, you might want to volunteer what home means to you. For example, “Home means being with my dog, eating the food I like, and relaxing.”)

Write participants’ responses on the easel chart. Note that there are no right or wrong responses in this exercise and that responses are all different.

Notes:
Exercise

ASK

What do you think of when you hear or see the word *home*? What does home mean to you?

DO

Write participants’ responses on the easel chart.

SAY

As we look at the responses, notice how different they are. Home means something different to each of us. It means more than just the physical place we live in. We are going to come back to this a little later.
Play Video Clip: I Want to Go Home—Slide 3 of 6

Instructor Guidance:

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen. Use the questions to lead a discussion about the clip.

This clip shows Mrs. Caputo, a nursing home resident with dementia, who wants to go home. It will prompt additional discussion about the reasons persons with dementia might say they want to go home.
Play Video Clip: I Want to Go Home

SAY

Home means different things to all of us. Let’s look at an example of a resident who wants to go home.

DO

Click the forward arrow to play the clip.
Discussion—Slide 4 of 6

Instructor Guidance:

After the clip, facilitate a group discussion, using the questions below in the order given.

What were Mrs. Caputo’s actions?

Possible answers are:

- She said she wanted to go home.
- She tried to leave the building.
- She banged on the glass.
- She said she needed to get to her children.

Note: It is important that participants recognize Mrs. Caputo’s saying that she wanted to go home as an action. If they do not identify this, ask a more direct question: What specifically was Mrs. Caputo saying? When they respond that she wanted to go home, make the point that Mrs. Caputo’s behavior of saying she wants to go home can be seen as an action.

What was the aide’s (Arthur’s) reaction?
Possible answers are:

- He told her she lived in the nursing home.
- He tried to get her out of the room and away from the door.
- He tried to distract her with a movie.

For a more guided discussion (if you have time), use the following questions in the order given.

What emotions was each person experiencing? How did Mrs. Caputo seem to feel?

Possible answers are:

- Anxious.
- Angry.
- Frustrated.
- Desperate.
- Determined.
- Agitated.

(Note: If the participants seem focused on describing her behavior as “agitated,” ask them to describe it in other ways. Although we tend to label this type of action as agitation, it is important for participants to try to see it differently, particularly the emotion behind the action.)

How did Arthur seem to feel?
Possible answers are:

- Frustrated.
- Angry.
- Impatient.
- Tired.

Can you relate to Arthur or Mrs. Caputo?

If participants have difficulty responding to this question, ask some follow-up questions to help them see that both Mrs. Caputo and Arthur had needs with which participants can identify.

For example, ask, “What did Arthur want?”

- He wanted to get off work so he could pick up his kids.

What did Mrs. Caputo want?

Possible answers are:

- She wanted to go home.
- She wanted to get to her children.
Discussion

SAY

Let’s talk about what happened in this clip.

ASK

- What were Mrs. Caputo’s actions?
- How did the aide, Arthur, react?
- What was Arthur feeling? What was Mrs. Caputo feeling?
- Can you relate to Arthur or Mrs. Caputo?
Instructor Guidance:

This slide sets the stage for the next lesson. Understanding the reasons behind a person with dementia's actions will help us understand what he or she is communicating. When we understand what the person is communicating, then we can determine how to respond.
Understanding the Action

SAY

If all behaviors or actions are a form of communication, we must try to understand their meaning.

Why was Mrs. Caputo acting like that? What was she trying to tell us through her actions? Let’s take a step back and look at the possible reasons behind the actions of persons with dementia. Then we’ll come back to Mrs. Caputo.
I Want to Go Home: Summary—Slide 6 of 6

Instructor Guidance:

In this lesson participants saw a specific example of a person with dementia saying she wanted to go home.

To review, ask the participants:

What one thing have you learned or relearned from this lesson?
I Want to Go Home: Summary

ASK

What one thing have you learned or relearned from this lesson?
VI. Actions and Reactions: Why?

Actions and Reactions: Why?: Goal—Slide 1 of 14

Instructor Guidance:

The goal of this lesson is to understand reasons why a person with dementia might act, or react, in a certain way.

Notes:
Actions and Reactions: Why?: Goal

SAY

There are many reasons why persons with dementia might act the way they do. All actions are a form of communication. Whatever the action, we must first try to understand why. Even though we may never know exactly why, trying to understand the world of a person with dementia helps us better understand what he or she is experiencing and what he or she needs. Then we can brainstorm how to respond.
Reasons—Slide 2 of 14

Instructor Guidance:

This slide is an overview of some possible reasons behind the actions of persons with dementia.
Reascons

SAY

In this lesson we’ll look at a number of possible reasons behind the actions of a person with dementia, including health conditions, medications, communication, the environment, the task, unmet needs, the resident’s life story, and you (caregivers).
Health Conditions—Slide 3 of 14

Instructor Guidance:

Many health conditions and symptoms may cause persons with dementia to act a certain way. This lesson mentions just a few. Make the point that a person’s emotional and physical health may impact how he or she acts.
Health Conditions

SAY

Consider how you may act when you are not feeling well. The reasons behind the actions of a person with dementia may be related to his or her health—both emotional and physical. Maybe he or she is depressed, in pain, or just not feeling well. A common health condition that causes people to act differently is a urinary tract infection. Some other health reasons could be:

- Pain.
- Problems with vision or hearing.
- Acute illness (short-term conditions like colds, stomach upsets, diagnostic procedures).
- Chronic (ongoing) illness such as diabetes or arthritis.
- Dehydration.
- Constipation.
- Fatigue.
- Anxiety.

Note that these are just examples and many other health conditions could be the cause.
This page intentionally left blank.
Instructor Guidance:

All medications, not just those used specifically to treat dementia, can affect the way a person with dementia acts. Caregivers need to observe residents for any changes when medications are adjusted, or new medications are started.
Medications

SAY

Medications can cause persons with dementia to act in certain ways. A new medication might have side effects that cause a person with dementia to act differently. For example, he or she might be more confused, angry, or disoriented. Report any changes in behaviors or conditions you observe (including physical, mental, and emotional changes) to the nurse who supervises you and ask whether the resident has started a new medication or whether a medication has been adjusted. Document the changes you see in the resident’s medical record. When trying to understand the actions of a person with dementia, consider that medications, both new and existing, could be the source.
Communication—Slide 5 of 14

Instructor Guidance:

We have to look at all actions of persons with dementia as a form of communication. Actions might be telling us something that a person with dementia cannot communicate with words.

Also, the way we communicate with persons with dementia can cause reactions, sometimes negative ones.

In Module 2, we looked at effective and ineffective ways of communicating with persons with dementia. Although we are not reviewing them in this module, here is a summary of communication strategies in case you need to provide examples.

- Always identify yourself.
- Call the person by the name he or she prefers.
- Keep in mind that, depending on the progression of dementia, he or she might not respond to certain names. For example, a resident who thinks she is in a time before she was married might not think of herself as “Mrs. ___.”
- Be at his or her eye level.
- Make eye contact with him or her.
- Sit down with him or her if possible.
- Really listen to him or her. Give him or her your complete attention.
- Pay attention to your body language. Is it showing you are “present”?
• Use visual and verbal cues to get your message across.
• Look at the body language of the person with dementia to see what he or she might be trying to communicate.
• Speak slowly.
• Speak in short, simple sentences.
• Be patient.
• Give him or her enough time to talk or to respond.
• Be specific.
• Ask one question at a time.
• Give one direction at a time.
• Repeat questions or instructions if necessary.
• Ask how you can help.
• Tell him or her what you are doing or going to do.
• Reassure with words and touch.
• Look for the feelings behind the words or actions.
• Laughing with someone is a universal way to connect.
• What are some things to avoid?
  o Using no, don’t, or other negative words.
  o Arguing with someone with dementia, even when you know that what he or she says is wrong. It might be right to him or her!
Communication

SAY

Because behavior is a form of communication, we must try to identify what a person’s behavior or action is trying to tell us. For example, when a person with dementia is “wandering,” he or she may be looking for something or someone—a bathroom, an aide, or a family member—or something to do.

Dementia causes changes in the way people send and receive messages. Their reactions to our actions, including what we say and how we do things, might also be seen as behaviors.

When you’re trying to understand the reaction of a person with dementia to something you have said or done, think about how you approached him or her. Were you calm? Were you at eye level? Did you speak simply and clearly? Could his or her reaction be related to the way you communicated?

Remember, we must change the way we communicate because persons with dementia might not be able to.
Environment—Slide 6 of 14

Instructor Guidance:

The environment, or a person's surroundings, is another reason behind the actions and reactions of persons with dementia. Understanding how the environment affects the reactions of a person with dementia can help us determine how to respond. It might be helpful to avoid or modify environments that cause negative reactions.
Their environment, or surroundings, can cause reactions in persons with dementia.

When we talk about the environment, it means many things. The environment includes the way things look and are laid out, sounds, smells, temperature, and even people. A person with dementia might react negatively to an environment that is:

- Too large.
- Excessively stimulating.
- Not easy to get around.
- Cluttered.
• Noisy.
• Unfamiliar.
• Poorly lit.

For example, a person with dementia in a dark hallway or room might react to the environment with fear. In a noisy environment, he or she might have a negative reaction because the noise is too loud.

The environment also has emotional aspects that residents can feel. For example, a resident with dementia might try to leave an environment that feels rushed and busy.
This page intentionally left blank.
The Task—Slide 7 of 14

Instructor Guidance:

Persons with dementia might react negatively to being helped with certain tasks. It helps to see things from their perspective. If we think about why they are reacting to a task, then we can modify or avoid that task.
The Task

SAY

A person with dementia might react to doing, or being helped with, certain tasks. The task itself might be the reason behind the person’s actions and reactions if the task is:

- Not enjoyable.
- Not something he or she wants.
- Embarrassing.
- Painful.
- Too complicated or has too many steps.
- Unclear or confusing.
• Not broken down enough to be accomplished successfully.

• Unfamiliar.

• Generally difficult.

• Something he or she would like to do, but is not able to do. For example, if a person with dementia is frustrated during meals, it might be because he or she cannot use the utensils easily or is confused about where to start.
This page intentionally left blank.
Unmet Needs—Slide 8 of 14

Instructor Guidance:

An unmet need can be the reason behind actions and reactions. An unmet need might be as simple as a physical need to go to the bathroom, but it might also be an emotional need for security, control, love, or companionship. Because a person with dementia might not be able to clearly articulate what he or she needs, he or she might communicate through actions.

Refer back to the “Home” exercise. Review participants’ responses to what home means to them. For many of us, home means much more than the physical space in which we live. It is also the things that are important to us, such as our families, pets, or favorite things. It can also be security or comfort.

Make the point that sometimes when persons with dementia talk about going home, they are talking about an unmet need. They might be talking about wanting to feel comfortable, safe, or secure. They might be remembering the things about home that were important to them and wishing they could have those things again.
Unmet Needs

SAY

A person with dementia might act in a certain way if he or she has needs that are not being met. Sometimes these needs might be as simple as needing to go to the bathroom. If the resident is unable to use words, he or she might have to use actions instead. Knowing your resident will help you recognize these signs.

Unmet needs can also be emotional. We all need safety, security, a sense of control, love, and companionship. A person with dementia who is sad or anxious might not be able to verbally express these emotional needs, but might do so through his or her actions.

Think back to the exercise we did earlier about the meaning of home.

DO

Refer back to the easel chart used for the “Home” exercise. Read aloud some of the things people said home means to them.
SAY

As we saw in this exercise, home means different things to each of us. It is much more than just the physical space we live in.

ASK

Think about a person with dementia who wants to go home. Is it possible that he or she is talking about an unmet need? That he or she just wants to feel safe and secure, like we do at home? That he or she is missing family and wanting to be with people he or she loves? Is he or she lonely? For many of us, going home at the end of the day is a habit. Maybe a person with dementia wants to do familiar activities that were always a part of his or her life.
Instructor Guidance:

Knowing residents, who they are now and who they were, is fundamental to understanding their actions and reactions.
Every person who lives in a nursing home has a life story—who they are, where they came from, what they did, what their family was like, where they lived—and we do not always know the whole story. Persons with dementia might not be able to tell us their whole life story, but their actions might be related to their pasts.

For example, a resident with dementia might get up at 4 a.m. and want to go to work. Perhaps that resident was a farmer or a nurse who wants to do rounds on the other residents. Knowing your residents and understanding their life stories will help you understand what they need and how to respond to those needs.
Instructor Guidance:

Staff can also cause persons with dementia to act or react in a certain way—they may “trigger” reactions. All of us, including persons with dementia, connect with certain people more easily than with others.
You

SAY

It is possible that a person with dementia is reacting to you. Perhaps you remind a resident of her favorite granddaughter and she wants to see you all the time. Or maybe you remind her of someone she didn't like earlier in her life.

Perhaps she is reacting to your actions. Are you impatient? Rushing around? Can the resident sense your frustration? Maybe she is reacting to that. Or maybe, for no reason you can understand, you are unintentionally upsetting her, and she wants nothing to do with you today.
Instructor Guidance:

This slide reinforces the importance of understanding the reasons behind residents’ actions and reactions. When we know why a person is acting in a certain way, we can consider how to respond in a way that meets that person’s needs.
Understanding the Reasons

SAY

So, why is it important to understand why? There might be a number of reasons why a person with dementia is acting a certain way. Whatever the actions, we need to understand that they are a form of communication. When we understand the reasons behind the person’s actions, we can better respond to his or her needs. Even when we are unable to determine a reason, actions tell us something about who the person is. Sometimes they may simply tell us where the person is in his or her experience of dementia, and they might be a sign that he or she is progressing. Our response might be to reassure and just be with the person.

Keep in mind that each person is an individual. Each person has different reasons for his or her actions and might need a different response. Being with a person with dementia means seeing things from his or her unique perspective and responding to that person as an individual.

So, let’s take a look back at how to respond to one individual—Mrs. Caputo.
Play Video Clip: I Want to Go Home—Slide 12 of 14

Instructor Guidance:

Show the clip of Mrs. Caputo again—I Want to Go Home. After the clip, lead a brief discussion with the participants.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen.
Now that we have considered the possible reasons behind the actions of a person with dementia, let’s look again at Mrs. Caputo’s specific situation.

Say:

Now that we have considered the possible reasons behind the actions of a person with dementia, let’s look again at Mrs. Caputo’s specific situation.

Do:

Click the forward arrow to play the clip.
Discussion—Slide 13 of 14

Instructor Guidance:

Why might Mrs. Caputo be saying she wants to go home?

Possible answers are:

- She remembers a time when she had to pick up her kids from school.
- She is homesick.
- She is bored.
- She is lonely.

Think about other residents. What are some other things a resident might mean when they say they want to go home?

- He or she might be remembering his or her home. Home could be any home he or she lived in throughout his or her life—his or her childhood home, his or her home with a spouse and children, or the home he or she left before coming to the nursing home.
- He or she could be talking about going home, as in dying.
- He or she may have a sense of going home at the end of a workday, which is a normal adult activity.
- He or she could be talking about one of the meanings of home that participants mentioned in the activity earlier (refer to the easel chart).

If participants need a reminder, review the reasons behind a person’s actions that we discussed in the lesson: health (physical and emotional), medications, communication, environment, the task, unmet needs, life story, and you.
This page intentionally left blank.
Discussion

ASK

- What are some of the reasons Mrs. Caputo might be saying she wants to go home?

- Think about other residents. What are some things residents might mean when they say they want to go home?

SAY (after participants have answered questions)

As we pointed out earlier, home means many things to each of us, as it may for a resident with dementia. Knowing your residents will help you understand the why behind their actions.
In this lesson we have discussed a number of reasons behind the actions and reactions of a person with dementia.
Actions and Reactions: Why? Summary

ASK

What is one thing you have learned or relearned from this lesson?
VII. Actions and Reactions: Ways to Respond

Instructor Guidance:

The goal of this lesson is to describe and demonstrate ways to respond to the actions of a person with dementia. It is important for participants to understand that each person with dementia is an individual. Although two residents might have the same action, there may be distinctly different reasons for their behaviors, and caregivers need to respond to each person individually. Being with a person with dementia means responding to that individual in a way that honors his or her unique perspective and needs.
Actions and Reactions: Ways to Respond: Goal

SAY

This lesson will provide examples of ways to respond to actions of persons with dementia.

It will also teach you questions to ask about a resident’s action that will help you think of your own person-centered responses.
Making the Connection—Slide 2 of 14

Instructor Guidance:

The purpose of this slide is to make the connection between understanding the reasons behind an action and responding to the action in a person-centered way.

Earlier in the training we noted that behaviors in people with dementia are typically seen as problematic. However, it is important participants understand that before they determine how they will respond to an action, they need to evaluate whether the action is truly a problem in the first place. For example, we may label a resident’s walking around the building as “wandering behavior.” But if the resident walks around the building because he enjoys walking, is this “behavior” a problem? Is it a matter of health or safety for anyone?

In evaluating these questions, a team approach works best. Teams include people from all departments—dining, housekeeping, nursing, administration, and so on. Encourage participants to recognize the value of a team discussing the resident’s actions and possible responses. Each member of the team has a different perspective and has something different to offer.
Making the Connection

SAY

We understand that persons with dementia might act or react in certain ways, and we have looked at a number of reasons behind the actions of persons with dementia. Understanding the why helps us with the next step—identifying how to respond.

As you are thinking about how to respond to an action, ask yourself, Do I need to do anything? Is this a matter of health or safety for anyone? If it is a question of health and safety, then you need to intervene. Another way to ask this is, Whose problem is it? If the action is not hurting the resident or anyone else, perhaps it is not a problem for anybody—it is just the way the resident acts. For example, we may label a resident’s walking around the building as “wandering behavior.” But if the resident walks around the building because he enjoys walking, is this “behavior” a problem? If it is not a matter of health or safety, perhaps the response is simply to let the resident walk around.
Ways to Respond—Slide 3 of 14

Instructor Guidance:

This slide introduces questions participants can ask themselves to identify ways to respond to the actions of a person with dementia.

We can think about them as the three Ps: prepare, prevent, and respond in the present.
SAY

In coming up with ways to respond to actions and reactions, there are a few questions you can ask yourself. Let’s think about them as the three Ps. How can you prepare, prevent, be present?

We’ll look at each of these ways to respond.
Prepare—Slide 4 of 14

Instructor Guidance:

Prepare: There are some actions and reactions of persons with dementia that you might anticipate. You might ask yourself:

- Knowing that this person will act or react in a particular way, are there things I can do to prepare myself or others to respond to the action?
- Do I need to ensure I am available to a person with dementia at a certain time of day if that is when his or her action occurs?
- Do I need to prepare others to know how to respond to this action if I am not available?

Here are some examples:

- You know that the overhead paging system confuses Mr. C, a resident with dementia. He thinks it is the loudspeaker at the factory where he used to work, announcing that it’s time to leave. How might you prepare for when this inevitably happens?
One way to respond might be to say, “Mr. C, it is okay. I understand. I need you here.” (Note: This might be a good opportunity to discuss with the class the distinction between lying and being with someone in his or her world. An example of lying to a person with dementia in this situation would be saying, “Mr. C, the factory needs you to stay and work late.” This is untrue and might further confuse the person with dementia. If the person with dementia suspects that you are lying to him or her, it also threatens your trusting relationship. Being with someone in his or her world means truly trying to understand the person’s emotion and what he or she needs. In this situation, the person with dementia expresses anxiety and confusion because he thinks it is time to leave work and go home. Being with him in his world necessitates a caring response to try to relieve his anxiety and reassure him that he does not need to leave.)

- Mrs. B, a resident with dementia, gets very sad when her daughter leaves after a visit, crying and asking to go see her daughter. How can you prepare for Mrs. B’s action?

One way to respond might be to prepare an activity in which you can engage Mrs. B after her daughter leaves. The activity needs to be meaningful to her.
This page intentionally left blank.
Prepare

SAY

Prepare: There are some actions and reactions of persons with dementia that you might anticipate. When you understand the reason behind an action, you might be able to prepare your response to that action. You might ask yourself:

- Knowing that this person will act or react in a certain way, are there things I can do to prepare myself or the person with dementia to respond to the action?
- Do I need to ensure I am available to a person with dementia at a certain time of day when his or her action occurs?
- Do I need to prepare others to know how to respond to this action if I am not available?
Prevent— Slide 5 of 14

**Instructor Guidance:**

Prevent: You may be able to prevent some actions and reactions of persons with dementia altogether. Some questions you might ask yourself are:

- How could this action be prevented?
- How could I redirect the person with dementia to avoid this action?
- Is there a need I can meet (so that the person with dementia does not have to express his or her need through these actions)?
- What seems to trigger the action? How could I intervene to prevent the action when I see that trigger?

Here are some examples:

- Mr. R, a resident with dementia, walks up and down hallways and into other people’s rooms. You have identified that this happens when he needs to go to the bathroom. How might you prevent Mr. R’s action?
  
  One response might be taking Mr. R to the bathroom on a regular and frequent basis so that he does not need to look for a bathroom.

- You have noticed that Mrs. J, a resident with dementia, becomes very upset at shift change. As staff are leaving and new staff are coming, she starts to verbalize loudly, “Don’t go,” and tries to leave the building. How might you prevent Mrs. J’s actions?
  
  One way might be to invite Mrs. J to a quieter place during shift change.
Prevent

SAY

Prevent: There are some actions and reactions of persons with dementia that you might be able to prevent altogether. Some questions you might ask yourself are:

- How could this action be prevented?
- How could I redirect the person with dementia to avoid this action?
- Is there a need I can meet (so that the person with dementia does not have to express his/her need through these actions)?
- What seems to trigger the action? How could I intervene to prevent the action when I see those triggers?
Present—Slide 6 of 14

Instructor Guidance:

Present: You might not be able to prepare for or prevent some actions and reactions of persons with dementia. Your response will be “in the present” as the action is happening or has happened. To determine your response, you might ask yourself:

- How can I respond to the immediate need of this person?
- How can I be with this person?
- How can I redirect this person?
- How can I remove the source of frustration or remove the person from the source of frustration?
- How can I make sure everyone is safe?

Here is an example:

- Mr. K, a resident with dementia, gets very upset at different times of the day when he is reminded of his wife in some way. It is hard to pinpoint what triggers this, and there is not much that can be done to prepare for his actions as they are often unanticipated. How might you respond to Mr. K in the present moment when he is upset?

  One response might be to touch him on the arm, make eye contact, and reassure him that you understand and are there for him.
As you think through these questions, think about having a toolkit of responses that are ready for you when you need them. There are some general responses you can have in your toolkit that might be helpful in all of these situations. They are things you can say to residents to respond to their emotions, redirect them, and so on. For example:

- I need your help.
- I need you.
- Will you please help me?
- May I help you?
- I understand.
- I understand what you are saying.
- I understand how you feel.

In thinking through these questions, it works best to brainstorm as a team why a resident might be acting a certain way and how you can respond to him or her. Remember, teams include people from all departments—dining, housekeeping, nursing, and administration, for example.
This page intentionally left blank.
Present

SAY

Present: There are some actions and reactions of persons with dementia that you might not be able to prepare for or prevent. Your response will be “in the present” as the action is happening or has happened. To determine your response, you might ask yourself:

- How can I respond to the immediate need of this person?
- How can I be with this person?
- How can I redirect this person?
- How can I remove the source of frustration or remove the person from the source of frustration?
- How can I make sure everyone is safe?
In the next few clips we will show some specific examples of ways to respond to Mrs. Caputo using the guide of prepare, prevent, be present.
This page intentionally left blank.
Responding to the Action—Slide 7 of 14

Instructor Guidance:

In the last few slides we made the connection between identifying the reasons behind actions and developing responses to actions. We looked at the thought process in developing responses to prepare, prevent, and be in the present. To pull this all together, we'll go back to the example of Mrs. Caputo and consider ways we might respond to her actions. In the last lesson we talked about the reasons why she might be saying she wants to go home. In thinking about how to respond, participants should identify that they need to respond since it would be dangerous for Mrs. Caputo to attempt to leave the building unattended. Mrs. Caputo’s need to go home also causes her frustration and anxiety, so responding to her emotional needs is equally important.

Mrs. Caputo commonly says she wants to go home so this is an anticipated action. How might you prepare yourself or others for Mrs. Caputo’s action?

Some possible answers:

- You are having a particularly bad day and do not think you will be able to respond to Mrs. Caputo with the patience she needs, so you might consider asking someone else to respond to her.

- You might identify an activity or event that Mrs. Caputo would enjoy, and use the activity to redirect her.

How might you prepare other staff to respond to Mrs. Caputo’s action of wanting to go home?
Some possible answers are:

- Share ways of responding to her with your coworkers.
- Communicate with your coworkers the possible meanings of Mrs. Caputo’s action of wanting to go home.
This page intentionally left blank.
Responding to the Action

SAY
Let’s look at Mrs. Caputo again and use her as an example of how to respond.

When we ask ourselves, Do I need to do anything? or Who is this action hurting?, it is clear that we need to respond to Mrs. Caputo’s actions. She is distressed, and we want to help her feel better. We also want to prevent her from going outside unattended since that is unsafe.

Because this is a common action that you can anticipate for Mrs. Caputo, let’s talk through how you might prepare for this action.

ASK
• How might you prepare yourself to respond to Mrs. Caputo’s action of wanting to go home?
• How might you prepare other staff to respond to Mrs. Caputo’s action of wanting to go home?
Play Video Clip: I Want to Go Home: Preventing—Slide 8 of 14

Instructor Guidance:

Show the clip. After the clip lead a brief discussion with the participants.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion screen.
Another way to approach the situation would be to try to prevent it. If we know that Mrs. Caputo acts this way at a certain time of day, we might think about how to distract her at this time to prevent her thinking about going home. Let’s look at an example.

Click the forward arrow to play the clip.
Discussion—Slide 9 of 14

Instructor Guidance:

After you show the clip, facilitate a brief discussion.

How did the aide, Maria, respond to Mrs. Caputo?

Possible answers are:

- She reassured her.
- She listened to her.
- She invited her to participate in cooking.
- She distracted her before she tried to go home.

Note: It is important to point out that Maria found Mrs. Caputo before she normally started wanting to go home and prevented her action by validating and distracting her.

How did Mrs. Caputo react?

- She was interested in cooking and went with Maria.
How was this different from the clip we saw earlier?

- Maria prevented the situation from escalating.
- Maria did not argue with Mrs. Caputo or physically stop her from leaving.
- Maria did not say “no” or “you can’t.” She validated Mrs. Caputo’s need and redirected her.
This page intentionally left blank.
Discussion

ASK

• How did the aide, Maria, respond to Mrs. Caputo?

• How did Mrs. Caputo react?

• What was different from the first clip we saw?

SAY

Notice that the activity the aide used to redirect Mrs. Caputo was something that was meaningful to Mrs. Caputo—she liked baking. If the aide had tried to redirect her with something that was not important to her or something she couldn’t do, the redirection might have only worked for a few minutes or not at all.
Instructor Guidance:

Now we’ll look at a way of responding to Mrs. Caputo in the present moment. In this example, the aide, Gloria, responds to her need by going outside with her. This validates Mrs. Caputo’s feelings of anxiety and her need to go home and get her children by letting her know that someone is listening to her and willing to help her. Gloria responds to her by simply being with her. This response might be more reasonable if her actions do not seem preventable.

Caregivers accompanying a resident outside is an acceptable response to a situation in which a resident wants to go outside but needs supervision to do so. It is suggested that nursing homes develop a procedure for this situation so that caregivers know what they can do and who to notify if they leave the building. For example, if a nurse aide leaving the building with a resident cannot notify the licensed nurse upstairs directly, she might notify the receptionist in the lobby or another caregiver that she is leaving so that the caregiver can alert the nurse. The policy or procedure should clearly state that a caregiver must inform the licensed nurse on duty that the nurse aide left the building with a resident and provide both the nurse aide’s and the resident’s names.
SAY

Sometimes you might not be able to prevent Mrs. Caputo’s actions or easily redirect her. You might not be able to gauge when she is going to act this way because it happens at different times of the day. Also, this action might be very important to Mrs. Caputo and preventing it would not meet her needs. Here is an example of a way to react to Mrs. Caputo’s action by being with her in the present.

DO

Click the forward arrow to play the clip.
Discussion—Slide 11 of 14

Instructor Guidance:
Facilitate a brief discussion about how the aide, Gloria, responded to Mrs. Caputo and how walking with Mrs. Caputo seemed to help her.

How did Gloria respond to Mrs. Caputo?

- Gloria first tried to distract Mrs. Caputo from leaving.
- When Gloria was not able to distract Mrs. Caputo, she accompanied Mrs. Caputo out the door.
- Gloria walked with Mrs. Caputo out the front door and focused Mrs. Caputo’s attention on flowers.
- Gloria led Mrs. Caputo back inside by saying it was time for dinner.

How did Mrs. Caputo react?

- Mrs. Caputo was determined to go outside.
- She appeared relieved when Gloria went outside with her.
- She let Gloria take her hand.
- She went back in with Gloria to have dinner.

Notes:
How did walking with Mrs. Caputo help her?

- It calmed her down.
- It allowed her to safely accomplish what she wanted to do (go outside).
- It gave her some control in the situation.

Note: Gloria's question about Mrs. Caputo's daughters might trigger her action again. Gloria could have asked a different question.
Discussion

ASK

- How did the aide, Gloria, respond to Mrs. Caputo?
- How did Mrs. Caputo react?
- How did walking with Mrs. Caputo help her?

SAY (after discussion)

Sometimes it is not easy to deter a person with dementia from his or her actions—like any of us, he or she has an “agenda” and will work hard to do what needs to be done. We need to just be with him or her. As we saw in the clip, Mrs. Caputo might only need to walk around the parking lot before being guided back into the building. Another time, however, she might need to walk farther.
Instructor Guidance:

We have presented some specific examples of ways to respond to the actions of a person with dementia. However, it needs to be clear that there is no one-size-fits-all way to respond to persons with dementia. There are a few things aides need to keep in mind:

- Each person with dementia is unique. Different people might have different reasons for their actions and need different responses. For example, one person with dementia who says, “I want to go home” might be thinking of her childhood home. Asking her “Where is home for you?” or “Tell me about where you grew up” might be ways of reminiscing with her about her childhood. That response might be what she needs to validate the story she wants to tell about herself. Another person with dementia who says, “I want to go home” might think that his wife is waiting for him for dinner. In this case, redirection might work. Sometimes just telling someone “I understand” and sitting with him or her responds to a need to be understood and listened to.

- A certain response might not work all the time. What works one day might not work another day. For example, distracting Mrs. Caputo with baking might work one day. But maybe the next day the aide, Maria, tries this approach and Mrs. Caputo still insists she needs to go home. To prepare for this, Maria would need to have ideas of other ways to respond.
• A response might work for one aide, but not another. For example, Gloria has found that walking outside with Mrs. Caputo really helps calm her. If Gloria walks outside with her, Mrs. Caputo does not talk about going home for the rest of the day. However, Arthur, another aide, might find that when he walks outside with Mrs. Caputo, he has difficulty getting her back inside and she continues to insist she has to go home.

• It is only through knowing the resident with dementia and seeking to understand what she is trying to communicate that we can find ways to respond. Patience is key in trying a response, seeing whether it’s effective and, if necessary, trying a different response. Communicate your findings of what works in de-escalating a situation to the rest of the team to empower them and help create a calm, proactive approach.
This page intentionally left blank.
One Size Does Not Fit All

SAY

Each person with dementia is a unique individual. Each person has different reasons for his or her actions, so your response needs to fit the action and needs of each individual. There is no one-size-fits-all way to respond to persons with dementia. Keep in mind that your approach to someone with dementia might work one day and not the next. And what works for you might not work for your coworker. You might be able to successfully redirect Mrs. Caputo with baking, but your coworker may not have any luck with the same approach.

It is only through knowing the resident with dementia and seeking to understand what he or she is trying to communicate that we can find ways to respond. Patience is key in trying a response, seeing whether it’s effective and, if necessary, trying a different response.
Out of Control—Slide 13 of 14

Instructor Guidance:

In most cases, knowing the person, understanding the meaning of his or her actions, and preparing, preventing, and being present are ways to respond to a person with dementia that avoid his or her actions or emotions from escalating into extreme aggression or violence. All of us can understand having moments when we might become very upset and we all have different ways of handling that. However, there might be times when a situation gets out of control and a person with dementia might become very upset, aggressive, or violent.

Here are some things to consider when responding to that type of situation:

- Stop what you are doing with that person. Your first goal is to keep everyone safe and let everyone in the situation calm down.
- Give the person with dementia space. If you are physically close to him or her, step away.
- Do not argue with the person or respond to the person in a way that will fuel his or her anger.
- Be calm and provide gentle reassurance.
  - To calm the situation, be the opposite of where the person with dementia is emotionally. For example, if the person with dementia has escalated to a “10”—a high level of being upset—you need to be a “1”—very calm, slow movements, etc.
o Say calming things to let the person know you are not upset. For example, say “It’s okay,” or “Everything’s fine.”

- Sometimes it helps to apologize to the person while you are backing away.
- If there are others in the room, try to remove them from the area or distract the upset person away from the other people.
- Call for help if needed.
- Report the situation to your supervisor.
- After the situation has passed, brainstorm as a team about what happened, why you think it happened, the possible reasons behind the actions of the person with dementia, and what you might try to do differently in the future to prepare, prevent, or be present.
This page intentionally left blank.
Out of Control

SAY

In most cases, knowing a person with dementia, understanding the meaning of his or her actions, and preparing, preventing, and being present are ways to respond to a person with dementia that avoid escalations in a person’s actions or emotions to extreme aggression or violence. All of us can understand having moments when we might become very upset, and we all have different ways of handling that. However, there might be times when a situation gets out of control and a person with dementia might become very upset, aggressive, or violent.

Here are some things to consider when responding to that type of situation:

- Stop what you are doing with that person. Your first goal is to keep everyone safe and let everyone in the situation calm down.
• Give the person with dementia space. If you are physically close to him or her, step away.

• Do not argue with the person or respond to the person in a way that will fuel his or her anger.

• Be calm and provide gentle reassurance.
  
  o To calm the situation, be the opposite of where the other person is emotionally. For example, if the person with dementia has escalated to a “10,” a high level of being upset, you need to be a “1”—very calm, slow movements and so forth.

  o Say calming things to let the person know you are not upset. For example, say “It’s okay,” or “Everything’s fine.”

• Sometimes it helps to apologize to the person while you are backing away.

• If there are others in the room, try to remove them from the area or distract the upset person away from the other people.

• Call for help if needed.

• Report the situation to your supervisor.

• After the situation has passed, brainstorm as a team, if possible, about what happened, why you think it happened, the possible reasons behind the actions of the person with dementia, and what you might try to do differently in the future to prepare, prevent, or be present. Another option is to debrief your supervisor and co-workers.
Instructor Guidance:

In this lesson we identified ways to respond to the actions of persons with dementia that are unique to the person and what he or she is trying to communicate to us.
Actions and Reactions: Ways to Respond: Summary

SAY

In this section we identified ways to respond to the actions of a person with dementia that are unique to the person and what he or she is trying to communicate to us.

ASK

What one thing did you learn or relearn from this lesson?
VIII. Brainstorming

Brainstorming: Goal—Slide 1 of 12

Instructor Guidance:

The purpose of this lesson is to provide an opportunity for participants to apply what they have learned using scenarios they might experience in their jobs. Participants will work in small groups.
Brainstorming: Goal

SAY

In this lesson, you’ll be able to practice what you have learned. We’ll work in small groups and brainstorm ways to respond to some actions of persons with dementia. We have talked about understanding the reasons behind a person’s actions in order to determine how to respond. Although a part of this process is also determining whether you need to respond at all, we are assuming in these brainstorming exercises that you have already decided you need to respond to the person with dementia.
Exercise—Slide 2 of 12

Instructor Guidance:

In this lesson, participants will work in small groups to brainstorm ways to respond to some actions of persons with dementia.

There are three actions of persons with dementia:

- Refusing to take a bath.
- Putting non-food items in his or her mouth (for example, buttons).
- Collecting items that do not belong to him or her (for example, towels).

Instructions for the small-group exercise:

- Break participants into three or more small groups.
- Assign an action to each group. If there are more than three groups, multiple groups can work on the same action.
- Give each participant a copy of the Brainstorming Worksheet found in the Appendix of this module, page A-3.
- Quickly review the Brainstorming Worksheet with participants.
• Point out that the first section says “Why” and lists categories of reasons a person with dementia might act a certain way. Explain that in their groups they will talk about the action they were given and brainstorm the reasons a person with dementia might be acting a certain way. Tell participants that there might not be a reason in every category, but to try to think of as many reasons as possible.

• The last section of the worksheet is titled “Ways to Respond.” Questions for preparing, preventing, and being present are listed to help participants think about different ways of responding.

• Tell the groups that they will have five minutes to complete the activity. After time is up, the groups will come back together and share their brainstorming with the rest of the class.
This page intentionally left blank.
Exercise

SAY

We are going to break into small groups to practice interpreting and responding to some actions of persons with dementia. Each group will be assigned an action. As a group, first discuss possible reasons behind the action. Then, identify ways of responding to it. We are assuming in these scenarios that you do need to respond. Use the three Ps—prepare, prevent, be present—as a guide to think of different ways of responding. Write your ideas on the Brainstorming Worksheet. You will have five minutes to complete this exercise. Then we’ll come back together as a large group and share with the rest of the class.
Debrief: Refusing to Take a Bath—Slide 3 of 12

Instructor Guidance:

After the groups have had time to discuss their actions, they will share their ideas with the rest of the class. For each action, ask the groups to share:

- Their reasons why a person might act that way.
- Possible ways to respond.

Below is an example of how this exercise might play out. This is not intended to be shared with the class, as it is important that they do their own brainstorming. Participants will likely identify many reasons why and ways to respond that are not included here. These are just some examples.

Why might this action be happening? Look at the eight areas.

For the action of refusing to take a bath, the reasons could be:

- Health (physical and emotional)—The resident with dementia is in pain and does not want to sit in the tub; the resident does not feel well; the resident is cold; the resident feels depressed.
- Medications—The resident with dementia is taking a new medication that has caused him or her to feel anxious; the dosage of a medication has changed and the resident has an upset stomach.
- Communication—The resident with dementia does not understand what you are saying; the resident does not want a bath right now.
• Environment—The bathroom is cold; the resident with dementia might have visuospatial challenges that cause him or her to think the tub is very deep and he or she might drown; the tub or shower room is very noisy.

• Task—The resident with dementia is modest and does not want someone seeing him or her naked and bathing him or her.

• Unmet need—The resident with dementia is feeling confused and unsafe.

• Life story—The resident with dementia is, in his or her mind, back in the Great Depression and only took baths on Saturdays, taking turns with other family members.

• You—you didn’t identify yourself; the resident with dementia does not recognize you or trust you; the resident is upset with you today.

What are some ways to respond to this action?

Some possible answers might be:

• Prepare the bathing area so that it is inviting and warm. Perhaps have music available to help calm the resident.

• Reassure the resident and make sure the water is warm—possibly use bubble bath or bath salts, if appropriate.

• Be sure you communicate clearly.
• Come back at another time.

• Offer alternatives, such as helping the resident wash up at the sink or in his or her bed.

• Cover the resident with towels or a robe while bathing.

• For visuospatial challenges, you might need to fill the tub as the resident sits in it.
Debrief: Refusing to Take a Bath

SAY
Let’s discuss refusing to take a bath.

ASK
Which group had this action? What are some reasons you came up with for why a person might act that way? (Guide the speaker through the various categories of reasons [health, medications, communication, etc.]).

Next, what are some ways to respond to this action? (To get more details, you might need to ask more specific questions: What might you do to prepare for this action? How might you prevent it? What would you do to respond “in the present” as the action is happening?)

Note: If multiple groups had the same action, give each group an opportunity to share their discussion.
Debrief: Putting Non-Food Items in His or Her Mouth—Slide 4 of 12

Instructor Guidance:

For the action of putting non-food items in his or her mouth, ask the groups to share:

- Their reasons why a person might act that way.
- Possible ways to respond.

Below is an example of how this exercise might play out. This is not intended to be shared with the class, as it is important that they do their own brainstorming. Participants will likely identify many reasons why and ways to respond that are not included here. These are just some examples.

Why might this action be happening? Look at the eight areas.

Reasons for the action of putting non-food items in his or her mouth could be:

- Unmet needs—The resident with dementia is hungry and thinks the buttons are food.
- Life history—The resident’s mother used to give him or her candy after school. The buttons remind the resident of the candy.
What are some ways to respond to this action?

Some possible answers might be:

- Redirect the resident from eating the button by giving him or her something else to hold.
- Invite him or her to have a snack.
This page intentionally left blank.
Debrief: Putting Non-Food Items in His or Her Mouth

SAY

Next, let’s discuss this action.

ASK

Which group had this action? What are some reasons you came up with for why a person might act that way? (Guide the speaker through the various categories of reasons [health, medications, communication, etc.]).

Next, what are some ways to respond to this action? (To get more details, you might need to ask more specific questions: What might you do to prepare for this action? How might you prevent it? What would you do to respond “in the present” as the action is happening?)

Note: If multiple groups had the same action, give each group an opportunity to share their discussion.
Debrief: Collecting Items That Don’t Belong to Him or Her—Slide 5 of 12

Instructor Guidance:

For the action of collecting items that don’t belong to him or her, ask the groups to share:

- Their reasons why a person might act that way.
- Possible ways to respond.

Below is an example of how this exercise might play out. This is not intended to be shared with the class, as it is important that they do their own brainstorming. Participants will likely identify many reasons why and ways to respond that are not included here. These are just some examples.

Why might this action be happening? Look at the eight areas.

For the action of collecting items that don’t belong to him or her, the reasons could be:

- Environment—The environment causes the resident with dementia (a former housekeeper) to think he or she is at work in the hospital. The resident is collecting towels to wash.
- Unmet needs—The resident with dementia is bored.
Life history—The resident used to work in a hospital in the housekeeping department. The resident thinks he or she is at work and collects towels from all the rooms for laundry.

What are some ways to prevent or respond in the moment to this action?

Some possible answers are:

- Involve the resident with dementia in laundry-related tasks.
- Ask the resident about laundry and housekeeping work as he or she is collecting towels, while redirecting to another area.
This page intentionally left blank.
SAY

Next, let’s discuss the action of collecting items that don’t belong to him or her.

ASK

Which group had this action? What are some reasons you came up with for why a person might act that way? (Guide the speaker through the various categories of reasons [health, medications, communication, etc.]).

Next, what are some ways to respond to this action? (To get more details, you might need to ask more specific questions: How might you prevent it? What would you do to respond “in the moment” as the action is happening?)

Note: If multiple groups had the same action, give each group an opportunity to share their discussion.
Play Video Clip: Refusing to Take a Bath—Slide 6 of 12

Instructor Guidance:

Participants will see video clips of person-centered approaches to the three actions they discussed.

Emphasize the following points to the class:

- As they identified, there are many different ways to respond to the actions of persons with dementia.

- There is no one-size-fits-all approach that works all the time.

- An approach might work for one person with dementia, but not another. It might work one day and not the next. It might even work for one caregiver, but not another.

The first clip shows a person-centered response to refusing to take a bath. In this clip, Gloria asks Mr. Johnson to take a bath. He does not want to. Gloria apologizes and asks her coworker, Dave, whom she knows Mr. Johnson likes, to see if he can get Mr. Johnson to take a bath. Dave is successful.
Play Video Clip: Refusing to Take a Bath

SAY

You have identified a number of different ways to respond to the actions of persons with dementia. Now we’re going to look at some person-centered approaches to each of these actions, some of which you have mentioned.

Keep in mind that there are no one-size-fits-all approaches that work all the time. Each person is different. What works for one person with dementia, might not work for another person. What works for a person one day, might not work the next day. You may even find that something might work for you, but not another caregiver.

This first clip shows what you might do to respond to a person with dementia who does not want to take a bath.
Discussion—Slide 7 of 12

Instructor Guidance:

Briefly discuss what the participants saw in the clip.

It is important that participants understand that Gloria recognized that she was not going to convince Mr. Johnson to take a bath. It is also important to point out that Gloria knows that Mr. Johnson likes Dave. Because she knows her resident well, she is able to respond to him in a way that prevents a negative reaction and helps him get what he needs.

How did Gloria respond to Mr. Johnson’s action of refusing to take a bath?

- Gloria did not pressure Mr. Johnson to take a bath.
- Gloria backed away.
- Gloria asked another aide, Dave, to help.

How did Mr. Johnson react to Gloria’s response?

- Mr. Johnson calmed down when Gloria left.
- Mr. Johnson let Dave help him.

Note: If participants notice that the aide did not put foot pedals on the wheelchair before transporting Mr. Johnson, remind them that this creates a potential for injury to the resident.
Discussion

ASK

- How did Gloria respond to Mr. Johnson’s action of refusing to take a bath?
- How did Mr. Johnson react to Gloria’s response?
Play Video Clip: Putting Non-Food Items in Mouth—Slide 8 of 12

Instructor Guidance:

This clip is about responding to a person with dementia putting non-food items in his mouth. This action in persons with dementia is usually related to confusion about the item being food. In this clip, a person with dementia (Mr. Davidson) is sitting with another resident during an activity that involves buttons. A caregiver coordinating the activity, Wendy, sees that Mr. Davidson is about to put a button in his mouth. Mr. Davidson thinks that the button is a piece of candy. Wendy redirects him and cues him to put the button down. She then invites him to have a snack to divert him from attempting to put other buttons in his mouth.
Now let’s look at a clip of a resident with dementia who puts non-food items in his mouth.

Click the forward arrow to play the clip.
Discussion—Slide 9 of 12

Instructor Guidance:

Briefly discuss what the participants saw in the clip.

How did Wendy respond to Mr. Davidson’s action of attempting to put non-food items in his mouth?

- Wendy redirected him.
- Wendy did not say “no” or “stop that.” She found a way to get him to put the button down.
- Wendy did not embarrass him by pointing out that he was trying to eat a button—she gently redirected him.

How did Mr. Davidson react to Wendy’s response?

- Mr. Davidson allowed her to take the button.
- Mr. Davidson was calm.
It is important to point out that Wendy successfully prevented Mr. Davidson from putting the button in his mouth by redirecting him and giving him cues on what to do with the button ("put it with the other buttons on the table"). She did not tell Mr. Davidson “no” or to not eat the button. If she had done that, she likely would have upset him. Because Wendy knew Mr. Davidson well, she understood that he sometimes mistakes buttons for candy, so she redirected him with food.
This page intentionally left blank.
Discussion

ASK

- How did Wendy respond to Mr. Davidson’s action of attempting to put non-food items in his mouth?

- How did Mr. Davidson react to Wendy’s response?
Play Video Clip: Collecting Items That Don’t Belong to Him—Slide 10 of 12

Instructor Guidance:

This clip shows an aide’s (Dave’s) response to a resident, Mr. Davidson, who is collecting items that don’t belong to him. This action is common in persons with dementia, but the action itself and the reasons behind the action vary. In this clip, we will see that Mr. Davidson has been collecting another resident’s (Mr. Ellis’) shoes. A sports enthusiast, Mr. Davidson sees the athletic shoes and thinks they are his. Dave knows the resident and understands his actions, so every night he removes the shoes from the resident’s room and returns them to the rightful owner.
Play Video Clip: Collecting Items That Don’t Belong to Him

SAY

Now let’s look at our last example—how to respond to a person with dementia who collects another resident’s belongings.

DO

Click the forward arrow to play the clip.
Discussion—Slide 11 of 12

Instructor Guidance:

Briefly discuss what the participants saw in the clip.

How did Dave respond to Mr. Davidson’s action of collecting items that don’t belong to him? (Hint: Think about what he didn’t do.)

- He understood that the action of collecting the shoes was important to the resident.
- He did not tell Mr. Davidson that he could not take items that don’t belong to him or prevent Mr. Davidson from carrying out his action. Instead, he returned the shoes and made sure Mr. Ellis’ family understood the action—a response that wouldn’t upset either resident.

How did this response meet the needs of both residents?

- Dave avoided upsetting Mr. Davidson by letting him collect the shoes.
- Dave avoided upsetting Mr. Ellis by returning his shoes. Mr. Ellis’ family did not get upset because the situation was explained to them.
Discussion

ASK

- How did Dave respond to Mr. Davidson’s action of taking the athletic shoes that did not belong to him?
- How did this response meet the needs of both residents?
Brainstorming: Summary—Slide 12 of 12

Instructor Guidance:

This lesson gave participants the opportunity to apply what they learned in the previous lessons and brainstorm ways to respond to the actions of persons with dementia.

Can you name three things from this lesson that you have learned or relearned?
Brainstorming: Summary

SAY

In this lesson you have learned how to brainstorm ways to respond to the actions of persons with dementia.

ASK

Can you name three things from this lesson that you have learned or relearned?
IX. Conclusion

Play Video Clip: Being with Mr. Haynes—Slide 1 of 3

Instructor Guidance:

This lesson uses the story of Mr. Haynes to tie together the learning objectives in this module. The video clip shows Mr. Haynes, a nursing home resident whose actions result in his being medicated for aggression. When caregivers finally understand the reasons for his actions, they are able to avoid medication by responding to the actions and meeting his needs.
SAY

We are going to watch a video clip about a nursing home resident named Mr. Haynes. After we watch the video, we will have a brief discussion.

DO

Click the forward arrow to play the clip.
Discussion: Being with Mr. Haynes—Slide 2 of 3

Instructor Guidance:

After the Mr. Haynes clip, facilitate a discussion with the group.

- What do you think about this clip?
- What one thing sticks out in your mind about this story?

In the discussion, you will want to make the following points:

- The nurse and the doctor did not understand Mr. Haynes’ actions and felt the only way to respond was to medicate him.
- There are ways we can respond to behaviors without using medications.
- When we see aggressive behavior in residents, we need to dig deeper to try to understand the reasons behind the behavior.
- Knowing Mr. Haynes’ life story was the key to understanding his actions.
- Mr. Haynes became excited when he heard the overhead page. When staff tried to stop him, he became more aggressive. In his mind, they were keeping him from something he needed to do. As a medic, his job was to treat the injured soldiers being brought into camp.
• When the caregivers came together as a team to try to understand why Mr. Haynes might be acting this way, they were able to come up with a person-centered response.

• The group of caregivers included people from different departments and roles (e.g., maintenance, nursing, and activities).

• In situations in which a resident becomes very upset and aggressive, it is important to make sure everyone is kept safe. Caregivers need to judge when a situation is an emergency and when others need to be involved to ensure safety.

• A proactive solution to preventing Mr. Haynes’ reaction would be to use the overhead paging system only in emergencies.
This page intentionally left blank.
Discussion: Being with Mr. Haynes

ASK

- What do you think about this clip?
- What one thing sticks out in your mind about this story?

SAY

The story of Mr. Haynes brings together all that we have learned in this module about the importance of understanding the meaning behind a person with dementia’s actions so that we know how to respond. Responding to Mr. Haynes by being with him meets his unique needs.
Congratulations!—Slide 3 of 3

Instructor Guidance:

We have learned about reframing behaviors as actions and reactions and the importance of understanding actions as a form of communication. When we understand what the action means, we can brainstorm ways to respond to the action and meet the needs of our residents with dementia.

Ask participants whether they have any questions.
Congratulations!

SAY

In this module we learned that all behavior has meaning. It is up to us to try to understand the reasons why persons with dementia act in certain ways. When we understand what the action means, we can think of ways to respond to the action and meet the needs of our residents with dementia.

ASK

Are there any questions or comments about what you learned?
Module 3 Video Clips—Slide 7 of 7

Instructor Guidance:
From this slide you can easily access any of the video clips in this module for review or additional discussion.

- Clip 1—I Want to Go Home.
- Clip 2—I Want to Go Home: Replay.
- Clip 3—I Want to Go Home: Preventing.
- Clip 4—I Want to Go Home: Being Present.
- Clip 5—Refusing to Take a Bath.
- Clip 6—Putting Non-Food Items in Mouth.
- Clip 7—Collecting Items that Don’t Belong to Him.
- Clip 8—Being with Mr. Haynes.
Module 3 Video Clips

<table>
<thead>
<tr>
<th>I Want to Go Home</th>
<th>Actions &amp; Reactions: Why</th>
<th>Actions &amp; Reactions: Ways to Respond</th>
</tr>
</thead>
<tbody>
<tr>
<td>Video Clip 1</td>
<td>Video Clip 2</td>
<td>Video Clip 3</td>
</tr>
<tr>
<td>Brainstorming</td>
<td>Conclusion</td>
<td>Video Clip 4</td>
</tr>
<tr>
<td>Video Clip 5</td>
<td>Video Clip 6</td>
<td>Video Clip 7</td>
</tr>
</tbody>
</table>

Select a video clip above

Module 3 Video Clips
This page intentionally left blank.
Appendix

Handout: Brainstorming Worksheet
This page intentionally left blank.
### Brainstorming Worksheet

<table>
<thead>
<tr>
<th>Resident:</th>
<th>Your Name:</th>
</tr>
</thead>
</table>

**Date you are filling this out:**

<table>
<thead>
<tr>
<th>ACTION of the resident</th>
</tr>
</thead>
<tbody>
<tr>
<td>TIME/DAY of action</td>
</tr>
<tr>
<td>What was happening right before?</td>
</tr>
<tr>
<td>Health Conditions (physical and emotional)</td>
</tr>
<tr>
<td>Medications</td>
</tr>
<tr>
<td>Communication</td>
</tr>
<tr>
<td>Environment</td>
</tr>
<tr>
<td>The Task</td>
</tr>
<tr>
<td>Unmet Needs</td>
</tr>
<tr>
<td>Life Story</td>
</tr>
<tr>
<td>You</td>
</tr>
</tbody>
</table>

**WAYS TO RESPOND**

PREPARE: How can I prepare for this action?

PREVENT: How can I prevent this action?

PRESENT: How can I respond to this action in the present moment?

What is our PLAN?

How do I communicate the PLAN to all caregivers?
This page intentionally left blank.
Module 4:
Being with a Person with Dementia:
Making a Difference
Hand in Hand: A Training Series for Nursing Homes—Module 4: Being with a Person with Dementia

This page intentionally left blank.
Methodology

This module uses lecture, interactive discussion, and exercises.

Contents

(Total Time: 60 minutes)

<table>
<thead>
<tr>
<th>Estimated Time</th>
<th>Lecture and Discussion</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 minute</td>
<td>Welcome</td>
<td>4</td>
</tr>
<tr>
<td>1 minute</td>
<td>Being with a Person with Dementia Overview</td>
<td>6</td>
</tr>
<tr>
<td>1 minute</td>
<td>Module Objectives</td>
<td>10</td>
</tr>
<tr>
<td>20 minutes</td>
<td>Meeting Persons with Dementia Where They Are</td>
<td>16</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Strengths and Abilities</td>
<td>56</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Still There: Connecting with Persons with Dementia</td>
<td>74</td>
</tr>
<tr>
<td>15 minutes</td>
<td>Each Person Makes a Difference</td>
<td>94</td>
</tr>
<tr>
<td>2 minutes</td>
<td>Conclusion</td>
<td>106</td>
</tr>
</tbody>
</table>

Training Resources

- Computer capable of playing an .IOS file.
- Downloaded .ISO file for Module 4.
- Module 4 Instructor Guide.
- Name tags (2 per participant).
- Pens, pencils, and writing tablets.
- Prizes (optional).
- Easel chart with markers.
- Post-it® Notes.

Instructor Preparation

- Review the Instructor Guide and .ISO. Practice exercise delivery. Rehearse with .ISO. Print copies of the handouts.
I. Welcome

Welcome to Module 4: Being with a Person with Dementia: Making a Difference—Slide 1 of 5

Instructor Guidance:

If the participants do not know one another, have each participant state his or her name, position, and where he or she works in the nursing home.

Be sure to pass out a sign-in sheet to track attendance.

This module is about being with persons with dementia wherever they are in their experience of dementia, finding ways to connect with them, and understanding the difference you make in their lives.

Note: Participants should complete modules 1, 2, and 3 before this module. Module 2 provided an overview of communicating with persons with dementia. Module 3 focused on understanding the actions of persons with dementia, what we traditionally have termed “behaviors.” A summary review of all the modules is found in the Orientation Guide.
Welcome to Module 4: Being with a Person with Dementia: Making a Difference

**DO**

- Greet participants.
- Welcome participants to the training.
- Have participants introduce themselves (if they don’t know one another).

**SAY**

This module is about being with persons with dementia wherever they are in their experience of dementia. It’s also about the difference you make every day in their lives.
II. Being with Persons with Dementia: Overview

Instructor Guidance:

Four of the modules in this Hand in Hand training series are about caring for persons with dementia. Three of the titles share a common introduction: Being with a Person with Dementia.

Being with a person with dementia means understanding his or her world by trying to see it from his or her perspective—trying to be with the person where he or she is. Being with a person with dementia is different from doing for. Being with persons with dementia recognizes them as whole individuals, who have strengths as well as weaknesses, unique needs, preferences, and histories. By building on strengths and knowing who they are as individuals, we support persons with dementia to do as much as they can and to live meaningfully.

Here are the titles in the Being with a Person with Dementia series:

Module 1: Understanding the World of Dementia: The Person and the Disease
Module 2: Being with a Person with Dementia: Listening and Speaking
Module 3: Being with a Person with Dementia: Actions and Reactions
Module 4: Being with a Person with Dementia: Making a Difference
This module is one of four modules on dementia. Three of the module titles begin with *Being with a Person with Dementia*. Being with a person with dementia means:

- **Understanding the world of persons with dementia by trying to understand things from their perspective.**

- **Being with persons with dementia where they are.** This means meeting them in their world, in their understanding of what is happening around them, and in what they are able to do and what they need help with. Being with is different from “doing for.”

- **Recognizing persons with dementia as whole individuals who have strengths as well as weaknesses, unique needs, preferences, and histories.**
• Building on strengths and knowing who they are as individuals.

• Supporting persons with dementia to do as much as they can and to live meaningfully.

• Connecting with persons with dementia through communication, laughter, touch, and so on to validate them as human beings and as equals.

• Recognizing that sometimes the best way we can support persons with dementia is to just be with them, to sit with them, and to listen to them.
This page intentionally left blank.
III. Module Objectives

**Module Objectives—Slide 3 of 5**

**Instructor Guidance:**

It’s important to set participant expectations by stating the module objectives. It is not necessary to explain the objectives on this screen; you are only introducing the anticipated instructional outcomes. This screen should take only about one minute.

This module is about being with persons with dementia wherever they are, which involves understanding strengths, as well as weaknesses. The causes of dementia are often progressive diseases. As the symptoms of dementia increase, it is important to continue to identify ways to connect with persons with dementia so that they are meaningfully engaged in life. There is a common feeling that persons with dementia “are no longer there” when they are further in their progression. However, when we say a person progresses, we mean that the symptoms become worse—the person does not become less of a person as dementia progresses.

Every interaction a nurse aide (or other caregiver) has with a person with dementia is an opportunity to connect with that person. For example, an aide bathing a person with dementia has an opportunity to connect with that person, to meet his or her emotional and social needs, as well as physical needs. This module addresses the importance of connecting with persons with dementia throughout their progression and at the end of life.
Module Objectives

SAY

At the end of this module, you will be able to:

- Explain what it means to meet persons with dementia where they are.
- Recognize the importance of focusing on the strengths and abilities of persons with dementia.
- Identify ways to connect with persons with dementia where they are.
- Recognize your role in making a difference in the lives of persons with dementia.
What Is Dementia?—Slide 4 of 5

Instructor Guidance:

It might be helpful to review the explanation of dementia in Module 1: Understanding the World of Dementia: The Person and the Disease.

Dementia is an umbrella term that refers to a wide range of disorders and symptoms that affect a person’s cognitive, physical, and social abilities severely enough to interfere with the person’s daily life. They include challenges with memory, concentration, orientation, language, judgment, visuospatial skills, and sequencing.

- Memory refers to the processes used to acquire, store, retain, and retrieve information.
- Concentration is the ability to focus one’s attention.
- Orientation refers to a person’s awareness of who and where he or she is, what time and date it is, and who other people are.
- Language refers to the communication of thoughts. It includes both spoken and written words, as well as nonverbal methods of communication.
- Judgment refers to the mental processes of making decisions.
- Visuospatial ability refers to the mental processes of how we make sense of what we see and how objects relate to each other.
What Is Dementia?

SAY

Let’s take a step back and revisit what dementia is. Dementia is not a specific disease. It is an umbrella term that refers to a wide range of symptoms related to loss of memory, judgment, language, complex motor skills, and other intellectual function, caused by the permanent damage or death of the brain's nerve cells, or neurons. It also includes challenges with concentration, orientation, language, visuospatial skills, and sequencing.

These dementia symptoms can be caused by many different illnesses and conditions—some are reversible and some are irreversible. The most common irreversible cause of dementia is Alzheimer’s disease.

The symptoms of dementia worsen as the disease that causes them progresses. Therefore, the needs of persons with dementia change as the symptoms get worse. This includes both physical and emotional needs. In this module we will look at how to meet persons with dementia where they are to meet their needs.
Instructor Guidance:

The menu screen allows you to easily navigate through the module lessons. It is intended for the class to go through all the lessons in order so that participants can build upon what they learn. However, you can easily return to any of the topics or video clips for a refresher. At the end of the module, you can click the forward arrow at the bottom of the screen to Module 4 Video Clips. These are the same video clips used in the lessons; they are available to you for review and discussion once all lessons have been covered.
Module 4 Menu

SAY

Let's get started with the first lesson, Meeting Persons with Dementia Where They Are.

DO

On the menu, click the first lesson, Meeting Persons with Dementia Where They Are.
IV. Meeting Persons with Dementia Where They Are

**Meeting Persons with Dementia Where They Are: Goal—Slide 1 of 16**

**Instructor Guidance:**

The goal of this lesson is to explain what it means to meet persons with dementia where they are. It includes a video clip that illustrates this concept in practice.
Meeting Persons with Dementia Where They Are: Goal

SAY

In this lesson we will explore what it means to meet persons with dementia “where they are.”
Instructor Guidance:

In order to meet persons with dementia where they are, we must try to understand and accept their reality. How do they see the world around them? What are their physical and emotional needs?

Dementia symptoms, especially those due to irreversible causes such as Alzheimer’s disease, tend to get worse as the disease progresses. As the dementia symptoms worsen, persons with dementia will have different needs. A resident who might have been able to dress herself before might need more assistance now. At the same time, we don’t want to assume that persons with dementia are incapable of being involved in their own care. When we say, “meet persons with dementia where they are,” what we mean is that we have to know where each person is in the disease process—what his or her strengths are as well as his or her weaknesses. Rather than just “doing for,” we want to see what the person can do and build upon that. A person with dementia does not become less of a person as the dementia progresses. Meeting persons where they are means always honoring them with dignity and respect and seeing them as whole individuals.

Meeting persons where they are also means understanding that you need to be a good communicator. The symptoms of dementia can cause challenges in communication. Therefore, we need to pay close attention to what persons with dementia are telling us, not only through their words, but also through nonverbal cues such as body language and behavior. It is also important that we communicate well through the way we speak and through our body language and behavior.
To illustrate the concept of meeting persons with dementia where they are, you will show a series of five video clips of Mrs. Johnson, a person with dementia who needs assistance with brushing her teeth. With each clip, Mrs. Johnson has progressed further in the progression of dementia. After each clip, facilitate a discussion with the class about how the aide, Gloria, meets Mrs. Johnson where she is.

Note: When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.
What Does It Mean to Meet Persons with Dementia Where They Are?

SAY

In order to be with persons with dementia, we must first try to understand their reality. Who are they as individuals? How do they see the world around them? What are their physical and emotional needs?

Dementia tends to get worse as time goes on. As the dementia symptoms worsen, persons with dementia will be in “different places” and have different needs. A resident who might have been able to dress herself before might need more assistance now. Meeting persons with dementia where they are means accepting their reality, knowing them as individuals, and knowing where they are in the progression of dementia. This includes knowing their strengths as well as their weaknesses. Rather than just “doing for,” we want to see what the person can do and build upon that.
Meeting persons where they are requires good communication. We need to pay close attention to what persons with dementia are telling us, not just through their words but through nonverbal cues such as body language and behavior. We also need to communicate well with persons with dementia through the way we speak to them and through our body language and behavior.

We are going to look at and discuss a series of video clips. In these clips we will see how Gloria, a nurse aide, meets Mrs. Johnson, a resident with dementia, where she is.
Instructor Guidance:

During this lesson participants will see a series of clips that show the progression of Mrs. Johnson’s dementia, as well as how Gloria, her aide, adapts to her changing needs. After each clip, discuss how Gloria is “meeting” Mrs. Johnson where she is at that time.

These clips demonstrate to participants that we have to adapt to the changing needs of persons with dementia. This does not mean that we simply do more for them; rather, it means that we continually consider how we can support them to do as much as they can while assisting them in meeting their needs.

In the first clip, Mrs. Johnson is in the earlier stages of dementia. She is still able to do many things on her own, but she needs reminders. The aide, Gloria, knows where Mrs. Johnson is in the progression of dementia and knows that she needs to be reminded to brush her teeth.
Play Video Clip: Mrs. Johnson, Part 1

SAY

In the first clip, Mrs. Johnson is in the earlier stages of dementia. She is still able to do many things on her own.

DO

Click the forward arrow to play the clip.
Discussion—Slide 4 of 16

Instructor Guidance:

During this discussion participants will likely point out that Mrs. Johnson appears to be in the earlier stages of dementia and needs less assistance.

When discussing how Gloria meets Mrs. Johnson where she is, participants should address how Gloria continues to adapt to Mrs. Johnson’s progression by understanding her strengths and weaknesses, accepting her reality, and using good communication techniques to help meet her needs.

How does Gloria meet Mrs. Johnson where she is in the progression of dementia?

Here are some things to point out during the discussion.

- Gloria communicates well with Mrs. Johnson.
  - Gloria greets Mrs. Johnson by name.
  - Gloria knocks on the door to let Mrs. Johnson know she is there.
  - Gloria guides Mrs. Johnson to the bathroom.
  - Gloria lets Mrs. Johnson know she will be back to check on her.
- Gloria knows Mrs. Johnson can do many things on her own and just needs verbal reminders.
• Gloria lets Mrs. Johnson know it is bedtime and reminds her to brush her teeth.

• Mrs. Johnson is able to brush her teeth mostly on her own.

Some participants may note:

• Gloria didn’t provide any set-up assistance for Mrs. Johnson.

• Gloria, while polite, may not have taken enough time communicating instructions with Mrs. Johnson.
Discussion

SAY

In the first clip, Mrs. Johnson is in the earlier stages of dementia.

ASK

How does Gloria meet Mrs. Johnson where she is in the progression of dementia?
In this clip, Mrs. Johnson’s dementia has progressed and she requires more assistance from Gloria. However, she is still able to brush her teeth on her own with visual and verbal cues.
Play Video Clip: Mrs. Johnson, Part 2

**SAY**

This clip shows Mrs. Johnson 6 months later, and she has experienced dementia progression.

**DO**

Click the forward arrow to play the clip.
Discussion—Slide 6 of 16

Instructor Guidance:

How does Gloria meet Mrs. Johnson where she is in the progression of dementia?

Here are some things to point out during the discussion.

- Gloria communicates well with Mrs. Johnson.
  - Gloria calls Mrs. Johnson by name.
  - Gloria knocks on the door when she enters the room from the bathroom. She understands that Mrs. Johnson might have forgotten that she was in the bathroom and does not want to startle her when she comes back into the room.
  - Gloria lets Mrs. Johnson know it is bedtime and cues her to brush her teeth.
- Gloria knows Mrs. Johnson needs help to get up from the chair and walks with her to the bathroom.
- Gloria knows that Mrs. Johnson needs more assistance in brushing her teeth.
  - Gloria prepares the items Mrs. Johnson needs for brushing her teeth—she puts toothpaste on a toothbrush and fills a cup of water.
  - Gloria takes more time communicating instructions and assures Mrs. Johnson that she will check on her a little later.
Discussion

SAY

In this clip, some more time has passed, and Mrs. Johnson’s dementia has progressed.

ASK

How does Gloria meet Mrs. Johnson where she is in the progression of dementia?
In this clip, Mrs. Johnson has had continued progression of dementia. Symptoms of dementia may cause a person to become disoriented. In this clip, Mrs. Johnson is disoriented and does not know where the bathroom is. It is sometimes helpful to put a sign on the bathroom door to remind the person with dementia where it is. The sign needs to be clearly visible and in a language that makes sense to the person. For example, Mrs. Johnson uses the term “bathroom” rather than toilet or restroom. In our clip, the caregivers have found that Mrs. Johnson identifies more with a sign that says, “Mary’s Bathroom” than one that says “Mrs. Johnson’s bathroom.”
Play Video Clip: Mrs. Johnson, Part 3

SAY

This clip, Part 3, shows Mrs. Johnson 8 months after the previous clip. It is now 14 months since the depiction in Part 1.

DO

Click the forward arrow to play the clip.
Discussion—Slide 8 of 16

Instructor Guidance:

How does Gloria meet Mrs. Johnson where she is in the progression of dementia?

- Gloria communicates well with Mrs. Johnson.
  - Gloria greets Mrs. Johnson by name.
  - Gloria lets Mrs. Johnson know it is bedtime and reminds her to brush her teeth.

- Mrs. Johnson seems confused about where the bathroom is so Gloria gently leads her in the right direction.

- There is a sign on Mrs. Johnson’s door to let her know where the bathroom is.

- Gloria goes into the bathroom with Mrs. Johnson. In the past, Gloria has verbally cued Mrs. Johnson to brush her teeth when she was in her room getting ready for bed. Gloria knows that Mrs. Johnson now needs more assistance. In addition to verbal cues, Mrs. Johnson also needs visual cues to show her where the bathroom is located, where she brushes her teeth, where the sink is, and so forth.
Discussion

SAY

Mrs. Johnson’s dementia has progressed further; she is more confused and needs more guidance from Gloria.

ASK

How does Gloria meet Mrs. Johnson where she is in the progression of dementia?
Play Video Clip: Mrs. Johnson, Part 4—Slide 9 of 16

Instructor Guidance:

Mrs. Johnson is in a different place in the progression of dementia. She now needs more assistance with brushing her teeth. Gloria still supports Mrs. Johnson so that she does as much as she can on her own.
Play Video Clip: Mrs. Johnson, Part 4

SAY

This clip, Part 4, shows Mrs. Johnson 5 months after the previous clip. It is now 19 months since the depiction in Part 1.

Do

Click the forward arrow to play the clip.
Discussion—Slide 10 of 16

Instructor Guidance:

How does Gloria meet Mrs. Johnson where she is?

- Gloria communicates well with Mrs. Johnson.
- Gloria calls Mrs. Johnson by name.
- Gloria uses her hand to guide Mrs. Johnson’s hand in brushing her teeth.
- Gloria watches Mrs. Johnson in the mirror and gently encourages her as she brushes her teeth. She smiles at Mrs. Johnson.
- When Gloria sees that Mrs. Johnson is having difficulty with brushing, she takes out a toothbrush and models toothbrushing for Mrs. Johnson.
- Gloria hands Mrs. Johnson the cup of water and reminds her to spit.
- Gloria guides her out of the bathroom when they are finished.

Notes:

• Gloria communicates well with Mrs. Johnson.
• Gloria calls Mrs. Johnson by name.
• Gloria uses her hand to guide Mrs. Johnson’s hand in brushing her teeth.
• Gloria watches Mrs. Johnson in the mirror and gently encourages her as she brushes her teeth. She smiles at Mrs. Johnson.
• When Gloria sees that Mrs. Johnson is having difficulty with brushing, she takes out a toothbrush and models toothbrushing for Mrs. Johnson.
• Gloria hands Mrs. Johnson the cup of water and reminds her to spit.
• Gloria guides her out of the bathroom when they are finished.
Discussion

SAY

Mrs. Johnson has experienced further progression of dementia and she needs even more assistance brushing her teeth.

ASK

How does Gloria meet Mrs. Johnson where she is in the progression of dementia?
Play Video Clip: Mrs. Johnson, Part 5—Slide 11 of 16

Instructor Guidance:

Mrs. Johnson has progressed further, and she is no longer able to go to the bathroom to brush her teeth. Gloria knows that she needs more assistance than in the past and meets her where she is by helping her brush her teeth in her room. Gloria continues to encourage Mrs. Johnson to be involved by talking to her as she is brushing her teeth and guiding her with verbal cues.
Play Video Clip: Mrs. Johnson, Part 5

SAY

Let’s look at one more clip of Mrs. Johnson. This clip, Part 5, shows Mrs. Johnson 4 months after the previous clip. It is now 23 months since the depiction in Part 1.

DO

Click the forward arrow to play the clip.
Discussion—Slide 12 of 16

Instructor Guidance:

How does Gloria meet Mrs. Johnson where she is?

- Gloria communicates well with Mrs. Johnson.
- Gloria knocks, greets Mrs. Johnson by name, and introduces herself.
- Gloria lets Mrs. Johnson know it is bedtime.
- Gloria approaches Mrs. Johnson from the side while brushing her teeth.
- Gloria gives verbal encouragement while brushing Mrs. Johnson’s teeth.
- Gloria guides Mrs. Johnson in drinking water and spitting into the basin.
- Gloria assures Mrs. Johnson that she will be right back.
- Gloria involves Mrs. Johnson as much as possible.

Notes:
Discussion

SAY

Mrs. Johnson’s dementia has progressed further so that she needs more assistance from Gloria.

ASK

How does Gloria meet Mrs. Johnson where she is in the progression of dementia?
Meeting Mrs. Johnson Where She Is: Wrap-Up—Slide 13 of 16

Instructor Guidance:

It’s important that participants understand the cycle of events that could happen if Gloria doesn’t know where Mrs. Johnson is in the progression of dementia.

If Gloria thinks that Mrs. Johnson is able to do most things on her own, she might assume that Mrs. Johnson is doing those things and not even give her a reminder. In that scenario, Mrs. Johnson would likely forget to brush her teeth. When Gloria discovers that Mrs. Johnson didn’t brush her teeth, she might conclude that she didn’t brush her teeth because she can’t. Mrs. Johnson can brush her teeth, but just needs reminders to do so. As a result of Gloria’s thinking Mrs. Johnson can’t brush her teeth, Gloria might brush her teeth for her or give her more help than she needs. This might cause Mrs. Johnson to lose her ability to brush her teeth. It might also cause Mrs. Johnson to become frustrated with Gloria, because she would like to be involved in her own care, or perhaps because having everything done “to her” results in feelings of helplessness, low self-esteem, or embarrassment.

It is important to point out to participants that a person with dementia might go up and down; in other words, a person with dementia might seem better some days and be able to do more. On other days we might have to go further to meet someone where she is because she is having a bad day and is able to do less.

When we meet persons with dementia where they are, we connect with them and can meet their emotional, as well as physical needs.
To wrap up, facilitate a discussion with the following questions:

Looking back at these clips, how did Gloria adapt to Mrs. Johnson as she progressed?

Some possible responses are:

- She supported Mrs. Johnson by encouraging her to be involved in toothbrushing as much as possible.
- Gloria knew where Mrs. Johnson was in the progression of dementia so she was able to adjust the type and amount of help she needed.

What would have happened if Gloria had not adapted to Mrs. Johnson’s progression?

Note: You might need to prompt discussion by specifically asking, What would have happened if Gloria had done too much for Johnson? (and) What would have happened if Gloria had done too little for Mrs. Johnson?

- If Gloria had done too much for Mrs. Johnson:
  - Mrs. Johnson might have lost her abilities to do things on her own.
  - Mrs. Johnson might have become frustrated with Gloria.
  - Mrs. Johnson might have felt helpless, depressed, and lacking self-esteem and self-worth.

- If Gloria had done too little for Mrs. Johnson:
  - Mrs. Johnson might not have brushed her teeth at all.
Mrs. Johnson might have tried to brush her teeth on her own, gotten frustrated, and given up.

If Gloria then noticed Mrs. Johnson had not brushed her teeth, she might assume she was not able to do it and Gloria might do it for her.

Mrs. Johnson might have lost the ability to brush her teeth on her own.
Meeting Mrs. Johnson Where She Is: Wrap-Up

ASK

- Looking back at these clips, how did Gloria adapt to the progression of dementia Mrs. Johnson experienced?
- What would have happened if Gloria had not adapted to Mrs. Johnson’s progression?
Meeting People Where They Are and Communication—Slides 14 and 15 of 16

Instructor Guidance:

Gloria’s ability to meet Mrs. Johnson where she was required good communication skills. This screen reviews effective ways of communicating with persons with dementia.

Which of these strategies do you remember Gloria using with Mrs. Johnson? (Note: Gloria used all of these.)

- Always identify yourself.
- Call the person by the name he or she prefers.
- Be at his or her eye level.
- Make eye contact with him or her.
- Really listen to him or her. Give him or her your complete attention.
- Pay attention to your body language—is it showing you are “present” to that person.
- Use visual and verbal cues to get your message across.
- Look at the body language of the person with dementia to see what he or she might be trying to communicate.
- Speak slowly.

Notes:
• Speak in short, simple sentences.
• Be patient.
• Give the person enough time to talk or to respond.
• Be specific.
• Ask one question at a time.
• Give one direction at a time.
• Repeat questions or instructions if needed.
• Ask how you can help.
• Tell him or her what you are doing or going to do.
• Reassure with words and touch.
• Avoid negative words.
• Avoid arguing.
This page intentionally left blank.
Which of these communication strategies do you remember Gloria using with Mrs. Johnson?
Meeting Persons with Dementia Where They Are: Summary—Slide 16 of 16

Instructor Guidance:

In this lesson we used the example of Mrs. Johnson and her aide Gloria to explore meeting persons with dementia where they are.
Meeting Persons with Dementia Where They Are: Summary

In this lesson we saw an example of meeting a person with dementia where she is throughout her progression.

ASK

What is one thing you learned or relearned from this lesson?
V. **Strengths and Abilities**

**Strengths and Abilities: Goal—Slide 1 of 6**

**Instructor Guidance:**

In order to meet persons with dementia where they are, we need to recognize their strengths and abilities as well as their weaknesses and disabilities. A strength-based approach to dementia care means focusing on what people *can* do rather than on what they *cannot* do.
Strengths and Abilities: Goal

SAY

The goal of this section is to understand the importance of seeing persons with dementia as having strengths and abilities, as well as weaknesses and disabilities. We all have strengths, as well as weaknesses.
Strengths and Abilities Exercise: Part 1—Slide 2 of 6

Instructor Guidance:

We often define persons with dementia by their weaknesses or disabilities. For example, we might refer to someone as a “dementia patient” or “dementia resident.” Labeling people and focusing on their disabilities does not allow us to see them as whole people with strengths and abilities. When we focus only on the negative, individuals become problems that need to be solved rather than people for whom we are caring.

The purpose of this exercise is to help participants understand the impact of focusing on a person’s weaknesses and disabilities.

Exercise Instructions

- Give each participant a name tag.
- Ask them to write on their name tags one thing about themselves that they consider a weakness—something they are not good at or have trouble doing, for example, “I am a terrible cook.”
- After they have written their weakness on their name tag, ask them to put the name tag on.
- Have the participants mingle with each other for a minute or two. Tell them that when they meet each other, they can only introduce themselves by their weakness and can only talk about each other’s weaknesses.
What would it feel like if you had to wear that label all the time and that was all other people focused on about you?

Some possible responses are:

- It made me feel bad about myself.
- I was embarrassed.
- I felt like other people didn’t really know me.
- I felt like that was all there was to me.
- I wanted them to know good things about me, too.

How did you feel about the other people you met?

- I felt bad (pity) for them.
- It was awkward.
- I felt like I didn’t know very much about them.
- I didn’t want to be around them very long.
Strengths and Abilities Exercise: Part 1

DO

Give each participant a name tag and have markers available.

SAY

Each of you has been given a name tag. On it, write one thing about yourself that you consider a weakness—something you are not good at or don’t know how to do. Then put your name tag on.

Now you’re going to mingle with each other for a minute or two. However, you can only introduce yourself by your weakness and you can only talk about each other’s weaknesses.
ASK (after a few minutes of mingling)

- How would you feel if you had to wear this label all the time and it was all other people focused on about you?
- How did you feel about the other people you met?
**Strengths and Abilities: Labeling Weaknesses—Slide 3 of 6**

**Instructor Guidance:**

This slide shows residents and aides who have been labeled by their weaknesses or disabilities. Facilitate a discussion by asking, What do you think about these people when you see only their negative labels or weaknesses?

Participants might say:

- I focused on what was wrong with them.
- I felt bad for them.
- I saw them in a negative way.
- I saw them as problems.
- I don’t really know them as whole individuals—just a part of them.

**Notes:**

How do you think that influences how you interact with them?

Participants might say:

- I might avoid them or not want to spend much time with them.
- I might not relate to them.
- I might focus on what’s wrong with them and not look at their needs.
Strengths and Abilities: Labeling Weaknesses

**ASK**

- What do you think about these people when you only see their negative labels or weaknesses?
- How do you think that influences how you interact with them?
Strengths and Abilities Exercise: Part 2—Slide 4 of 6

Instructor Guidance:

For the second part of this exercise, participants will focus on their strengths.

Exercise Instructions

- Give each participant another name tag.
- Ask them to write on their name tags one thing about themselves that they consider a strength—something they are good at or are proud of, for example, “I speak two languages.” Encourage them to think of something others might not know about them.
- After they have written their strength, ask them to wear their name tag. If they are still wearing the first name tag, ask them to cover it with the new name tag.
- Direct the participants to mingle with each other for a minute or two—when they meet each other, they can only introduce themselves by their strengths and can only talk about each other’s strengths.

What was the difference when you focused on your strengths?

Participants might say:

- The interaction was more positive.
- I felt better about myself.

Notes:
• I could connect more with the other person. I felt like they could understand me better.

• I had positive feelings about them.
This page intentionally left blank.
Strengths and Abilities Exercise: Part 2

**DO**

Give each participant another name tag.

**SAY**

On this name tag, write down one thing about yourself that you consider a strength—something you are good at or something you are proud of, for example, “I speak two languages.”

After you have written down your strength, put on your name tag and mingle with each other for a minute or two. You can only introduce yourself by your strengths and you can only talk about each other’s strengths.

**ASK (after a few minutes of mingling):**

What was the difference when you focused on your strengths?
**Focusing on Strengths and Abilities—Slide 5 of 6**

**Instructor Guidance:**

This slide shows the same residents and aides as before with labels of their strengths and abilities. Ask, What did you think about these people when you saw their strengths and abilities?

Participants might say:

- I saw them differently.
- I saw them in a more positive light.
- I saw them as people rather than just diagnoses or problems.
- I related to them better.
- I felt more connected to them.
- I saw them as individuals.

How do you think that influences how you interact with them?

Participants might say:

- I could relate to them better.
- I felt more connected to them.
Focusing on Strengths and Abilities

ASK

- What did you think about these people when you saw their strengths and abilities?
- How do you think that influences how you interact with them?
Strengths and Abilities: Summary—Slide 6 of 6

Instructor Guidance:

No instructor guidance for this slide.
In this lesson, you’ve learned the importance of recognizing strengths and abilities, as well as weaknesses and disabilities of persons with dementia.
VI. Still There: Connecting with Persons with Dementia

Instructor Guidance:

Every interaction with persons with dementia is an opportunity to connect with them. We can connect with persons with dementia throughout the progression of dementia and even at the end of life. We might have to find different ways to connect with persons with dementia as they progress, but the person is “still there” and deserves dignity and respect.
Still There: Connecting with Persons with Dementia: Goal

SAY

Every interaction with persons with dementia is an opportunity to connect with them. We can connect with persons with dementia throughout the progression of dementia and even at the end of life. We might have to find different ways to connect with persons with dementia as they progress, but the person is “still there” and is deserving of dignity and respect.
Instructor Guidance:

Person-centered dementia care is based on the work of Dr. Tom Kitwood. Dr. Kitwood suggested that all human beings have five fundamental psychological needs.\(^1\) Good dementia care involves fulfilling these needs:

- **Comfort**—The provision of warmth and strength.
- **Attachment**—The forming of specific bonds or attachments. Persons with dementia might have an even greater need to have strong attachments because they need someone to guide them through scary, frustrating, and unfamiliar situations.
- **Inclusion**—Being part of a group. The actions of persons with dementia might be communicating that they feel left out and want to feel included.
- **Occupation**—Being involved in the process of life. Occupation is not just about work, but also about doing things that are meaningful to us.
- **Identity**—Having a sense and feeling of who one is. Persons with dementia are still there.

Persons with dementia have these basic needs regardless of where they are in the progression. Every interaction we have with them is an opportunity to connect with them and help fulfill these needs.

---

All human beings have five fundamental psychological needs. Good dementia care involves fulfilling these needs:

- **Comfort**—Providing warmth and strength.
- **Attachment**—Forming specific bonds or attachments.
- **Inclusion**—Being part of a group.
- **Occupation**—Being involved in the process of life; having purpose and meaning.
- **Identity**—Having a sense and feeling of who one is.
Persons with dementia continue to have these basic needs regardless of where they are in the progression. Every interaction we have with people with dementia is an opportunity to connect with them and help fulfill these needs.
This page intentionally left blank.
Communicating Through the Senses—Slide 3 of 6

Instructor Guidance:

Persons with dementia often have challenges with communication—both sending and receiving messages. As a person progresses with dementia, he or she might no longer be able to communicate through words. When persons with dementia can no longer communicate with words, we can use other ways to connect with them. Communicating through the senses is particularly important at the end of life.

Taste

Taste is very important to us. It brings back memories and can provide a great source of pleasure. Think about the tastes you like the most and how they make you feel.

Touch

Touch is something most of us experience every day. Touch is a form of communication that acknowledges and connects with others. Touching certain objects can also provide comfort and pleasure. For example, people might enjoy the touch of a soft blanket or a kitten’s fur.

Sound

Persons with dementia can participate in the communication process through listening. Although they may have difficulty understanding the meaning of words, they might respond to the sound of a person’s voice, singing, music, or sounds of nature.
Smell

Certain smells can bring back memories, give us pleasure, or make us feel safe. For example, the smell of certain foods might bring back pleasant memories for many of us, perhaps of good times we shared with family during meals.

Sight

We can communicate with persons with dementia through their sense of sight. Simply watching people, animals, or nature might provide pleasure for persons with dementia and make them feel connected to the world. They might enjoy looking at artwork; looking at artwork together might be a way you can connect with persons with dementia.
This page intentionally left blank.
Communicating Through the Senses

DO

Discuss communicating through the five senses using the explanations in the instructor guidance.
Discussion—Slide 4 of 6

Instructor Guidance:

Facilitate a discussion with the group about how they can engage the five senses to communicate with persons with dementia.

What are some ways to communicate with persons with dementia through taste?

Some possible answers are:

- Offering foods a person enjoys.
- Offering different foods.
- Finding out a person’s favorite foods.

What are some ways to communicate with persons with dementia through touch?

Some possible answers are:

- Hugging.
- Touching their arm or hand.
- Holding their hand.
- Massaging their hand.
• Rubbing their back.
• Giving manicures.
• Putting lotion on their hands.
• Giving them something soft or furry to touch.

What are some ways to communicate with persons with dementia through sound?

Some possible answers are:

• Offering music.
• Singing to them.
• Talking to them about your day.
• Listening to sounds of nature (birds singing, waves, and so on).

What are some ways to communicate with persons with dementia through smell?

Some possible answers are:

• Smells of cooking and baking (freshly baked bread, chocolate chip cookies).
• Aromatherapy.
• Fragranced lotions or favorite perfumes.
• Fresh flowers.
What are some ways to communicate with persons with dementia through sight?

Some possible answers are:

- Providing access to nature and the outside.
- Looking at artwork.
- Making direct eye contact with them.

Each person with dementia is an individual and has unique preferences regarding each of the senses. Knowing a person and having a relationship with him or her is fundamental to communicating in a way that is meaningful to him or her. Consistent staffing is a way to encourage caregivers to build relationships with residents.
Discussion

ASK

What are some ways to communicate with persons with dementia through
Taste? Touch? Sound? Smell? Sight?

SAY

Keep in mind that these ways of communicating depend on knowing the
person and your relationship with him or her. Be mindful that we all have
individual preferences for taste, touch, sound, smell, and sight. While one
person might enjoy receiving hugs, another might prefer a simple touch on the
hand. While one person might enjoy music, another might find it
overwhelming. When you know your resident, you know how to best connect
with him or her.
Everyday Moments—Slide 5 of 6

Instructor Guidance:
Through everyday moments such as bathing, dressing, and eating, you can connect with persons with dementia and fulfill fundamental psychological needs. Use the five senses in these everyday moments to connect with persons with dementia, even those who cannot communicate verbally.

To illustrate this point, use the scenario below to lead a brief discussion about how to connect with someone during an everyday activity such as eating.

You are helping Mrs. K, a resident with dementia, eat her breakfast. Mrs. K is far along in the progression of dementia and cannot communicate with words. What are some ways you might fulfill each of these needs while helping her eat breakfast? (Hint: Think about using the five senses.)

Some possible answers are:

- Comfort—providing warmth and strength.
  - Look for signs that Mrs. K is comfortable or uncomfortable (nonverbal communication).
  - Providing comfort items such as blankets or pillows sends the message of care and concern.
  - Touch her hand to let her know you are with her.
  - Talk to her. Talk to her about having breakfast, what you like for breakfast, or what you know she likes for breakfast. Talking to her in a familiar way shows that you have a connection with her and provides comfort to her.
• Attachment—the forming of specific bonds or attachments.
  o Sit next to Mrs. K.
  o Talk to her, even if she cannot respond.
  o Make eye contact with Mrs. K.
  o Touch her hand or arm to let her know you are with her.

• Inclusion—being part of a group.
  o Invite others to join Mrs. K at the table.
  o Talk to Mrs. K about her family or tell Mrs. K about your family.
  o Facilitate a conversation with the whole table, even if some persons cannot verbally participate.
  o Consider offering something that everyone can enjoy together, such as music.
  o Include Mrs. K in what is happening in the room through the senses. Tell her what you smell, see, and hear.

• Occupation—being involved in the process of life; having purpose and meaning.
  o Focus on Mrs. K’s strengths. For example, if she can pick up food on her own, encourage her to do so.
While waiting for meals to be served or plates to be cleared, involve Mrs. K in something that is meaningful to her. For example, if she enjoys wiping the table, provide her with a cloth so that she can do so.

- **Identity**—having a sense and feeling of who one is.
  - Call Mrs. K by her name.
  - Serve Mrs. K food that she likes and has meaning for her. For example, if Mrs. K is German, serve her German foods that she enjoys.
Everyday Moments

ASK

You are helping Mrs. K, a resident with dementia, eat her breakfast. Mrs. K is far along in the progression of dementia and can no longer communicate with words.

How can you use this opportunity to meet Mrs. K’s needs for:

- Comfort?
- Attachment?
- Inclusion?
- Occupation?
- Identity?
Still There: Connecting with Persons with Dementia: Summary —Slide 6 of 6

Instructor Guidance:

No instructor guidance for this slide.

Notes:
Still There: Connecting with Persons with Dementia: Summary

SAY

In this lesson you’ve learned about ways to connect with persons with dementia throughout the progression of dementia.

The progression of dementia does not make someone less of a person. Meeting persons with dementia where they are means always honoring them with dignity and respect and seeing them as whole individuals.
VII. Each Person Makes a Difference

Each Person Makes a Difference: Goal—Slide 1 of 5

Instructor Guidance:

In this lesson participants will see a video clip that demonstrates the role we all play in making a difference in the lives of others. After the clip, facilitate a discussion.
Each Person Makes a Difference: Goal

SAY

The goal of this lesson is to illustrate the role we all play in making a difference in the lives of people who live and work in nursing homes.
Play Video Clip: Each Person Makes a Difference—Slide 2 of 5

Instructor Guidance:
The purpose of this video clip is to show the impact each of us has on everyone around us. Each character in the clip sees or is part of something that inspires him or her to “pay it forward” and show kindness to someone else. It is a value of person-centered care that every person, no matter his or her job, makes a difference. It is often in these small moments that the greatest impact occurs.
Play Video Clip: Each Person Makes a Difference

DO

Click the forward arrow to play the clip.
Discussion—Slide 3 of 5

Instructor Guidance:

What do you think about what you have just seen?

Some discussion points are:

- Different caregivers were shown in this clip and each of them made a difference.
- Residents and families also make a difference in our daily lives.
- One act of kindness becomes “contagious” and might inspire other acts of kindness.
- These small acts of kindness make people’s days and you have the power to do that every day.
Discussion

ASK

What do you think about what you have just seen?

SAY

You have the power to make a difference in the lives of the people who live and work here. Even one small thing for one person makes a difference.
Optional Exercise: Appreciating the Difference You Make—Slide 4 of 5

Instructor Guidance:

The purpose of this exercise is for participants to acknowledge the difference each person makes in the lives of the people with whom they work and for whom they care. This is an important value of person-centered care. It is also important to note that it is only through working together as a team that we can adequately care for persons with dementia. This activity can contribute to team-building.

Note: If your participants have not worked together and do not know one another well enough to comfortably complete this activity, you may choose to omit it. Reiterate that we all have gifts and thank participants for the gifts they bring to the residents and other caregivers.

Exercise Directions

Write each participant’s name across the top of a separate easel chart page. Give each participant enough Post-it® Notes to have at least one for every other participant. Ask participants to write, on a Post-it® Note, one thing they are grateful for about each of the other participants and then stick their notes on the appropriate easel chart page. Some questions to stimulate thinking are:

- How has this person made a difference in my life?
- How has this person made a difference in the lives of others (other co-workers or residents)?
• What has this person done that I appreciated (whether it was for you or for someone else)?

Note: An alternative way of doing this exercise is to use sheets of notebook paper, each with a participant’s name at the top. Pass the sheets around and ask everyone to write one thing they are grateful for about that person. When everyone is done, post the papers on the wall.

Gratitude exercises like this can be done outside the classroom and become a permanent program at your nursing home. Here are some ideas:

• “You Rock”—Find or draw a picture of a big rock and write “You Rock” above it. Encourage staff to write the names of their co-workers with a quick explanation of why they “rock.”

• “Caught ya!”—Use a box (such as a shoebox) with a slot in which caregivers can leave index cards of “good deeds” and caring things they caught others doing, either for other caregivers or for residents. Share these good deeds with everyone at staff meetings to recognize the difference caregivers make and to express gratitude for them.
This page intentionally left blank.
Optional Exercise: Appreciating the Difference You Make

DO

Conduct the gratitude exercise using the instructions in the instructor guidance.

SAY

We all have gifts. Thank you for the gifts you bring to us here.
Each Person Makes a Difference: Summary—Slide 5 of 5

Instructor Guidance:

No instructor guidance for this slide.

Notes:
Each Person Makes a Difference: Summary

SAY

In this lesson you’ve learned that each of us makes a difference in the lives of everyone we work with and care for.
VIII. Conclusion

Congratulations!—Slide 1 of 2

Instructor Guidance:

Before concluding the training, ask whether participants have any final questions.

Notes:
Congratulations!

SAY

In the last hour, we have learned about connecting with and meeting persons with dementia where they are.

ASK

Do you have any final questions?
Module 4 Video Clips—Slide 2 of 2

Instructor Guidance:

From this slide you can easily access any of the video clips in this module for review or additional discussion.

- Video Clip 1—Mrs. Johnson, Part 1.
- Video Clip 2—Mrs. Johnson, Part 2.
- Video Clip 3—Mrs. Johnson, Part 3.
- Video Clip 5—Mrs. Johnson, Part 5.
- Video Clip 6—Each Person Makes a Difference.
Module 4 Video Clips

Meeting Persons with Dementia Where They Are

Each Person Makes a Difference

Video Clip 1
Video Clip 2
Video Clip 3
Video Clip 4
Video Clip 5

Select a video clip above

Module 4 – Being with a Person with Dementia: Making a Difference

Slide 2 of 2
Module 5:
Preventing and Responding to Abuse
Methodology

This module uses lecture, interactive discussion, and exercises.

(Total Time: 120 minutes)

<table>
<thead>
<tr>
<th>Estimated Time</th>
<th>Lecture and Discussion</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 minute</td>
<td>Welcome</td>
<td>4</td>
</tr>
<tr>
<td>5 minutes</td>
<td>Warm-Up Exercise: What is Abuse?</td>
<td>8</td>
</tr>
<tr>
<td>1 minute</td>
<td>Module Objectives</td>
<td>10</td>
</tr>
<tr>
<td>13 minutes</td>
<td>What is Abuse?</td>
<td>16</td>
</tr>
<tr>
<td>14 minutes</td>
<td>Recognizing Abuse</td>
<td>44</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Signs of Abuse</td>
<td>82</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Actions and Reactions: Understanding How Abuse Happens</td>
<td>108</td>
</tr>
<tr>
<td>20 minutes</td>
<td>Preventing Abuse</td>
<td>128</td>
</tr>
<tr>
<td>45 minutes</td>
<td>Responding to and Reporting Abuse</td>
<td>144</td>
</tr>
<tr>
<td>1 minute</td>
<td>Conclusion</td>
<td>196</td>
</tr>
</tbody>
</table>

Appendix

Handout: Actions and Reactions: WHY? .......................................................... A-3
Circle of Abuse ................................................................................................. A-5
Handout: How to Report Abuse ........................................................................... A-7
Handout: How to Report Abuse: Writing the Report ........................................... A-9

Training Resources

- Computer capable of playing an .ISO file
- Downloaded .ISO file for Module 5.
- Module 5 Instructor Guide.
- Pens, pencils, and writing tablets.
- Prizes (optional).
- Easel chart with markers.

Instructor Preparation

- Review the Instructor Guide and .ISO. Practice exercise delivery. Rehearse with .ISO. Print copies of the handout. Have available your nursing home’s policy on reporting abuse.
1. Welcome

Welcome to Module 5: Preventing and Responding to Abuse—Slide 1 of 4

Instructor Guidance:

If the participants do not know one another, have each participant state his or her name, position, and where he or she works in the nursing home.

To give you more flexibility in introducing the module, there isn’t a recommended script. Instead, you will find a DO action that outlines the topics to cover on the welcome slide. You will want to ensure that participants are comfortable, that they know who you are, and that they understand that Module 5: Preventing and Responding to Abuse will take approximately two hours to complete.

To prepare for an upcoming exercise, write each of these category names on a separate page of the easel chart:

- Health: Physical, Mental, Emotional.
- Medications.
- Communication.
- Environment.
• Task.
• Unmet Needs.
• Life Story.
• You.

Tape the pages to the wall so that participants can see them.

Be sure to pass out a sign-in sheet to track attendance.
Welcome to Module 5: Preventing and Responding to Abuse

DO

- Greet participants.
- Welcome participants to the training.
- Have participants introduce themselves (if they don’t know one another).

SAY

Before we get started, I want to let you know that you will see some videos that graphically portray abuse situations. They may disturb or upset you, but they help us understand this very important topic of abuse.
This page intentionally left blank.
II. Warm-Up Exercise: What Is Abuse?

Warm-Up Exercise—Slide 2 of 4

Instructor Guidance:

Instructor Goals

- To set the stage for participation throughout the training.
- To gather the participants’ thoughts on the meaning of abuse.
- To point out that people might think about abuse differently.

Materials Needed:

- Easel chart with markers.
- Treats (candy).

Participants will likely call out a wide variety of terms and examples. Point out that participants might see abuse differently. There are no wrong answers in this exercise.

If you think the participants might be uncomfortable talking in a large group, you can separate the class into smaller groups and have each group share the results of its discussion.
Warm-Up Exercise

ASK
To get us started, what do you think of when you hear the word *abuse*? There are no right or wrong answers—this is what *you* think.

DO
As the participants call out words or phrases, write them on the easel chart.

Notes:
III. Module Objectives

Module Objectives—Slide 3 of 4

Instructor Guidance:

Module 5 begins with an introduction to abuse—what it is, what are the types, and how to recognize it.

It is strongly recommended that participants complete modules 1 through 4 before this module. These modules build an important foundation to preventing abuse. Module 1: Understanding the World of Dementia: The Person and the Disease provides an overview of dementia, which more than half of nursing home residents experience. Module 2: Being with a Person with Dementia: Listening and Speaking focuses on communicating effectively with persons with dementia. Module 3: Being with a Person with Dementia: Actions and Reactions discusses understanding and responding to the actions of persons with dementia. Module 4: Being a Person with Dementia: Making a Difference discusses being with persons with dementia wherever they are in their experience of dementia, finding ways to connect with them, and understanding the difference you make in their lives. It is important to learn about dementia when addressing abuse. The Center of Excellence on Elder Abuse and Neglect has reported that persons with dementia are thought to be at greater risk of abuse and neglect.¹

¹ Center for Excellence on Elder Abuse and Neglect, University of California, Irvine, Fact Sheet, http://www.centeronelderabuse.org/docs/PwDementia_Factsheet.pdf.
Module 5 builds on these concepts to help staff understand how they might prevent abuse by stopping the chain of events that can lead to abuse. Module 5 will also prepare participants to respond to abuse that they might witness and to report all suspected abuse.
Module Objectives

SAY

You already have your own ideas of what abuse is. We are going to build on those ideas to further explore the concept of abuse.

Unfortunately, abuse can and does happen in many forms. Resident abuse can come from many different individuals, including staff, visitors, family members, and other residents.

We know that you are working here because you care about the people who live here. Because you care so much about them, we need your help in preventing abuse. Working together, we can prevent it; we all have a part in stopping abuse.
By the end of this module, you will be able to:

- Identify types and signs of abuse.
- Evaluate how a series of actions and reactions might lead to abuse.
- Recognize how abuse might be prevented.
- Respond to abuse if you see it happening.
- Report abuse and suspicion of crime.
Module 5 Menu

Instructor Guidance:

The menu screen allows you to easily navigate through the module by selecting the lesson you want to present. It is intended for the class to go through all the lessons in order so that they can build on what they learn.

At the end of the module, if you want to look at the clips again or use them for additional training, you can click the forward arrow at the bottom of the screen. These are the same clips used in the lessons; they are available to you for review and additional discussion.
Module 5 Menu

SAY

Let’s get started with the first lesson, What is Abuse?

DO

On the menu, click the first lesson, What is Abuse?
II. What is Abuse?

Instructor Guidance:

The goals of this lesson are for participants to:

- Understand the Centers for Medicare & Medicaid Services definition of abuse.
- Learn about different types of abuse so that they are able to recognize abuse if it happens to their residents.
What is Abuse?: Goals

SAY

As we saw in our warm-up exercise at the beginning of class, we might think of abuse differently.

In this lesson, we will learn how CMS defines abuse. We’ll also learn about different types of abuse and give you examples of each. Knowing about different types of abuse will prepare you to recognize and report abuse if you see it.

Then, we’ll watch some video clips and talk about what type of abuse might be happening.
Instructor Guidance:

Each time you click the forward arrow, a bullet point will appear on the slide. Explain each one to the participants, using the explanations and examples in the table below.

<table>
<thead>
<tr>
<th>CMS Definition</th>
<th>Explanation</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Willful infliction of injury, unreasonable confinement, intimidation, or punishment.</td>
<td>Willful means that the individual acted deliberately, not that the individual intended to inflict injury or harm.</td>
<td>Striking a combative resident.</td>
</tr>
<tr>
<td>Deprivation by an individual of goods or services that are necessary to attain or maintain physical, mental, and psychosocial well-being.</td>
<td>Staff has knowledge and ability to provide care and services, but choose not to do it.</td>
<td>Removing a resident's access to requesting for assistance.</td>
</tr>
<tr>
<td>Instances of abuse of all residents, irrespective of any mental, or physical condition, cause physical harm, pain, or mental anguish.</td>
<td>Abuse can occur to any resident.</td>
<td>Verbally abusing a cognitively impaired resident who is not able to respond.</td>
</tr>
<tr>
<td>It includes verbal abuse, sexual abuse, physical abuse, and mental abuse including abuse facilitated or enabled through the use of technology.</td>
<td>See slides 2 of 13 through 10 of 13.</td>
<td>See slides 2 of 13 through 10 of 13.</td>
</tr>
</tbody>
</table>
CMS Definition of Abuse

SAY

CMS, the Federal agency responsible for oversight of nursing home inspections and other nursing home-related activities, has a specific definition of abuse.

DO

Click the forward arrow to build the definition on the slide. Use the chart in the Instructor Guidance on page 18 to discuss each bullet.
Types of Abuse—Slide 3 of 12

Instructor Guidance:

This slide, Types of Abuse, lists the types of abuse that are covered in this lesson:

- Mental.
- Verbal.
- Physical
- Sexual.
- Deprivation of goods or services.
- Neglect.
- Involuntary seclusion.
- Missappropriation of resident property.
- Exploitation.

These slides are intended to introduce the types of abuse covered in this lesson. Do not define them. Definitions and examples of each type of abuse follow.
Types of Abuse

Let’s define abuse more specifically. There are different types of abuse: verbal, mental, physical, and sexual abuse and the deprivation of goods or services. In addition, there are other areas related to abuse, which we’ll be discussing today: neglect, involuntary seclusion, and misappropriation of resident property and exploitation. You mentioned some of them in our warm-up
exercise.

Over the next several slides, we will go over the types of abuse listed here and the other areas related to abuse and provide examples of each.
Instructor Guidance:

Note that these are broad definitions and there are many possible examples.
What Is Mental Abuse?

SAY

Mental abuse is the use of verbal or nonverbal conduct that causes or has the potential to cause the resident to experience humiliation, intimidation, fear, shame, agitation, or degradation.

Some examples of mental abuse are:

- A resident urinates on herself. A staff person tells her that to teach her a lesson, she has to go to dinner wet.
- A resident who can no longer get out of bed by himself is told he is lazy.
- Staff posts a video of a resident on social media, where staff are taunting the resident to solicit a response.
What Is Verbal Abuse?—Slide 6 of 13

Instructor Guidance:

Note that these are broad definitions and there are many possible examples.
What Is Verbal Abuse?

SAY

Verbal abuse may be considered to be a type of mental abuse. Verbal abuse includes the use of oral, written, or gestured communication, or sounds, to residents within hearing distance, regardless of age, ability to comprehend, or disability.

Some examples of verbal abuse are:

- Threats: If you don’t stop yelling, I am going to make you stop!

- Saying things to frighten a resident: You are never going to be able to see your family again!

- Insults: It’s too bad that you lost your mind and have no idea what is going on! You’re crazy!
What Is Physical Abuse?—Slide 7 of 13

Instructor Guidance:

Note that these are broad definitions and there are many possible examples.

Notes:
What Is Physical Abuse?

SAY

Physical abuse includes hitting, slapping, punching, biting, and kicking. It also includes controlling behavior through corporal punishment.

An example of corporal punishment is slapping a resident’s hand as he or she reaches for an object.
What Is Sexual Abuse?—Slide 8 of 13

Instructor Guidance:

Sexual abuse is a very sensitive topic; the participants might be uncomfortable and resort to giggling or inappropriate comments. It is important to reiterate that sexual abuse is a serious issue and that it happens to people of all ages.

Note that these are broad definitions and there are many possible examples.
What Is Sexual Abuse?

SAY

Sexual abuse happens to people of all ages. Sexual abuse is defined as non-consensual sexual contact of any type with a resident. It includes:

- Unwanted intimate touching of any kind, especially of breasts or perineal area;
- All types of sexual assault or battery, such as rape, sodomy, and coerced nudity;
- Forced observation of masturbation or pornography; and
- Taking sexually explicit photographs and audio and video recordings of a resident(s) and maintaining and distributing them (e.g. posting on social media). This would include, but is not limited to, nudity, fondling, and intercourse involving a resident.
• Generally, sexual contact is nonconsensual if the resident either:
  o Appears to want the contact to occur, but lacks the cognitive ability to consent; or
  o Does not want the contact to occur.

These definitions are broad and there are many examples. Some examples of sexual abuse are:

• A staff person asks a resident to perform a sexual act on him.

• A staff person fondles a resident’s breasts while bathing her.

• While helping a resident with toileting, a staff person makes fun of the resident’s genitals, telling him he is “no longer a man.”
This page intentionally left blank.
What Is Deprivation of Goods and Services?—Slide 9 of 13

Instructor Guidance:

Deprivation of goods and services happens when staff do not provide the goods or services that are required to attain physical, mental, and psychological well-being. Staff have the knowledge and ability to provide these goods and services, but choose not to or fail to assist residents when requested. This can lead to deficits in care.

Note that these are broad definitions and there are many possible examples.
What Is Deprivation of Goods and Services?

SAY

Abuse also includes staff depriving a resident of goods or services that a resident needs to attain or maintain physical, mental, and psychosocial well-being. In these cases, staff has the knowledge and ability to provide care and services, but choose not to, or fail to acknowledge the request for assistance from a resident(s), which result in care deficits to a resident(s).

- An example may include when a resident asks for water before she goes to bed. The staff person refuses to give it to her because she does not want to help the resident to the bathroom during the night.
What Is Neglect?—Slide 10 of 13

Instructor Guidance:

Note that these are broad definitions and there are many possible examples.
What Is Neglect?

SAY

Neglect is the failure of the facility, its employees, or service providers to provide goods and services to a resident that are necessary to avoid physical harm, pain, mental anguish, or emotional distress.
What Is Involuntary Seclusion?—Slide 11 of 13

Instructor Guidance:

Note that these are broad definitions and there are many possible examples.
What Is Involuntary Seclusion?

SAY

Involuntary seclusion means the separation of a resident from other residents or from his or her room or confinement to his or her room (with or without roommates) against the resident’s will, or the will of the resident representative.

Some examples of involuntary seclusion are:

- Forcing a resident to stay in her room because she is “too loud.”

- Placing a resident in an area without access to call lights, and other methods of communication creating an environment of seclusion and isolation for the resident.

- Keeping a resident from entering her room because she “makes too much of a mess in there.”
What Is Misappropriation of Resident Property and Exploitation?—Slide 12 of 13

Instructor Guidance:

Note that these are broad definitions and there are many possible examples.
What Is Misappropriation of Resident Property and Exploitation?

SAY

Misappropriation of property is probably most commonly thought of as stealing, but it is more than that. It is defined as “the deliberate misplacement, exploitation, or wrongful, temporary, or permanent use of a resident’s belongings or money without the resident’s consent.”

Exploitation is defined as “taking advantage of a resident for personal gain, through the use of manipulation, intimidation, threats, or coercion.”

- Some examples of misappropriation of property and exploitation are:
  - A staff person persuades a resident to provide a gift to him or her, in order to receive ongoing care.
  - A staff person finds $20.00 in a resident’s room. She takes it and uses it to buy lunch for herself and other staff.
  - A staff person takes a painting from a resident’s room and hangs it in her home.
  - A staff person takes a resident’s medications for personal use.
Instructor Guidance:

This lesson has covered several types of abuse and issues related to abuse. Note that these are broad definitions and there are many possible examples.

Let’s recap. Who can tell me one of the types of abuse?

- Verbal.
- Mental.
- Physical.
- Sexual.
- Deprivation of goods and services.
- Neglect.
- Involuntary seclusion.
- Missapropriation of resident property.
- Exploitation.
Types of Abuse: Summary

SAY

This lesson has covered the CMS definition of abuse and several types of abuse.

ASK

Let’s recap. Who can tell me one of the types of abuse?
V. Recognizing Abuse

Recognizing Abuse: Goals—Slide 1 of 14

Instructor Guidance:

The goals of this lesson are to help participants recognize abuse, neglect, misappropriation of resident property, exploitation, and involuntary seclusion and to understand why situations might escalate to abuse.
Recognizing Abuse: Goals

SAY

The goals of this lesson are for you to recognize abuse, neglect, misappropriation of resident property, exploitation, and involuntary seclusion and understand why situations might escalate.
Instructor Guidance:

This lesson uses six video clips to provide practice in recognizing different types of abuse. You should plan to spend about 2–3 minutes discussing each video clip.

After each clip, ask participants to identify the type(s) of abuse they saw in the clip. They may identify more than one type of abuse or issues related to abuse. Write their answers on an easel chart (or have a participant write the answers).

After participants have identified the type(s) of abuse, help them process what they saw by asking what led them to that determination. If participants ask how abuse could have been prevented in these situations, respond that we will address that in another module. In terms of preventing abuse, it is important for participants to see that, in each of these situations, there were two individuals with different needs. It is important to note that understanding the aide’s motivation does not excuse or justify his or her behavior. The intention is for participants to see how situations escalate and how escalation possibly can be prevented. In subsequent training modules, we will discuss in more depth how to address each person’s needs to help prevent abuse.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.

You will need:

- Easel chart with markers.
Now that we have discussed different types of abuse, we’re going to see six video clips that will give you practice in recognizing abuse.

We’ll watch each clip and discuss it afterwards. Here’s the first clip.

Click the forward arrow to play the clip.
Discussion: Misappropriation of Property—Slide 3 of 14

Instructor Guidance:

What type or types of abuse did you see?

- In this clip, we saw stealing, which is misappropriation of property.

Write each type of abuse that participants identify on the easel chart (or have a participant write it). Then ask for specifics about what they saw that led them to that determination.

Specifically, what did you see that led you to that determination?

Different types of abuse might occur at the same time. If participants suggest other types of abuse, ask them to explain what they saw.

Consider asking some follow-up questions to help participants see the impact of the staff’s action. Some additional discussion questions are:

How do you think this made the resident feel?

Possible answers: upset, angry, mistrustful, scared, and sad.

Would it be different if the watch weren’t valuable?
Discussion: Misappropriation of Property

ASK

What did you observe or suspect happened?

Instructor Guidance:

You should plan to spend about 2–3 minutes discussing each video clip.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.

SAY

Now we are going to watch the second clip.

Again, we will discuss the clip afterward.

DO

Click the forward arrow to play the clip.
Discussion: Neglect—Slide 5 of 14

Instructor Guidance:

What did you observe or suspect happened?

- In this clip, there is evidence of neglect, as well as abuse.

Write what participants identify on the easel chart (or have a participant write it). Then ask for specifics about what they saw that led them to that determination.

Specifically, what did you see that led you to that determination?

- Deprivation of goods or services: Knowingly leaving a resident in a wet bed could lead to serious physical consequences, such as pressure ulcers or a decline in functioning. It could also lead to embarrassment to the resident and loss of dignity.

- Neglect: Specifically, the neglect in this situation was the aide not providing the resident with a service she needed. Rather than helping Mrs. Bowers go to the bathroom, the aide told her she would just have to go in her bed.
Different types of abuse might occur at the same time. If participants suggest other types of abuse, ask them to explain what they saw.

An additional discussion question is:

How do you think this made the resident feel?

- Possible answers: angry, sad, scared, embarrassed, and mistrustful.

You might also want to point out that the aide mentioned the name of the other resident she needed to help. Was this an invasion of his privacy?
This page intentionally left blank.
Discussion: Neglect

ASK

What did you observe or suspect happened?

Instructor Guidance:

You should plan to spend about 2–3 minutes discussing each video clip.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.

**SAY**

Now we are going to watch another clip, and you will have the chance to see if you recognize what abuse looks like.

Again, we will discuss the clip afterward.

**DO**

Click the forward arrow to play the clip.
Discussion: Verbal and Mental Abuse—Slide 7 of 14

Instructor Guidance:

What did you observe or suspect happened?

- Participants may identify several types of abuse, including verbal, mental, and physical.

Write each type of abuse that participants identify on the easel chart (or have a participant write it). Then ask for specifics about what they saw that led them to that determination.

Specifically, what did you see that led you to that determination?

- Mental and Verbal abuse: The aide humiliated the resident by using degrading and derogatory language. Also, the aide threatened to punish Mrs. Anderson by having Lester bathe her.

- There could be physical abuse in the way the aide grabbed the resident’s chin.

Different types of abuse might occur at the same time. If participants suggest other types of abuse, ask them to explain what they saw.
An additional discussion question is:

How do you think this made Mrs. Anderson feel?

- Possible answers: upset, angry, mistrustful, scared, sad, loss of control.

If you would like to dig deeper, ask the participants:

Person-centered means to focus on the residents as the locus of control and support the residents in making their own choices and having control over their daily lives. How could this situation have been handled in a person-centered way?

- Using a person-centered care approach, the caregivers would work with Mrs. Anderson to accommodate her preferences for bathing, rather than Mrs. Anderson having to accommodate the caregivers. Also, in person-centered care, the person comes first. This means that the resident is not a task to be completed, but a person who has needs and preferences. In this situation, Mrs. Anderson is not a bath to be completed, but a person who wanted to finish her TV show. Caregivers would be sensitive to this and work with her to discover a better time to accommodate her preferences and communicate in a more professional manner.
This page intentionally left blank.
Discussion: Verbal and Mental Abuse

ASK

What did you observe or suspect happened?
Play Video Clip: What Does Abuse Look Like? Video Clip 4—Slide 8 of 14

Instructor Guidance:

You should plan to spend about 2–3 minutes discussing each video clip.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.
Play Video Clip: What Does Abuse Look Like? Video Clip 4

SAY

Now we are going to watch another clip, and you will have the chance to see if you recognize abuse.

Again, we will discuss the clip afterward.

DO

Click the forward arrow to play the clip.
Instructor Guidance:

What type or types of abuse do you suspect?

- In this clip, we saw signs that sexual abuse had happened.

Write each type of abuse that participants identify on the easel chart (or have a participant write it). Then ask for specifics about what they saw that led them to that determination.

Why do you suspect this?

Some signs that sexual abuse may have occurred are:

- Resident was crying and clearly in distress.
- Her bed was disheveled.
- She was in a fetal position.
- A male staff person was exiting her room and checking to see if anyone saw him leaving.
- The male staff person was tucking in his shirt as he left the room.
Point out that the resident in the clip was younger than many nursing home residents. However, sexual abuse happens to residents of any age. Sexual abuse can happen to men as well as women.

Participants might point out that because we did not actually see sexual abuse happening, we do not know that it did happen. Explain that many times—maybe even most of the time—we might not actually see the abuse happening, but we might see signs that abuse has occurred. Later in this training, we will talk more about watching for signs that abuse may have occurred.
Discussion: Sexual Abuse

ASK

What did you observe or suspect happened?

**Instructor Guidance:**

You should plan to spend about 2–3 minutes discussing each video clip.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.

SAY

Now we are going to watch another clip, and you will have the chance to see if you recognize abuse.

Again, we will discuss the clip afterward.

DO

Click the forward arrow to play the clip.
Discussion: Physical Abuse—Slide 11 of 14

Instructor Guidance:

What type or types of abuse did you see here?

- Participants might identify physical abuse and verbal abuse. (Note: If the participants do not identify physical abuse, point it out.)

Write each type of abuse that participants identify on the easel chart (or have a participant write it). Then ask for specifics about what they saw that led them to that determination.

Specifically, what did you see that led you to that determination?

- We saw possible physical abuse when the aide grabbed Mrs. Caputo roughly by the arm and she winced as the other aide was assisting her. Because he was also yelling at her, we could say there may have been verbal abuse as well.

Different types of abuse might occur at the same time. If participants suggest other types of abuse, ask them to explain what they saw.

Later in this training module, we will revisit this scenario with another clip that will show the impact of the abuse—the signs that indicate that a person might have been abused.
In the modules on understanding the behavior of and communicating with persons with dementia, we will take a more in-depth look at what happened in this situation. A different approach to the resident might have prevented the physical abuse.

Some additional discussion questions are:

How do you think the abuse made Mrs. Caputo feel?

- Possible answers: upset, angry, mistrustful, scared, sad.

How could this abuse possibly have been prevented?

- The aide’s responses to Mrs. Caputo escalated the situation so that the resident became angrier and the aide became more frustrated. Telling Mrs. Caputo that she was home did not help the situation, as that is not her reality. She believes she needs to go home to pick up her children. To avoid escalation, the aide could have calmly approached Mrs. Caputo, redirected her attention to him, asked her to tell him about her children and walked with her away from the doors she was trying to exit.
This page intentionally left blank.
Discussion: Physical Abuse

ASK

What did you observe or suspect happened?

Instructor Guidance:

You should plan to spend about 2–3 minutes discussing each video clip.

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.

SAY

Now we are going to watch the last of our six clips.

Again, we will discuss the clip afterward.

DO

Click the forward arrow to play the clip.
Discussion: Involuntary Seclusion—Slide 13 of 14

Instructor Guidance:

What did you observe or suspect happened?

Participants may identify involuntary seclusion, mental abuse, verbal abuse, and neglect.

Write each type of abuse that participants identify on the easel chart (or have a participant write it). Then ask for specifics about what they saw that led them to that determination.

Specifically, what did you see that led you to that determination?

- Involuntary seclusion: The aide placed Mr. Mauer in a separate area away from the other residents, and eventually, facing a wall.

There may have also been:

- Deprivation of goods or services: Mr. Mauer did not receive assistance in eating. Also, after the aide moved him, the food was not placed within reach of Mr. Mauer.

- Mental abuse: Putting Mr. Mauer into seclusion was humiliating and suggested a threat of punishment for not eating properly.

- Verbal abuse: The aide made disparaging remarks about Mr. Mauer—that he was disgusting and like a one-year-old.
Different types of abuse might occur at the same time. If participants suggest other types of abuse, ask them to explain what they saw.

Later in this module, we are going to revisit this situation and see what impact this abuse has had on Mr. Mauer.

Some additional discussion questions are:

- How do you think this made Mr. Mauer feel?
  - Possible answers: embarrassed, upset, angry, mistrustful, scared, sad.

- Was it right for the aide to move Mr. Mauer because the other residents complained about him?

- How could this have been handled differently?
  - Possible answer: The aide could have offered Mrs. Anderson—the resident who did not want to sit with Mr. Mauer—a seat at another table.
Discussion: Involuntary Seclusion

ASK

What did you observe or suspect happened?
Recognizing Abuse: Summary—Slide 14 of 14

Instructor Guidance:

No instructor guidance for this slide.
Recognizing Abuse: Summary

SAY

In this lesson, you’ve learned about recognizing abuse and how situations can escalate to abuse.
VI. Signs of Abuse

Signs of Abuse: Goals—Slide 1 of 10

Instructor Guidance:

The three clips in this lesson show what changes we might see in residents after abuse has occurred. The intention is to help participants recognize signs that a resident might have been abused.
Signs of Abuse: Goals

SAY

The goals of this lesson are for you to recognize signs that abuse may have occurred and realize the impact of abuse.
Play Video Clip: Signs of Abuse: Example 1—Slide 2 of 10

**Instructor Guidance:**

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.

**Notes:**
We already watched six video clips that showed abuse happening. However, most of the time, we will not actually witness abuse.

We might see signs and symptoms that something has happened. A resident might act differently. We might notice changes in a resident.

Let’s look at what we might see in residents after abuse happens.

Click the forward arrow to play the clip.
Discussion—Slide 3 of 10

Instructor Guidance:

Discussion points might include how a nurse aide knows whether something is wrong with a resident and what the aide can do about it. It is important to point out that it is only through really knowing their residents that nurse aides will be able to tell that something is wrong. It is also important to encourage aides to report any changes they see to their supervisors.

Note: Throughout these modules, we talk about knowing residents. Consistent staffing encourages building relationships and supports caregivers in knowing residents. For more information on consistent staffing and how you can implement it in your nursing home, see the Resources tab.

What are some signs that something might have happened to Mrs. Caputo?

- Some signs might be that Mrs. Caputo winced when the aide touched her arm; the bruise on her arm; and her general jumpiness and nervousness when touched.

What else could these signs mean?

- The resident could have hurt herself accidentally. She could be upset by something else that happened.
The intention of this discussion is to make the point that bruises, nervousness, and other signs of possible abuse do not always mean abuse happened. For example, the resident might walk around a lot and bump into things frequently, or the resident might usually be a nervous person. However, we should never ignore or dismiss these signs, but this speaks to the importance of knowing the resident. It is by knowing a resident that an aide can tell whether something is wrong or unusual for that resident. In the case of Mrs. Caputo, the aide knows that Mrs. Caputo does not normally have bruises or skin tears and is not normally nervous. She suspects that something has happened. All injuries or changes in behavior need to be reported to a supervisor.

Note how the aides are talking about Mrs. Caputo behind her back. How might this make her feel?

Talking behind Mrs. Caputo’s back is disrespectful. It might cause her to feel disrespected and she might not trust the aides. It might also make her angry and she might be more unlikely to allow the aides to help her.
This page intentionally left blank.
Discussion

**ASK**

What are some signs that something might have happened to Mrs. Caputo?
Play Video Clip: Signs of Abuse: Example 2—Slide 4 of 10

Instructor Guidance:
When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.
We’re going to watch the second clip now. Again, look for signs that the resident might have been abused.

Click the forward arrow to play the clip.
Discussion—Slide 5 of 10

Instructor Guidance:

What signs are there that something might have happened to Mrs. Anderson?

- Mrs. Anderson jumped when Bill, the therapist, touched her. She looked frightened. She seemed jumpy and distrustful. She was not talking.

What else could these signs mean?

- The purpose of this question is to generate discussion about the importance of knowing the resident and how he or she “normally” acts. These signs could mean a number of things, but the better staff know their residents, the better they are able to interpret these signs to understand if something is wrong. If Bill did not know Mrs. Anderson, he might think that her behavior was normal for her. But because he knows Mrs. Anderson, he knows that these signs mean something is wrong.

Be sure to discuss that, in addition to physical signs, there are emotional and behavioral signs.
Additional discussion questions are:

Should Bill report his concerns about how upset Mrs. Anderson was? If so, to whom would he report this?

Note how the therapist, Bill, soothes Mrs. Anderson. What are some of the things he did to help her feel better?

How did he know what she needed to make her feel better?

Note how he positioned himself in front of her to be at her level when he talked to her. What message do you think this sent to Mrs. Anderson? What did it do for their relationship?

At the end of the clip, Mrs. Anderson asked to call her daughter. What do you think this means? Do you think Mrs. Anderson is going to tell her daughter what happened?

(Note: You may want to point out that Bill should have stepped away so that Mrs. Anderson could speak privately with her daughter.)
This page intentionally left blank.
Discussion

ASK

What signs did you see that something might have happened to Mrs. Anderson?
Play Video Clip: Signs of Abuse: Example 3—Slide 6 of 10

Instructor Guidance:

When you click the forward arrow, the video will play. When the video is complete, the presentation will automatically advance to the discussion slide.
Play Video Clip: Signs of Abuse: Example 3

SAY

Let's watch one more clip and look for signs we might see in residents who have been abused.

DO

Click the forward arrow to play the clip.
Discussion—Slide 7 of 10

**Instructor Guidance:**

What are some signs that something might have happened to Mr. Mauer?

- Mr. Mauer seemed sad and depressed. He was withdrawn. He was “hiding” in his room. He did not speak to the activity director who came to invite him to an activity, nor did he make eye contact with her.

What else could these signs mean?

- The purpose of this question is to discuss the importance of knowing the resident and how he or she “normally” acts. These signs could mean a number of things, and the better staff know their residents, the better they are able to interpret these signs to understand if something is wrong. If the activity director did not know Mr. Mauer, she might just think this was “the way he is,” that these behaviors are a part of his personality. Because she knows him, she knows that this is not normal for him, and she talks to the nurse about it. These signs could mean many things, so it is important to try to find out why he is acting this way. It could mean he is not feeling well or is feeling depressed or anxious for other reasons.
At the end of the clip, the activity director and a nurse are discussing the fact that Mr. Mauer is no longer interested in his favorite activities.

For additional discussion, you might ask the participants, What should the activity director and nurse do next? Point out that when nurse aides see changes in a resident, they need to let their supervisors know about these changes.
This page intentionally left blank.
Discussion

ASK

What are some signs that something might have happened to Mr. Mauer?
Signs of Abuse—Slide 8 of 10

Instructor Guidance:

No instructor guidance for this slide.
Signs of Abuse

SAY

You have already identified a number of these signs and symptoms of possible abuse. Here are some others to think about.

Remember, signs of abuse are not always physical.
Can you think of other signs?

- The intent of this question is to give the participants an opportunity to share other signs they have seen, or simply to restate the ones that are listed. There are no right or wrong answers. It is hoped that asking this question helps participants think about signs of abuse according to their own experience. It is also intended to help participants see that overall changes in a resident’s behavior might be a sign of abuse.
Signs of Abuse (cont.)

ASK

Can you think of other signs?

Do you have residents that usually show some of these types of body language or signs? How would you know whether the behavior indicated possible abuse or was their normal behavior?

SAY

You might know what is normal for a resident because you know that resident. If you know what he or she normally acts like, you would probably recognize changes. Always report changes in a resident to your supervisor.
Signs of Abuse: Summary—Slide 10 of 10

Instructor Guidance:

No instructor guidance for this slide.
Signs of Abuse: Summary

SAY

In this lesson, you’ve learned about signs that may indicate that a resident has been abused.
In Action and Reactions: Understanding How Abuse Happens: Goal—Slide 1 of 7

Instructor Guidance:

The goal of this lesson is to understand possible abuse situations as a series of actions and reactions that might be preventable. Although there are many reasons why abuse happens, some abuse might be the result of a chain of events that escalates in an interaction between a resident and a nurse aide.

In Module 3, “behaviors” of persons with dementia were presented as actions and reactions. Actions are what we do, and reactions are how we respond to what someone else has done or to a situation.
Actions and Reactions: Understanding How Abuse Happens: Goal

SAY

Although there are many reasons why abuse happens, some abuse situations might be the result of a chain of events that escalates in an interaction.
Play Video Clip: Mrs. Wilson—Slide 2 of 7

Instructor Guidance:

In this video clip, a nurse aide is trying to give a resident, Mrs. Wilson, a bath. Mrs. Wilson clearly does not want a bath, as evidenced by her crying, yelling “no,” and resisting the aide. The aide forces her to take a bath against her will. Most of the abuse happens off-screen. The yelling suggests that the aide physically abuses Mrs. Wilson by physically forcing her into the tub and that Mrs. Wilson is resisting.

After the clip is shown, lead a discussion about what participants saw in the clip and whether they considered it abuse.

Note: When you click the forward arrow, the video will play. When the video is finished, the presentation will automatically advance to the discussion screen.
Play Video Clip: Mrs. Wilson

SAY

We are going to look at a video clip and then discuss what happened in terms of a series of actions and reactions to understand what happened and how it could have been prevented. Actions are what we do, and reactions are how we respond to what someone else has done or to a situation.

DO

Click the forward arrow to play the clip.
**Instructor Guidance:**

Was this abuse? Why?

- This could be considered abuse because the aide physically forced the resident out of the wheelchair. She also physically forced her to take a bath.
- The resident clearly communicated she did not want a bath and the aide physically forced her to take a bath.
- The aide was verbally abusive by yelling at her and telling her to “stop it.”
- There might also have been mental abuse because the resident was clearly frightened.
- This was a violation of resident rights.

**What types of abuse do you think happened?**

- Physical—physically forcing her into the tub.
- Verbal—yelling; scolding.
- Mental—causing mental anguish and fear.

Note: This exercise might result in a discussion about resident rights, the right to refuse care, and your nursing home’s formal and informal policies on how to handle this type of situation. Reiterate that all abuse must be reported.
Discussion

ASK

- Is this abuse? Why?
- What types of abuse did you see?
### Actions and Reactions—Slide 4 of 7

**Instructor Guidance:**

A fundamental point of this module is that abuse sometimes results from a series of actions and reactions that could have been prevented.

Each action and reaction will appear on the screen as you click the forward button. Use this table to provide more information as needed about each action and reaction.

<table>
<thead>
<tr>
<th>Action and Reaction</th>
<th>More Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aide’s action: Bringing Mrs. Wilson into the bathroom.</td>
<td>The aide brought Mrs. Wilson into the bathroom. Mrs. Wilson was already upset because the aide had told her in her room that she had to take a bath.</td>
</tr>
<tr>
<td>Mrs. W’s reaction: Crying, saying “No!”</td>
<td>Mrs. Wilson was crying and saying “no” as she entered the bathroom.</td>
</tr>
<tr>
<td>Aide’s action: Taking Mrs. Wilson’s nightgown off.</td>
<td>The aide told Mrs. Wilson to take her nightgown off and started to lift her from her wheelchair.</td>
</tr>
<tr>
<td>Mrs. Wilson’s reaction: Yelling and saying “No! Get away from me!”</td>
<td>Mrs. Wilson continued to cry “no” as the aide lifted her from the wheelchair. She said, “Get away from me.”</td>
</tr>
<tr>
<td>Action and Reaction</td>
<td>More Detail</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Aide’s action: “You have to take a bath!”</td>
<td>The aide continued to move her to the bath. She scolded her, “Please! You have to take your bath today.”</td>
</tr>
<tr>
<td>Mrs. Wilson’s reaction: “No! Go away! Don’t do that!”</td>
<td>Off-screen, we hear Mrs. Wilson yelling.</td>
</tr>
<tr>
<td>Aide’s action: Forces bath, “Sit still! Stop it!”</td>
<td>Off-screen, the aide forced Mrs. Wilson into the tub and yelled at her to sit and be quiet.</td>
</tr>
<tr>
<td>Mrs. Wilson’s reaction: Crying and yelling.</td>
<td>Mrs. Wilson continued to yell and cry.</td>
</tr>
</tbody>
</table>
This page intentionally left blank.
Actions and Reactions

SAY

Let’s break down what you saw by action and reaction. This situation started with the aide’s action of telling Mrs. Wilson she had to take a bath. This happened off-screen, so when we first see Mrs. Wilson, she is already upset.

DO

Click the forward button for each action and then click again for each reaction to appear. Use the instructor guidance to talk through each one. Be sure to frame each action or reaction as such. For example, “The aide’s action was…” and “Mrs. Wilson’s reaction was…”

SAY (after all the actions and reactions are on the screen)

As you see from this chain of events, Mrs. Wilson’s actions or “behaviors” are reactions to the aide’s actions. In the next few slides we will explore why she might be reacting this way and why her reactions might be very understandable.
Actions and Reactions: Discussion—Slide 5 of 7

Instructor Guidance:

After breaking the clip down into actions and reactions, participants should have a clear idea of the chain of events that led to abuse. The purpose of this discussion is to explore how the abuse could have been prevented by stopping the chain of events.

When in the chain of actions and reactions should the aide first have done something different?

- When the resident first said “no,” which probably was before she even got to the tub room.

Note: If the group is having difficulty determining the answer, you might provide this alternative scenario to personalize the situation and encourage them to put themselves in that situation.

Alternative scenario: Imagine that one of your coworkers is in the nursing home because she was in a car accident and broke both of her legs. What if you heard the exchange that happened in the clip—the yelling outside the bathroom door—but it was your friend who was in that wheelchair instead of Mrs. Wilson? In this situation with your friend, when should the aide have acted differently? What if you were in the wheelchair? When would you have wanted the aide to stop?
**Actions & Reactions: Discussion**

**ASK**

When in the chain of actions and reactions should the aide have acted differently?

**SAY**

At any point in this chain of events, the aide could have changed her actions to prevent or stop the abuse. This situation could have been prevented if we better understood the reasons behind Mrs. Wilson not wanting to take a bath.
**Actions and Reactions: Why?—Slide 6 of 7**

**Instructor Guidance:**

There are many reasons why residents might act the way they do. Trying to understand why helps us to better understand what they are experiencing and what they need—even if we never know *exactly* why. Then we can better understand how to respond. With persons with dementia, we need to be particularly tuned in to the meaning of their actions because this is how they might best communicate their needs. Understanding why may help us find a better approach to a situation and prevent the series of events that might lead to abuse.

**Exercise Instructions**

If you have not already done so, put up on the wall the easel chart pages you made for each category of why residents might act a certain way (from page 4 in the Instructor Guide for this module).

Divide the class into small groups and give each group a copy of the handout Actions and Reactions: Why? on page A-3. The handout has questions to get them thinking.

To encourage participants to work with people they might not know well, have each person count off to form a group or pair for each category (1, 2, 3, 4, 5, 6, 7, 8). Assign each group a category.

Give each group Post-It® Notes and ask them to write down all the possible reasons why Mrs. Wilson might not have wanted a bath, using their category as a guide. Groups can then stick each Post-it® Note on the appropriate easel chart page.
For each category, ask, What could Mrs. Wilson be experiencing that causes her not to want a bath?

Possible answers for each category are:

- **Health:** Physical, Mental, Emotional: There are many health issues that might cause a person to act in a certain way. For example, if Mrs. Wilson has arthritis, it might be painful to sit in the tub. Other health issues might be a urinary tract infection, overall pain, depression, or anxiety.

- **Medications:** Side effects or changes in medications can cause residents to act in certain ways. How could medications cause Mrs. Wilson to not want a bath? For example, a particular medication upsets Mrs. Wilson’s stomach and she does not feel like taking a bath.

- **Communication:** A resident might have difficulty communicating something or might not understand what you are saying. For example, Mrs. Wilson might not be able to communicate with words that she is not feeling well and doesn’t want a bath.

- **Environment:** The physical environment might cause a resident to act in a certain way. What about the physical environment of the bathroom might cause Mrs. Wilson not to want to take a bath? For example, the bathroom might be too cold for her.

- **Task:** The resident might not enjoy the task or activity. Why might Mrs. Wilson not enjoy taking a bath? For example, Mrs. Wilson might be very modest and uncomfortable about being naked in front of someone.

- **Unmet Needs:** Sometimes when we are trying to meet one particular resident need, we might not focus as much on other needs. What unmet needs might be causing Mrs. Wilson to not want to take a bath?
For example, Mrs. Wilson feels very scared.

- Life Story: What in Mrs. Wilson’s past would explain why she doesn’t want to take a bath? For example, Mrs. Wilson rarely took baths in her past; she usually took showers.

- You (the person interacting with Mrs. Wilson): Sometimes we trigger a reaction in a resident. How did the way the aide acted cause Mrs. Wilson to not want to take a bath? For example, Mrs. Wilson did not know the aide.
Actions and Reactions: Why?

SAY

There are many reasons why residents might act the way they do. Whatever the action, we must first try to understand why. Even though we may never know exactly why, trying to understand their perspective helps us to better understand what they are experiencing and what they need. Then we can better understand how to respond. Here are some categories of reasons that might explain a resident’s actions. Looking at these categories, let’s brainstorm possible reasons why Mrs. Wilson was acting that way—why she did not want a bath. Understanding why helps prevent the series of events that might lead to abuse because we can find a better approach.

DO

Explain what each category means using the notes in the instructor guidance. If you have not already done so, put up on the wall the easel chart pages you made for each category. Divide the class into small groups.
Give each group a copy of the handout on page A-3, and assign each group a category.

Give each group Post-It® Notes and ask them to write down reasons why Mrs. Wilson did not want a bath, using their category as a guide. The handout has questions to get them thinking. Groups can stick their completed Post-It® Notes on the appropriate easel chart page.

SAY (after exercise is completed)

You identified many possible reasons why Mrs. Wilson didn’t want her bath. These are just a few examples. Just as we have our own reasons for the way we act, residents have many reasons for the way they act. When we better understand the reasons why people act the way they do, we can better respond to them. With Mrs. Wilson, the aide might have prevented the chain of events that led to abuse if she had understood why Mrs. Wilson was acting that way and responded to her differently.

Next, we are going to look at different approaches that might prevent the series of actions and reactions that lead to abuse.
This page intentionally left blank.
Instructor Guidance:

Understanding the series of actions and reactions and the possible reasons behind them helps prevent situations from escalating to abuse. When we understand why people are acting a certain way, we can think of approaches that meet their needs.
Actions and Reactions: Understanding How Abuse Happens: Summary

SAY

In this lesson we considered that abuse is sometimes the result of a series of actions and reactions that might be preventable.
VIII. Preventing Abuse

Preventing Abuse: Goal—Slide 1 of 8

Instructor Guidance:

The goal of this lesson is to identify some ways to respond to resident actions that might prevent a negative series of actions and reactions that lead to abuse.

Each resident is an individual with unique needs and preferences. Identifying approaches that address individuals' unique needs prevents abuse.
Preventing Abuse: Goal

SAY

The goal of this lesson is to identify ways to respond to resident actions that might prevent a negative series of actions and reactions that can lead to abuse.
How Can We Prevent Abuse?—Slide 2 of 8

Instructor Guidance:

Participants will see four video clips that demonstrate different approaches that might prevent the negative series of actions and reactions that lead to abuse.

The video clips all use the example of Mrs. Wilson, a resident who does not want a bath, but the approaches can be modified to use in many situations. These approaches might not always be effective with every resident. Knowing the resident is key to determining the best approach.

Remember, residents have a right to refuse a bath. If a resident says she does not want a bath, try other approaches to meet her needs.

This screen offers some basic principles on how to prevent abuse.
How Can We Prevent Abuse?

SAY

To look at all the possible reasons why Mrs. Wilson did not want a bath, we need to know Mrs. Wilson and see things from her perspective. There are other ways the aide could have responded to her that would have prevented the chain of actions and reactions that led to abuse. To prevent abuse, we need to put ourselves in the shoes of the other person. We need to know the person, be aware of how we are acting, know ourselves, and know our own limits.

When we approach a person from a place of empathy, we can be with her. When we approach her from a place of pity or apathy, we “do to her” rather than “be with her.” Being with a person is having that human connection—this is the reason why many of us are doing this important work.

We’re going to watch some video clips that will show examples of different ways to respond to Mrs. Wilson that might have prevented that chain of events.
Instructor Guidance:

We can respond in a number of ways when a resident does not want to take a bath. In the next few clips participants will see examples of different ways to respond to a resident who does not want to take a bath. It is important to understand that knowing a resident and the reasons behind his or her actions is necessary to determine what approach to use.

One way to prevent abuse is to accept a resident’s refusal to do something and come back at another time. In this clip you will see Lisa, an aide, ask Mrs. Wilson if she would like to take a bath. Mrs. Wilson refuses and Lisa decides to skip her and come back later.

Use your easel chart with these clips to reinforce the different approaches. For the first clip, write “Try later” on the easel chart.

Refer to the words on the easel chart frequently and repeat your message to make sure your information is being heard.
DO
Write “Try later” on the easel chart.

SAY
One way to respond to a resident who doesn’t want a bath is to try later. Think about all the different reasons why a resident might not want to take a bath at that moment, and remember that a resident has the right to refuse a bath. Maybe Mrs. Wilson wanted to finish combing her hair. Maybe another resident is in the middle of a favorite TV show and does not want to miss it, while yet another believes her children are about to come home from school and she doesn’t want to miss them. Maybe she doesn’t know who you are at the moment or maybe you remind her of someone she doesn’t like. Perhaps the best way to respond to these residents is to let them have their moment and come back later. Trying at another time might prevent a chain of actions and reactions that could possibly lead to abuse.

DO
Click the forward arrow to play the clip.
Play Video Clip: Step Into Their World—Slide 4 of 8

Instructor Guidance:

To respond to residents in a way that does not cause a negative reaction or abuse, we have to step into their world. For example, if a resident believes that he or she has already had a bath and an aide insists that the resident did not, this might lead to a series of actions and reactions that could lead to abuse.

In this clip Mrs. Wilson insists that she has had a bath already. Rather than argue with her, Lisa accepts her response because she knows that Mrs. Wilson believes she had a bath and she will not change Mrs. Wilson’s mind. When she investigates and finds that Mrs. Wilson did not have a bath, she still does not correct her. She steps into her world, accepts that Mrs. Wilson believes she has had a bath, and finds another way to help her be clean. She approaches her with trust and acceptance and Mrs. Wilson agrees to using a cleansing lotion that will help her get washed up in her room without having to take a bath.

On the easel chart, write “Step into their world.”
Play Video Clip: Step Into Their World

DO

Write “Step into their world” on the easel chart under “Try later.”

SAY

A resident might truly believe she had a bath yesterday. How would you feel if you knew that you had just had a bath—no doubt in your mind—and some person you aren’t sure you know told you that you did not just have a bath and that you must take one now? This would probably lead to a series of negative actions and reactions.

We have to step into the world of the resident and accept what he or she is telling us. In the example of bathing, we would like to help residents be clean, but we need to think of other ways we can help them to be clean if they are not interested in a bath at that time.

DO

Click the forward arrow to play the clip.
Play Video Clip: Tag Out—Slide 5 of 8

Instructor Guidance:

This clip explains the importance of aides knowing themselves and their limits. Removing themselves from a situation when they are at their limit prevents possible abuse. In some situations, an aide might need to ask a coworker to “tag out” for him or her. Tagging out means removing yourself from a situation and asking someone else to take your place. It is about working as a team and helping one another out.

In this clip, Mrs. Wilson clearly does not want a bath. Although Lisa uses positive approaches, Mrs. Wilson becomes upset that Lisa is pressuring her to take a bath. She yells at her and throws her comb at her. Lisa realizes that she is at her limit and retreats from Mrs. Wilson. Her coworker, Gloria, suggests that Lisa bathe another resident who really enjoys baths and offers to give Mrs. Wilson a bath.

On the easel chart, write “Tag out.”
Play Video Clip: Tag Out

DO

Write “Tag out” on the easel chart under “Step into their world.”

SAY

You know your limits. Some days you might need someone to help you, someone you can “tag out” with. Removing yourself from a situation when you are at your limit prevents a series of negative actions and reactions that might lead to abuse. Let Gloria assist Mrs. Wilson today.

DO

Click the forward arrow.
Play Video Clip: Take a Breath—Slide 6 of 8

Instructor Guidance:

This clip also addresses the importance of aides knowing themselves and their limits. In some situations, we have to take a breath and compose ourselves. This might mean stepping out of a room for a moment or just taking a deep breath and counting to five. It might mean going outside during a lunch break and getting some fresh air and a different perspective. Having a “calming cue” might also be helpful. A calming cue is something that you can carry around with you that reminds you of something pleasant, calms you or gives you strength.

In this clip, Lisa is at her limit. She knows herself and knows that she needs to take a breath and compose herself before continuing to assist Mrs. Wilson. Lisa carries a calming cue with her, a picture of her grandmother that she uses to calm herself when she is at her limit. By taking a moment to take a breath and look at that picture, she can “reset” herself and continue with her work. Allowing herself to take a breath might prevent a series of negative actions and reactions that result in abuse.

On the easel chart, write “Take a breath.”
Play Video Clip: Take a Breath

DO

Write “Take a breath” on the easel chart.

SAY

We need to know ourselves and our limits. We all have those moments. We have to allow ourselves to take a breath and compose ourselves. This might mean stepping out of a room for a moment, or just taking a deep breath and counting to five. It might mean going outside during a lunch break and getting some fresh air and a different perspective. It might mean asking yourself, What if this were my mother or grandmother? Having a “calming cue” might also be helpful. A calming cue is something that you can carry around with you that reminds you of something pleasant, calms you or gives you strength. Lisa carries a calming cue with her.

DO

Click the forward arrow.
Discussion—Slide 7 of 8

Instructor Guidance:

What do you think Lisa was looking at?

It was a picture of her grandmother, but encourage the class to come up with their own ideas. The point is that the picture gave her strength and calmed her.

• What helps you stay calm?
• What do you do to not lose your patience? What would you tell a new nurse aide about how to have patience?

Note: As a supplemental activity, you might introduce breathing exercises.

Note: Share with the participants programs and services available to assist them with difficulties in their personal lives, such as Employee Assistance Programs (EAP) or support groups.
Discussion

ASK

What do you think Lisa was looking at?

SAY (affirm all participant’s responses as being possible)

Maybe Lisa has a picture of her grandmother that she uses to calm herself when she is at her limit. Mrs. Wilson might remind her of her grandmother.

ASK

• This is what makes Lisa feel calm. What helps you stay calm?

• We all have had times when we lost our patience. What do you do to not lose your patience? What would you tell a new aide about how to have patience?
Preventing Abuse: Summary—Slide 8 of 8

Instructor Guidance:

This lesson identified ways we can respond to a resident that will prevent the series of negative actions and reactions that lead to abuse. These responses are based on our knowledge of the resident and understanding the reasons behind his or her actions.
Preventing Abuse: Summary

**SAY**

In this lesson, you’ve learned about responding to residents in a way that prevents the series of negative actions and reactions that lead to abuse. Knowing our residents and the reasons behind their actions helps us to identify these ways to respond.

**ASK**

What is one thing you’ve learned in this lesson?
IX. Responding to and Reporting Abuse

Responding to and Reporting Abuse: Goal—Slide 1 of 24

Instructor Guidance:

The goal of this lesson is to identify how to respond to and report abuse. All observed and suspected abuse must be reported.

Your nursing home has its own policies for how to respond to and report abuse, and you will want to go over these with the participants during this lesson. The information here serves as general guidelines for reporting.

The intent of this lesson is to help participants understand that they are obligated to report abuse and suspicion of crime.

In some cases, a nurse aide might witness abuse happening and might need to intervene at that moment. This lesson will describe what to consider when responding to an abuse situation.
Responding to and Reporting Abuse: Goal

SAY

The goal of this lesson is to identify how to respond to abuse, including intervening at the moment, and how to report abuse and suspicion of crime.
Staff Reporting Requirements—Slide 2 of 24

Instructor Guidance:

After you go over the information on the slide, explain your nursing home’s policy for reporting abuse and distribute any relevant materials to participants.

If nurse aides are considered mandated reporters in your State, explain to the participants what this means.

Provide the specific information applicable to your nursing home on reporting to particular agencies or individuals (e.g., State licensing laws regarding mandated reporting).
Staff Reporting Requirements

SAY

It is a violation of State and Federal laws for any person, including nursing home staff, volunteers, visitors, family members or guardians, or another resident, to neglect or abuse a resident.

Because you know your residents, you are the eyes and ears of what is going on with them. Because you spend so much time with them, you are likely to notice when something is wrong.

You are one of the best sources of information about the resident, and you have a professional and legal responsibility to report suspected abuse or neglect.
Staff Reporting Requirements (cont.)—Slide 3 of 24

Instructor Guidance:

After you go over the information on the slide, explain your nursing home’s policy for reporting abuse.

If nurse aides are considered mandated reporters in your State, explain to the participants what this means.

Please provide the specific information applicable to your nursing home on reporting to particular agencies or individuals.
Notes:

SAY

If a resident tells you he or she is experiencing abuse, neglect, misappropriation, exploitation or mistreatment, it is important to report the allegation promptly.

Possible abuse must be reported immediately to the nursing home administrator.

- According to your State laws and processes, you may also have to report it to the State or local ombudsman, local police, Adult Protective Services Agency, and the State survey agency.
A nursing home is required, by Federal regulation, to report alleged violations involving mistreatment, neglect, abuse, misappropriation of resident property, and exploitation to the State survey agency and Adult Protective Services. The nursing home then must investigate this violation and report the results of the investigation to the administrator, the State survey agency, and appropriate authorities. There may be additional State requirements.
Suspicion of a Crime—Slide 4 of 24

Instructor Guidance:

Section 1150B of the Social Security Act, as established by Section 6703 (b)(3) of the Patient Protection and Affordable Care Act of 2010, requires specific individuals in long term care facilities to report any reasonable suspicion of crimes committed against a resident of, or person receiving care from, a long-term care facility. A covered individual is defined as anyone who is an owner, operator, employee, manager, agent, or contractor of the long-term care facility. Reporting suspicion of a crime is the responsibility of “covered individuals.”

As established by Section 6703 (b)(3) of the Patient Protection and Affordable Care Act of 2010, reasonable suspicion of crime must be reported to both the State Agency and local law enforcement.

Section 1150B requires the reporting of suspected crimes:

1. Immediately, but not later than 2 hours: If the events that cause the reasonable suspicion result in serious bodily injury to a resident, the covered individual shall report the suspicion immediately, but not later than 2 hours after forming the suspicion. (See the glossary for the definition of “serious bodily injury.”)

2. Not later than 24 hours: If the events that cause the reasonable suspicion do not result in serious bodily injury to a resident, the covered individual shall report the suspicion, not later than 24 hours after forming the suspicion.
Note: What is the difference between reporting alleged violations to the State survey agency and reporting the suspicion of a crime to the State survey agency and local law enforcement?

Current regulation requires a facility to report alleged violations: §483.12(c). The facility must ensure that all alleged violations involving mistreatment, neglect, or abuse, and misappropriation of resident property and exploitation are reported to the administrator of the facility and to other officials in accordance with State law through established procedures (including to the State survey and certification agency and Adult Protective Services). However, reporting the suspicion of a crime is the responsibility of “covered individuals.” There may be instances that would require both the facility to report the alleged violations and “covered individuals” to report the suspicion of a crime to the State survey agency and to local law enforcement.
Suspicion of a Crime

SAY

As established by Section 6703 (b)(3) of the Patient Protection and Affordable Care Act of 2010, reasonable suspicion of crime must be reported to both the State Agency and local law enforcement.

Section 1150B requires the reporting of suspected crimes:

1. **Immediately but no later than 2 hours**: If the events that cause the reasonable suspicion result in serious bodily injury to a resident, the covered individual shall report the suspicion immediately, but not later than 2 hours after forming the suspicion.

2. **Not later than 24 hours**: If the events that cause the reasonable suspicion do not result in serious bodily injury to a resident, the covered individual shall report the suspicion, not later than 24 hours after forming the suspicion.
Protection Against Retaliation—Slide 5 of 24

Instructor Guidance:

Be sure that participants understand that they are protected from retaliation by the nursing home when they report abuse.

Under Section 1150B of the Patient Protection and Affordable Care Act, a covered individual may file a complaint with the State Agency against a facility that retaliates against a covered individual.

Facilities are required to post notification in a conspicuous location of the covered individual’s right to file a complaint and the notice must include information about the manner of filing the complaint.

Provide your nursing home’s policy and a copy of the notification against retaliation. Remind participants where it is posted.

Notes:
Protection Against Retaliation

SAY

When you report suspicion of a crime, you are protected under the Elder Justice Act. Actions that constitute retaliation include:

- When a facility discharges, demotes, suspends, threatens, harasses, or denies a promotion or other employment-related benefit to an employee, or in any other manner discriminates against an employee in the terms and conditions of employment because of lawful acts done by the employee.

- When a facility files a complaint or a report against a nurse or other employee with the State professional licensing agency because of lawful acts done by the employee for reporting a reasonable suspicion of a crime to law enforcement.
If you believe that the nursing home has retaliated against you, you can file a complaint with the State Agency.

Employers who violate the anti-retaliation provision may be fined up to $200,000 and may be excluded from Federal programs, including Medicaid and Medicare, for up to two years.
This page intentionally left blank.

Instructor Guidance:

No instructor guidance for this slide.

SAY

It is important to be as factual as possible in reporting suspected abuse.

This means reporting only what you saw and heard, not what you think you saw or heard.

If you did not witness the possible abuse yourself, report information you have about the incident. Be as objective as possible.

Write down your observations or information, date the document, and keep a copy for your own records.

There are some basic elements you need to include in your report.
Who?—Slide 7 of 24

Instructor Guidance:

Who: Who was involved? The name of the resident who may have been abused, including age and gender; the name of the nursing home and the people responsible for the resident’s care; the identity of the person you believe abused or neglected the resident; any other people who were involved or witnessed the abuse.
Who?

SAY

When reporting abuse, you need to identify those who were involved.

Include:

- The name of the resident who may have been abused, including age and gender.
- The name of the nursing home and the people responsible for the resident’s care.
- The identity of the person you suspect abused or neglected the resident.
- Any other people who were involved or witnessed the abuse.
What?—Slide 8 of 24

Instructor Guidance:

What: Include the nature and extent of harm and any signs of abuse or neglect (physical, psychological, verbalizations of abuse, etc.); what happened; any statements made by the resident or other people involved.

Notes:
What?

SAY

You should answer these questions:

- What happened?
- What did you see or hear?
- What was the extent of the harm?
- What signs of abuse or neglect exist?
- What did the resident say?
- What did other people say?
- Have there been previous incidents?
Where and When?—Slide 9 of 24

**Instructor Guidance:**

Where and when: Include the place where the incident happened, and the time and date of the incident.
Where and When?

SAY

It’s important to document both where and when the suspected abuse happened.
Just the Facts!—Slide 10 of 24

Instructor Guidance:

This slide is a building slide. Initially, you will see only one bulleted item that is labeled “Interpretation.” When you click the forward arrow, the second bulleted item will appear under the title “Factual.”

Explain how the two examples are different and emphasize that the second item includes specific details that clearly describe what happened.
Just the Facts!

SAY

It is better to describe what happened in factual detail than to use terms that indicate personal feelings about an event.

For example, the following statement is your interpretation of the event:

- “The aide was so angry and just lost her temper. So, she pushed the resident out of frustration.”

A more factual statement is:

- “I walked down the hall toward the aide [name] and resident [name]. The aide was attempting to keep the resident from exiting the building. She yelled at the resident, “Do not go there,” and the resident yelled back, “I am going!” The aide told her again not to go, and the resident tried to open the door. The aide pushed the resident away from the door, and the resident fell to the floor.”
Instructor Guidance:

Remind participants that it is important to use language that is appropriate to the role of a nurse aide. They should not try to use legal terms. Reports should be factual.
Language

SAY

Use language that fits your role as a nurse aide rather than legal terms.

For example:

- Use “resident” instead of “victim.”
- Use “reported” or “suspected” instead of “alleged.”
Describe Rather Than Label—Slide 12 of 24

**Instructor Guidance:**

Explain the difference between descriptive language and labels. Remind participants to avoid using labels.
Describe Rather Than Label

SAY

When you describe rather than label behavior, the information is usually more accurate and complete as you see in the example on the slide.

Descriptive documentation is helpful for reporting other incidents as well. Avoid labels that are derogatory to the resident such as “non-compliant” or “uncooperative.”

When documenting statements made by residents, family members, or caregivers, be very specific that the statements are from those individuals. Don’t sanitize their words or convert them into medical terminology. Rather, write down their statements verbatim, in quotation marks, including any slang terms used for body parts.
Play Video Clip and Group Exercise—Slide 13 of 24

Instructor Guidance:

Divide the class into small groups.

Materials needed:

- Handout: How to Report Abuse: Writing the Report (1 for each group).
- Pencils.
Play Video Clip and Group Exercise

**SAY**

To practice reporting abuse, we are going to break into small groups and watch a clip. In this clip, you are the observer who is walking by.

As a group, you will write a report about what you saw and heard using who, what, where, and when. I’m going to give each group a handout to use for writing the report.

**DO**

Click the forward arrow to play the clip.
Discussion: Reporting Abuse—Slide 14 of 24

Instructor Guidance:

You may want to distribute the How to Report Abuse handout for learners to use during the experience.

When the groups are done, ask for volunteers to share some things they wrote. As you review their responses, ask the participants whether each response was factual or an interpretation. Ask them to suggest changes to those that are interpretations.

You may give participants this example: If you were to write in your report, “The resident in the video was really angry,” how could you explain what you saw that made you think he was angry? You might write instead, “The resident was hitting the aide and fighting with her and yelling.” It is not wrong to say he was angry, but this is your interpretation of what happened—it is important to describe exactly what you saw.

Note: After watching the video, if participants ask about whether or how they should have intervened as a “bystander,” let them know that they should.

(Note: Information in this lesson was taken from Module 11 (Documentation in Elder Mistreatment Cases) of the International Association of Forensic Nurses’ Nursing Response to Elder Mistreatment Curriculum. For additional instruction to nurses on how to document elder mistreatment, please refer to this curriculum at http://www.iafn.org.)
Discussion: Reporting Abuse

ASK

What did you see during that short walk by the resident’s room?

SAY

Working in your group, take two minutes to write down what you saw and heard. Use the tips we just talked about and the format of who, what, where, and when.
Discussion—Slide 15 of 24

**Instructor Guidance:**

How might you have responded if you were walking by and saw this abuse happening?

- The intention of this discussion is for participants to identify a need to respond to the situation they are witnessing. If participants do not indicate the need to intervene and stop the situation, ask additional questions to determine whether they would seek help or alert others.

Would you report this?

- All suspected abuse must be reported. If participants say they would not report this, ask why.
**Discussion**

**ASK**
- How might you have responded if you were walking by and saw this abuse happening?
- Would you report this?

**SAY**

As you just saw in the clip, in some cases you might witness (see or hear) abuse happening in the moment. You might need to respond to the situation to try to stop it. Let’s talk about how to respond to abuse in the moment. First, keep in mind these two things:

- Rule #1: No one should get hurt.
- Rule #2: If you see or hear possible abuse, you must intervene.
Challenges in Reporting Abuse—Slide 16 of 24

Instructor Guidance:

What challenges do you see in reporting abuse?

- This question is intended to allow participants to bring up any concerns they have about reporting abuse or how to report abuse.

What if you saw a coworker abusing a resident?

Participants might feel uncomfortable with the idea of reporting suspected abuse when one of their coworkers is the suspect. This is a good opportunity to discuss this issue and let participants share their concerns.

- It is important for participants to understand that there is no decision to be made about whether to “tell on someone.” They are required to report all suspected abuse situations.

What if you heard about abuse but didn’t see it yourself?

Participants may be unsure about what to do if they do not actually see the abuse, but hear about it secondhand or suspect something happened. This is a good opportunity to discuss that suspected abuse should be reported, even if you did not witness it yourself.
Challenges in Reporting Abuse

ASK

Now that you have heard about how to report abuse, what do you see as challenges in reporting abuse?
Instructor Guidance:

The SAFE acronym provides some guidance on how to respond to abuse as it is happening. SAFE stands for stop, alert, friend, emergency.

If you have a nursing home policy on how to respond in this situation, review it with the participants at this time.

It is important that participants understand not to put themselves in danger.
SAFE Acronym

SAY

Keeping those two rules in mind, how do you respond to abuse you see or hear happening? Here is an acronym to help you consider what to do when you encounter possible abuse:

SAFE stands for stop, alert, friend, emergency.
STOP—Slide 18 of 24

Instructor Guidance:

It is important for participants to understand their role in safely stopping abuse from happening. They need to be able to determine whether to intervene and how to intervene in these situations according to the protocol at your nursing home.
Stop

SAY

Stop.

If you see abuse happening or about to happen, ask yourself:

- Can I interrupt the chain of events before the situation escalates to abuse?
- Can I safely stop the abuse from happening?
- Can I intervene between the abuser and the person being abused?
Alert—Slide 19 of 24

Instructor Guidance:

Participants need to understand when to alert others for help. They also need to be alert to what is happening, who is involved, and who is in danger.
Alert

SAY

Alert.

Be alert and do not get hurt trying to intervene. If you can’t stop the abuse, then alert others (e.g., use the call button or yell for help).

Remember that if a resident is fighting back, it may be in self-defense. Too many people crowding around the resident may only exacerbate the situation.

Even if you are able to stop the action, you still need to alert your supervisor.

If you have reasonable suspicion that a crime is being or has been committed, report it to the State Agency and to local law enforcement.
Friend—Slide 20 of 24

Instructor Guidance:

Being a friend means being with all the persons involved. It is about trying to stop or defuse the situation by being calm.
Friend

SAY

Friend.

Be a friend to anyone in the situation who is upset or agitated—whether he or she is a coworker, a resident, or a resident’s family member.

Try to calm those involved. Speak in a respectful, calm voice while maintaining an appropriate distance.

Reassure those involved. Try to maintain their attention in order to stop the situation or prevent its escalation.
Instructor Guidance:

Anytime there is serious bodily injury, call 911. Remember, you must report serious bodily injury to both the State Agency and local law enforcement immediately but no later than two hours.
Emergency

SAY

Emergency.

If you see that the situation is becoming an emergency, call 911.

Anytime there is serious bodily injury, call 911.
Circle of Abuse—Slide 22 of 24

Instructor Guidance:

To bring this module’s lessons together and to underscore each individual’s role in preventing abuse, lead a brief discussion about how participants would have responded to the abuse Mrs. Wilson experienced. Point out that it is likely that staff walking by the tub room heard her cries of “no” and screams that she did not want to take a bath. Discuss whether participants would’ve intervened or reported this situation and why or why not.

So, think back to Mrs. Wilson in the tub room. She didn’t want to take a bath but was forced to. Imagine you were on the other side of that closed door and heard that happening. What would you have done?

Possible answers are:

- I would’ve opened the door to see what was happening and how I could help.
- I would’ve suggested that I tag out with the aide.
- I would’ve tried to calm the aide down.
- I would’ve reported the situation to my supervisor.
Circle of Abuse

SAY

Anybody can be a part of the circle of abuse. At the center of this circle is the person being abused. Next in the circle is the abuser. However, all the others around them are part of the circle and are involved in the circle of abuse, including:

- The person who witnesses the abuse.
- The person who hears about the abuse from someone else.
- The person who sees the signs of abuse.

We all are part of this circle, and we all have a role in identifying, reporting, and, ultimately, preventing abuse.

So, let’s think back to Mrs. Wilson, who didn’t want to take a bath but was forced to. What would you have done?
Discussion—Slide 23 of 24

Instructor Guidance:

Think about the people in your own lives.

- What if your loved one were living in a nursing home?
- What if he or she were being abused? What would you do?
- What would you hope someone else would do if he or she saw your loved one being abused?
- What if the abuser were your best friend at work?

Abuse must always be reported.
Discussion

ASK

Think about the people in your own lives.

- What if your loved one were living in a nursing home?
- What if he or she were being abused? What would you do?
- What would you hope someone else would do if he or she saw your loved one being abused?
- What if the abuser were your best friend at work?

SAY

Abuse is abuse, no matter who is involved. It must be reported.
Instructor Guidance:

This lesson covered how to respond to and report abuse and suspicion of crime. All suspected abuse must be reported.

What is one thing you’ve learned in this lesson?
Responding to and Reporting Abuse: Summary

SAY

In this lesson, you’ve learned how to respond to abuse in the moment and how to report abuse and suspicion of crime.

ASK

What is one thing you’ve learned in this lesson?
X. Conclusion

Congratulations!—Slide 1 of 2

Instructor Guidance:

Congratulations!
Congratulations!

SAY

In this module you’ve reviewed types and signs of abuse. You’ve learned to evaluate how a series of actions and reactions might lead to abuse and to recognize how abuse might be prevented through different approaches. Finally, you’ve learned how to respond to abuse if you see it happening and how to report it.

Thank you for all you do. Each of you can and does make a difference!

ASK

Do you have any questions?
Module 5 Video Clips—Slide 1 of 2

Instructor Guidance:

From this slide you can easily access any of the video clips in this module for review or additional discussion.

- Video Clip 1—What Does Abuse Look Like?
- Video Clip 2—What Does Abuse Look Like?
- Video Clip 3—What Does Abuse Look Like?
- Video Clip 4—What Does Abuse Look Like?
- Video Clip 5—What Does Abuse Look Like?
- Video Clip 6—What Does Abuse Look Like?
- Signs of Abuse: Sample 1
- Signs of Abuse: Sample 2
- Signs of Abuse: Sample 3
- Mrs. Wilson
- Mrs. Wilson: Try Later
- Mrs. Wilson: Step into their World
- Mrs. Wilson: Tag Out
- Mrs. Wilson: Take a Breath
Module 5 Video Clips

<table>
<thead>
<tr>
<th>Recognizing Abuse</th>
<th>Signs of Abuse</th>
<th>Actions and Reactions: Understanding How Abuse Happens</th>
</tr>
</thead>
<tbody>
<tr>
<td>Video Clip 1 - What Does Abuse Look Like?</td>
<td>Signs of Abuse Sample 1</td>
<td>Mrs. Wilson: Hit Me Later</td>
</tr>
<tr>
<td>Video Clip 2 - What Does Abuse Look Like?</td>
<td>Signs of Abuse Sample 2</td>
<td>Mrs. Wilson: Step into their World</td>
</tr>
<tr>
<td>Video Clip 3 - What Does Abuse Look Like?</td>
<td>Signs of Abuse Sample 3</td>
<td>Mrs. Wilson: Log Out</td>
</tr>
<tr>
<td>Video Clip 4 - What Does Abuse Look Like?</td>
<td></td>
<td>Mrs. Wilson: Take a Breath</td>
</tr>
<tr>
<td>Video Clip 5 - What Does Abuse Look Like?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Video Clip 6 - What Does Abuse Look Like?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Select a video clip above

Module 5 Video Clips
Appendix

Handout: Actions and Reactions—WHY? .......................................................... A-3
Circle of Abuse ................................................................................................. A-5
Handout: How to Report Abuse ........................................................................ A-7
Handout: How to Report Abuse: Writing the Report ........................................ A-9
### Actions and Reactions—WHY?

What are the possible reasons why Mrs. Wilson might not want to have a bath?

<table>
<thead>
<tr>
<th>WHY?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Conditions</strong></td>
<td></td>
</tr>
<tr>
<td>(Physical, Mental, and</td>
<td></td>
</tr>
<tr>
<td>Emotional)</td>
<td>What specific health issues could Mrs. Wilson be experiencing that are causing her to not want a bath?</td>
</tr>
<tr>
<td><strong>Medications</strong></td>
<td>How could medications cause Mrs. Wilson to not want a bath?</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td>How might communication challenges cause Mrs. Wilson to not want to take a bath? (Consider how you are communicating and challenges Mrs. Wilson might have in communicating.)</td>
</tr>
<tr>
<td><strong>Environment</strong></td>
<td>How might the physical environment of the bathroom cause Mrs. Wilson to not want to take a bath?</td>
</tr>
<tr>
<td><strong>The Task</strong></td>
<td>Why might Mrs. Wilson not enjoy taking a bath?</td>
</tr>
<tr>
<td><strong>Unmet Needs</strong></td>
<td>What unmet needs might cause Mrs. Wilson to not want to take a bath? What else might she need from you at that moment?</td>
</tr>
<tr>
<td><strong>Life Story</strong></td>
<td>What about Mrs. Wilson’s past would explain why she doesn’t want to take a bath?</td>
</tr>
<tr>
<td><strong>You</strong></td>
<td>How did the way the aide acted cause Mrs. Wilson to not want to take a bath?</td>
</tr>
</tbody>
</table>
Circle of Abuse

The person who:

Sees the behavior of the resident or the signs

Hears about it from another person

Witnesses the abuse

Is the abuser

Is Abused
This page intentionally left blank.
How to Report Abuse

It is important to be as factual as possible in reporting possible abuse. This means reporting only what you saw and heard yourself, not what you think you saw or heard. If you did not witness the possible abuse yourself, report the information you have. Be as objective as possible. Put down your information and observations in writing, date the document, and keep a copy for your own records.

Writing the Report

Who, What, Where, When?

WHO: Who was involved?
• Name of the resident who may have been abused, including age and gender.
• Name of the nursing home and people responsible for the resident’s care.
• Identity of the person you believe abused or neglected the resident.
• Any other people who were involved or were witnesses.

WHAT: What happened?
• Nature and extent of harm and any signs of abuse or neglect (physical, psychological, verbalizations of abuse, etc.).
• Description of what happened.
• Any statements made by the resident or other people involved.

WHERE and WHEN?
• Place where the incident happened.
• Time and date of the incident.

TIPS:
• It is better to describe something in factual detail than to use terms that might indicate personal feelings about an event. For example, “I saw Arthur hit Mrs. Caputo,” rather than “Arthur got out of hand on Mrs. Caputo!”
• Use language in documentation that fits your role as an aide rather than legal terms, for example, “resident” rather than “victim.”
• Avoid labels that are derogatory to the resident such as “noncompliant,” “refused,” or “uncooperative.” Describe the behavior rather than label it.
• Write other people’s statements about the incident verbatim (or as close to verbatim as possible).

Remember: We ALL have a role in identifying and reporting abuse.
This page intentionally left blank.
How to Report Abuse: Writing the Report

Who, What, Where, When?

You have just seen a video clip of a possible abuse situation. Working in pairs or small groups, write a report about what you saw and heard.

<table>
<thead>
<tr>
<th>WHO: Who was involved?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Name of the resident who may have been abused, including age and gender.</td>
<td></td>
</tr>
<tr>
<td>• Name of the nursing home and the people responsible for the resident’s care.</td>
<td></td>
</tr>
<tr>
<td>• Identity of the person you believe abused or neglected the resident.</td>
<td></td>
</tr>
<tr>
<td>• Names of any other people involved or witnesses.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>WHAT: What happened?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Nature and extent of harm and any signs of abuse or neglect (physical, psychological, verbalizations of abuse, etc.).</td>
<td></td>
</tr>
<tr>
<td>• Description of what happened.</td>
<td></td>
</tr>
<tr>
<td>• Any statements made by the resident or other people involved.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>WHERE and WHEN?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Place where the incident happened.</td>
<td></td>
</tr>
<tr>
<td>• Time and date of the incident.</td>
<td></td>
</tr>
</tbody>
</table>
Glossary of Terms
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abuse</td>
<td>The willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish. Abuse also includes the deprivation by an individual, including a caretaker, of goods or services that are necessary to attain or maintain physical, mental, and psychosocial well-being. Instances of abuse of all residents, irrespective of any mental or physical condition, cause physical harm, pain or mental anguish. It includes verbal abuse, sexual abuse, physical abuse, and mental abuse including abuse facilitated or enabled through the use of technology. Source: 42 CFR 483.5</td>
</tr>
<tr>
<td>Adult protective services</td>
<td>Those services provided to ensure the safety and well-being of elders and adults with disabilities who are in danger of being mistreated or neglected, are unable to take care of themselves or protect themselves from harm, and have no one to assist them. Generally based in State government or services. Source: <a href="https://www.acl.gov/programs/elder-justice/supporting-adult-protective-services">https://www.acl.gov/programs/elder-justice/supporting-adult-protective-services</a></td>
</tr>
<tr>
<td>AIDS-related dementia</td>
<td>The primary symptoms of AIDS-related dementia include cognitive impairment, such as the inability to concentrate and impaired short-term memory; motor dysfunction, including leg weakness, affected gait, and slow hand movements; and behavioral changes, such as depression, apathy, and social withdrawal. Source: <a href="http://www.the-aids-pandemic.blogspot.com/2008_09_01_archive.html">www.the-aids-pandemic.blogspot.com/2008_09_01_archive.html</a></td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>--------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Alois Alzheimer</td>
<td>In 1906, German psychiatrist and neuropathologist Alois Alzheimer summarized the case of Auguste Deter, who had told him early in her treatment, “I have lost myself.” She had been a normal, healthy woman, but beginning at age 51 she developed progressive memory lapses, disorientation, and aphasia (inability to use language), and she grew unable to care for herself, eventually dying at the age of 55. After her death, Alzheimer examined her brain under his microscope and described the plaques that had accumulated in the ordinarily empty space between nerve cells, and tangles of string-like substances, now known to be characteristic of the disease that bears Alzheimer’s name. Source: <a href="http://www.nndb.com/people/217/000165719/">www.nndb.com/people/217/000165719/</a></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>Alzheimer’s disease causes brain changes that gradually get worse. It’s the most common cause of dementia—a group of brain disorders that cause progressive loss of cognitive and social skills, severe enough to interfere with day-to-day life. In Alzheimer’s disease, brain cells degenerate and die, causing a steady decline in memory and mental function. Source: <a href="http://www.mayoclinic.com/health/alzheimers-disease/DS00161">www.mayoclinic.com/health/alzheimers-disease/DS00161</a></td>
</tr>
<tr>
<td>Amyloid plaques</td>
<td>One of the hallmarks of Alzheimer’s disease is the accumulation of amyloid plaques between nerve cells (neurons) in the brain. Amyloid is a general term for protein fragments that the body produces normally. Beta amyloid is a protein fragment snipped from an amyloid precursor protein (APP). In a healthy brain, these protein fragments are broken down and eliminated. In Alzheimer’s disease, the fragments accumulate to form hard, insoluble plaques. Source: <a href="http://www.brightfocus.org/alzheimers/infographic/amyloid-plaques-and-neurofibrillary-tangles">www.brightfocus.org/alzheimers/infographic/amyloid-plaques-and-neurofibrillary-tangles</a></td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Auguste D</td>
<td>In November 1901, German psychiatrist Alois Alzheimer encountered a woman named Auguste Deter (Auguste D, as she came to be known) who had been brought to Alzheimer’s Frankfurt clinic by her husband.</td>
</tr>
<tr>
<td></td>
<td>According to the husband, the couple had been harmoniously married since 1873, but he had recently noticed a gradual decline in his wife that went beyond short- and long-term memory loss. At the relatively young age of 51, she had become disturbingly absent-minded, making obvious mistakes in food preparation, neglecting her housework, stashing objects in nooks and crannies around their apartment, wandering aimlessly from room to room, and suffering from intense bouts of jealousy and paranoia.</td>
</tr>
<tr>
<td></td>
<td>As the months went by, thoughts of Auguste D. stayed with Dr. Alzheimer. He recognized that Auguste D’s case could prove to be of great scientific importance because of her young age. At 51, she was exhibiting the behavioral symptoms that one might expect to observe in a dementia patient in their seventh, eighth, or ninth decade.</td>
</tr>
<tr>
<td></td>
<td>In 1906, Auguste D. passed away. Dr. Alzheimer performed an autopsy, finding a high volume of senile plaques and neurofibrillary tangles in the tissue of her brain. In November of that year, Dr. Alzheimer delivered a now famous lecture to the Assembly of Southwest German Psychologists in Tbingen. Alzheimer stood before nearly 90 of his colleagues in this lecture theatre and reported on the case of Auguste D, interspersing his lecture with wonderfully drawn slides of the plaques and tangles found in and on Auguste D’s brain in postmortem investigation.</td>
</tr>
<tr>
<td></td>
<td>Source: <a href="http://www.alzheimer.neurology.ucla.edu/pubs/alzheimerLancet.pdf">www.alzheimer.neurology.ucla.edu/pubs/alzheimerLancet.pdf</a></td>
</tr>
<tr>
<td>Consistent assignment</td>
<td>Residents see and receive care from the same caregivers (registered nurse, licensed practical nurse, direct care worker/certified nursing assistant) during a typical work week.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Corporal punishment</td>
<td>Corporal punishment, which is physical punishment, is used as a means to correct or control behavior. Corporal punishment includes, but is not limited to, pinching, spanking, slapping of hands, flicking, or hitting with an object. Source: Appendix PP of the State Operations Manual (SOM)</td>
</tr>
<tr>
<td>Covered individual</td>
<td>A “covered individual” is anyone who is an owner, operator, employee, manager, agent or contractor of the facility. Source: Appendix PP of the SOM</td>
</tr>
<tr>
<td>Creutzfeldt-Jakob disease (CJD)</td>
<td>Creutzfeldt-Jakob disease is a rare, degenerative, fatal brain disorder. It affects about one person in every one million people per year worldwide; in the United States there are about 350 cases per year. CJD usually appears in later life and runs a rapid course. Typically, onset of symptoms occurs about age 60, and about 70 percent of individuals die within one year. In the early stages of disease, people may have failing memory, behavioral changes, lack of coordination, and visual disturbances. As the illness progresses, mental deterioration becomes pronounced and involuntary movements, blindness, weakness of extremities, and coma may occur. Source: <a href="http://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Creutzfeldt-Jakob-Disease-Fact-Sheet">www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Creutzfeldt-Jakob-Disease-Fact-Sheet</a></td>
</tr>
<tr>
<td>Crime</td>
<td>Section 1150B(b)(1) of the Act provides that a “crime” is defined by law of the applicable political subdivision where a long-term care facility is located. A political subdivision would be a city, county, township or village, or any local unit of government created by or pursuant to State law. Source: Appendix PP of the SOM</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>----------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Culture change</td>
<td>The common name given to the national movement for the transformation of older adult services, based on person-directed values and practices, where the voices of elders and those working with them are considered and respected. Core person-directed values are choice, dignity, respect, self-determination and purposeful living. Culture change transformation supports the creation of both long- and short-term living environments as well as community-based settings where both older adults and their caregivers are able to express choice and practice self-determination in meaningful ways at every level of daily life. Culture change transformation may require changes in organizational practices, physical environments, relationships at all levels and workforce models—leading to better outcomes for consumers and direct care workers without being costly for providers. Source: <a href="http://www.pioneernetwork.net/culture-change/what-is-culture-change/">www.pioneernetwork.net/culture-change/what-is-culture-change/</a></td>
</tr>
<tr>
<td>Delirium</td>
<td>Delirium is a serious disturbance in a person's mental abilities that results in a decreased awareness of one's environment and confused thinking. The onset of delirium is usually sudden, often within hours or a few days. Delirium can usually be traced to one or more contributing factors, such as a severe or chronic medical illness, medication, surgery, or drug or alcohol abuse. The symptoms of delirium and dementia are similar, and input from a family member or caregiver may be important for a doctor to make a diagnosis. Source: <a href="http://www.mayoclinic.com/health/delirium/DS01064">www.mayoclinic.com/health/delirium/DS01064</a></td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Dementia</td>
<td>Dementia is not a specific disease. It is a term that describes a group of symptoms related to loss of memory, judgment, language, complex motor skills, and other intellectual function, caused by the permanent damage or death of the brain's nerve cells, or neurons. There are many causes of dementia. Alzheimer's disease is the most common cause of a progressive dementia. Memory loss generally occurs in dementia, but memory loss alone doesn't mean you have dementia. Dementia indicates problems with at least two brain functions, such as memory loss and impaired judgment or language. Dementia can make someone confused and unable to remember people and names. They also may experience changes in personality and social behavior. Source: <a href="http://www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013">www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013</a></td>
</tr>
<tr>
<td>Early-onset Alzheimer’s disease (also known as younger-onset Alzheimer’s disease)</td>
<td>Of all the people who have Alzheimer’s disease, only about five percent develop symptoms before age 65. So, if 4 million Americans have Alzheimer’s, at least 200,000 people have the early-onset form of the disease. Most people with early-onset Alzheimer's develop symptoms of the disease in their 40s and 50s. Source: <a href="http://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers/art-20048356">www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers/art-20048356</a></td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>Frontotemporal dementia (frontotemporal lobar degeneration) is a term for a diverse group of uncommon disorders that primarily affect the frontal and temporal lobes of the brain—the areas generally associated with personality, behavior and language.</td>
</tr>
<tr>
<td></td>
<td>In frontotemporal dementia, portions of these lobes atrophy or shrink. Signs and symptoms vary, depending upon the portion of the brain affected. Some people with frontotemporal dementia undergo dramatic changes in their personality and become socially inappropriate, impulsive or emotionally indifferent, while others lose the ability to use and understand language.</td>
</tr>
<tr>
<td></td>
<td>Frontotemporal dementia is often misdiagnosed as a psychiatric problem or as Alzheimer’s disease. But frontotemporal dementia tends to occur at a younger age than does Alzheimer’s disease, typically between the ages of 40 and 45.</td>
</tr>
<tr>
<td></td>
<td>Source: <a href="http://www.mayoclinic.com/health/frontotemporal-dementia/DS00874">http://www.mayoclinic.com/health/frontotemporal-dementia/DS00874</a></td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td>Huntington’s disease is an inherited disease that causes the progressive breakdown (degeneration) of nerve cells in the brain. Huntington’s disease has a broad impact on a person’s functional abilities and results in movement, thinking (cognitive) and sometimes psychiatric disorders.</td>
</tr>
<tr>
<td></td>
<td>Most people with Huntington’s disease develop signs and symptoms in their 30s or 40s, but the onset of disease may be earlier or later in life. When disease onset begins before age 20, the condition is called juvenile Huntington’s disease. Earlier onset often results in a somewhat different presentation of symptoms and faster progression of dementia.</td>
</tr>
<tr>
<td></td>
<td>Medications are available to help manage the symptoms of Huntington’s disease, but treatments can’t prevent the physical, mental and behavioral decline associated with the condition.</td>
</tr>
<tr>
<td></td>
<td>Source: <a href="http://www.mayoclinic.com/health/huntingtons-disease/DS00401">www.mayoclinic.com/health/huntingtons-disease/DS00401</a></td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Lewy body dementia           | Lewy body dementia, also known as dementia with Lewy bodies, is the second most common type of progressive dementia after Alzheimer’s disease dementia. Protein deposits, called Lewy bodies, develop in nerve cells in the brain regions involved in thinking, memory and movement (motor control).  
Lewy body dementia causes a progressive decline in mental abilities. People with Lewy body dementia may experience visual hallucinations, and changes in alertness and attention. Other effects include Parkinson’s disease-like symptoms such as rigid muscles, slow movement and tremors. | www.mayoclinic.org/diseases-conditions/lewy-body-dementia/symptoms-causes/syc-20352025        |
<p>| Long-term care ombudsman program  | States’ Long-Term Care (LTC) Ombudsman programs work to resolve problems related to the health, safety, welfare, and rights of individuals who live in LTC facilities (i.e. nursing homes, board and care, assisted living, and other residential care communities). Ombudsman programs promote policies and consumer protections to improve long-term services and supports (LTSS) at the facility, local, state, and national levels. | <a href="http://www.acl.gov/programs/protecting-rights-and-preventing-abuse/long-term-care-ombudsman-program">www.acl.gov/programs/protecting-rights-and-preventing-abuse/long-term-care-ombudsman-program</a>    |
| Mental abuse                  | Mental abuse is the use of verbal or nonverbal conduct which causes or has the potential to cause the resident to experience humiliation, intimidation, fear, shame, agitation, or degradation.                                                                                      | Appendix PP of the SOM                                                                       |
| Mild cognitive impairment     | Mild cognitive impairment (MCI) causes a slight but noticeable and measurable decline in cognitive abilities, including memory and thinking skills. A person with MCI is at an increased risk of developing Alzheimer’s or another dementia. | <a href="http://www.alz.org/dementia/mild-cognitive-impairment-mci.asp">www.alz.org/dementia/mild-cognitive-impairment-mci.asp</a>                                       |</p>
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Misappropriation of resident property</td>
<td>The deliberate misplacement, exploitation, or wrongful, temporary or permanent use of a resident’s belongings or money without the resident’s consent. Source: 42 CFR 483.5</td>
</tr>
<tr>
<td>Neglect</td>
<td>The failure of the facility, its employees or service providers to provide goods and services to a resident that are necessary to avoid physical harm, pain, mental anguish or emotional distress. Source: 42 CFR 483.5</td>
</tr>
<tr>
<td>Neurofibrillary tangles</td>
<td>Neurofibrillary tangles are insoluble twisted fibers found inside the brain’s cells. These tangles consist primarily of a protein called tau, which forms part of a structure called a microtubule. The microtubule helps transport nutrients and other important substances from one part of the nerve cell to another. In Alzheimer’s disease, however, the tau protein is abnormal and the microtubule structures collapse. Source: <a href="http://www.brightfocus.org/alzheimers/infographic/amyloid-plaques-and-neurofibrillary-tangles">www.brightfocus.org/alzheimers/infographic/amyloid-plaques-and-neurofibrillary-tangles</a></td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>---------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Parkinson’s disease       | Parkinson’s disease is a progressive disorder of the nervous system that affects movement. It develops gradually, often starting with a barely noticeable tremor in just one hand. But while tremor may be the most well-known sign of Parkinson’s disease, the disorder also commonly causes a slowing or freezing of movement and balance problems.  

The face of a person with Parkinson’s disease may show little or no expression and the arms don’t swing when they walk. Speech often becomes soft and mumbling. Parkinson’s symptoms tend to worsen as the disease progresses.  

While there is no cure for Parkinson’s disease, many different types of medicines can treat its symptoms.  

Source: [www.mayoclinic.com/health/parkinsons-disease/DS00295](http://www.mayoclinic.com/health/parkinsons-disease/DS00295) |
<p>| Person-centered care      | Person-centered care means to focus on the resident as the locus of control and support the resident in making their own choices and having control over their daily lives.                                                  |
|                           | Source: Appendix PP of the SOM                                                                                                                                                                             |
| Physical abuse            | Includes hitting, slapping, punching, biting, and kicking.                                                                                                                                                  |
|                           | Source: Appendix PP of the SOM                                                                                                                                                                             |
| Serious bodily injury     | “Serious bodily injury” means an injury involving extreme physical pain; involving substantial risk of death; involving protracted loss or impairment of the function of a bodily member, organ, or mental faculty; requiring medical intervention such as surgery, hospitalization, or physical rehabilitation; or an injury resulting from criminal sexual abuse [see Section 2011(19)(A) of the Social Security Act)]. |
|                           | Source: Appendix PP of the SOM                                                                                                                                                                             |</p>
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual abuse</td>
<td>Sexual abuse is defined as non-consensual sexual contact of any type with a resident. Source: 42 CFR 483.5</td>
</tr>
</tbody>
</table>
| Vascular dementia      | Vascular dementia is a general term describing problems with reasoning, planning, judgment, memory and other thought processes caused by brain damage from impaired blood flow to your brain.  
Vascular dementia may develop after a stroke blocks an artery in the brain, but strokes don’t always cause vascular dementia. Whether a stroke affects thinking and reasoning depends on the stroke’s severity and location. Vascular dementia also can result from other conditions that damage blood vessels and reduce circulation, depriving the brain of vital oxygen and nutrients.  
Factors that increase the risk of heart disease and stroke—including high blood pressure, high cholesterol and smoking—also raise vascular dementia risk. Controlling these factors can help lower the chances of developing vascular dementia. Source: www.mayoclinic.com/health/vascular-dementia/DS00934 |
<p>| Verbal abuse            | Verbal abuse may be considered to be a type of mental abuse. Verbal abuse includes the use of oral, written, or gestured communication, or sounds, to residents within hearing distance, regardless of age, ability to comprehend, or disability. Source: Appendix PP of the SOM                                                                                                                                 |
| Visuospatial skills     | Visuospatial skills consist of the ability to understand what we see around us and interpret spatial relationships. This includes both the images we see (visual), as well as our perception of the size and location of our surroundings (spatial). Source: <a href="http://www.verywell.com/how-does-dementia-affect-visual-spatial-abilities-98586">www.verywell.com/how-does-dementia-affect-visual-spatial-abilities-98586</a> |</p>
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wernicke-Korsakoff syndrome</td>
<td>Wernicke’s encephalopathy is a degenerative brain disorder caused by the lack of thiamine (vitamin B1). It may result from alcohol abuse, dietary deficiencies, prolonged vomiting, eating disorders, or the effects of chemotherapy. Source: <a href="http://www.ninds.nih.gov/Disorders/All-Disorders/Wernicke-Korsakoff-Syndrome-Information-Page">www.ninds.nih.gov/Disorders/All-Disorders/Wernicke-Korsakoff-Syndrome-Information-Page</a></td>
</tr>
</tbody>
</table>
Resources
This page intentionally left blank.
Resources

Modules 1, 2, 3 and 4 Resources

These additional resources are available if you want to learn more about dementia and person-centered care for persons with dementia.

Websites

- National Partnership to Improve Dementia Care in Nursing Homes
- National Nursing Home Quality Improvement Campaign
- Alzheimer's Association
- Alzheimer's Foundation of America
- Dementia Action Alliance
- Lewy Body Dementia Association
- National Parkinson Foundation
- Pioneer Network
Books

Reframing Dementia


* Books written by persons with dementia
**Being With a Person with Dementia**


**Leadership/Operational**


**Photographs**


Module 5 Resources

These additional resources are available if you want to learn more about abuse and preventing abuse.

If your nursing home would like to learn more about nursing home abuse risk prevention:

- *Nursing Home Abuse Risk Prevention Profile and Checklist*—National Center on Elder Abuse

  This prevention resource developed by the National Association of State Units on Aging has been designed not only to root out the “hidden” risks to vulnerable nursing home residents, but also to inspire and catalyze communitywide response.

  This free tool includes:

  - An abuse risk prevention profile, which describes nursing home risk factors, resident risk factors and relationship risk factors so that you can understand the risk factors that put residents in danger of abuse.
  
  - Suggestions for risk prevention planning in your nursing home (e.g., setting up an abuse prevention committee, how to evaluate the risk factors in your nursing home, etc.).
  
  - A Nursing Home Abuse Risk Prevention Checklist.
Empowering nurse aides...

...to improve the quality of care and quality of life for persons living with dementia.
...to understand and prevent abuse.
...to create a person-centered environment for all residents.
...to make their work more fulfilling through tools, knowledge, and shared learning.