

Module 17. Working with Consumers with Dementia

Goals

The goals of this module are to help participants to understand:

- What is Dementia;
- How Dementia affects people – workers and family, as well as consumers; and
- How to respond to challenging situations that may arise when working with consumers with Dementia.

Time

3.5 hours (includes 30 minutes for break and warm-up or closing)

Activities	Methods	Time
17.1 Introduction to a Consumer with Dementia.	Interactive presentation, large-group exercise, discussion	35 minutes
17.2 Understanding Dementia	Interactive presentation, scripted role play, and discussion	50 minutes
17.3 Working with Challenging Behaviors	Interactive presentation, demonstration role plays and discussion, small-group work, practice role plays and discussion	1 hour & 35 minutes

Supplies

- Flip chart, markers, and tape
- Paper and pencils
- *Instructor's Guide*: Mr. Ralph Turner

Handouts

- Handout 17.1 Role Play: Mr. Ralph Turner
- Handout 17.2 Challenging Behaviors
- Handout 17.3 Responding to Challenging Behaviors
- Handout 17.4 Pulling Back
- Handout 17.5 Body Language Speaks
- Handout 17.6 How Would You Respond to Mr. Turner?

Advance Preparation

Review all training and presentation materials for this module.

Copy all handouts for participants.

Activity 17.1: Introduction to a Consumer with Dementia

Prepare flip chart pages of the Learning Agenda (step 1), the discussion guide “Mr. Ralph Turner” (step 5), and Observe, Record, and Report (step 9).

Activity 17.2: Understanding Dementia

Prepare a flip chart page on Dementia (step 1).

Activity 17.3: Working with Challenging Behaviors

The “pulling back” activity includes a demonstration role play. If you are the only instructor, identify a participant or another staff member to role-play with you. Prepare this person in advance by describing the purpose of the activity and their role. Explain that their role involves saying things that might hurt your feelings or make you angry, but that you will be clear with everyone that this is part of the role play. Practice the two role plays together until your helper is comfortable with his or her “lines.”

Prepare flip chart pages on “Pulling Back” (step 11) and “Instructions for Group Work” (step 16).

ACTIVITY 17.1 Introduction to a Consumer with Dementia

35 minutes

Learning Outcomes

By the end of this activity, participants will be able to:

- Describe some of the challenges faced by people with Dementia and their families.
- Describe services available to consumers with Dementia and their families.

Key Content

- ❖ Mr. Ralph Turner has Dementia related to Alzheimer's disease and spends his weekdays in an adult day services center. In this module, participants will learn how Dementia affects a consumer and those around him or her, and how direct-care workers can cope with challenging situations related to Dementia.

Activity Steps

Interactive presentation (10 minutes)

1. Explain that the third consumer, Mr. Ralph Turner, is a participant at an adult day services center. Post and review the prepared flip chart page with the topics for this module. Explain that Mr. Turner has a disease that affects his brain -- Alzheimer's disease. Although this module focuses on the adult day setting, many long-term care consumers in other settings have Dementia, so it is important to know how to work with consumers who have Dementia and their families. In this module, participants will consider how to work with challenging behaviors from the consumer. In the next module, they will continue the focus on assisting consumers with Dementia and their families. As before, participants will review and build on what they have already learned from Carmen Garcia and Oscar Feldman.

LEARNING AGENDA: MODULE 13

- Dementia
- Responding to challenging behaviors
- The services that are available



2. Ask participants:
 - *What do you know about Dementia?*
 - *Do you know anyone who has had it?*
 - *What was that like for the person? For their family?*
3. Explain that, as before, you will read Mr. Turner's story aloud. Again, they should be working on their listening skills. This time, the story is told by Mr. Turner's daughter. While participants are listening, they should imagine meeting Mr. Turner for the first time. Ask them to imagine what he looks like and how he thinks and acts in the adult day services center.
4. Read *Instructor's Guide*: "Mr. Ralph Turner" out loud to participants.

⇒ **Teaching Tip**

Again, do not distribute the *Instructor's Guide*. It is more realistic for participants to *hear* a consumer's story than to read it. Also, they will be developing their listening skills, to be better able to learn what they need to know from listening to consumers.

Large-group exercise: Brainstorm and discussion (15 minutes)

5. Post the prepared flip chart pages with discussion questions. Ask participants to brainstorm their responses to the first question. List their responses on the flip chart page.

MR. RALPH TURNER (1)

- What do you remember from what Mr. Turner's daughter said?

MR. RALPH TURNER (2)

- Why do you think his story is told to us by his daughter?
- What do you think Mr. Turner will need from you?
- How are his needs different in adult day services than in home care?

6. Facilitate a brief discussion on the remaining three questions. (Do not record on flip chart paper.)

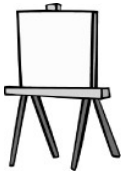
Interactive presentation (10 minutes)

7. Review the description of services available for consumers with Dementia and their families.
8. Note that Mr. Turner might not have a formal care plan for adult day services, as in home care or a nursing home, but there will be some kind of document explaining what services he will receive. Direct-care workers are oriented to how this is managed in each service site where they work.

⇒ **Teaching Tip**

If you have a care plan from an adult day program, review it at this time.

9. Whether there is a care plan or not, whenever a direct-care worker is with a consumer, he or she should always be aware of signs of potential problems. So they should still be thinking about what to observe, record, and report throughout these two modules. Post the flip chart pages for future discussions (especially in Activity 14.2).



OBSERVE, RECORD, REPORT:

Consumers with
Dementia

- Changes in client behavior
- Increase agitation
- Medical problems
- Refusing care
- Not eating

ACTIVITY 17.2 Understanding Dementia

50 minutes

Learning Outcomes

By the end of this activity, participants will be able to:

- Explain what Dementia is.
- Recognize the signs and symptoms of Dementia.
- Explain that challenging behaviors (e.g., being verbally or physically abusive) are a symptom of Dementia and not a reflection on the person who has the disease.
- Describe reality orientation and validation therapy.

Key Content

- ❖ For a direct-care worker, working with a person who has dementia for the first time can be an unsettling experience. Learning about dementia can help the worker to separate the behavior from the person, and learn ways to address the behavior.
- ❖ Dementia is a brain disorder that gradually destroys a person's memory and ability to think, communicate, and carry out daily activities. Individuals may also experience changes in personality and behavior, such as anxiety or agitation. Some Dementia, like Alzheimer's Disease is "progressive" (i.e., it always gets worse) and ends in death; there is no cure, although newer medicines can slow the affects of Dementia.
- ❖ Dementia is not a disease. It is the result of diseases such as Alzheimer's or Parkinson's disease. There are other brain disorders that cause Dementia. These include stroke, and some brain injuries.
- ❖ Sometimes, when someone with Dementia becomes anxious and confused, they then become angry and aggressive. It is important to understand that the aggressiveness is a symptom of the Dementia, not a true expression of the person.
- ❖ One of the main roles of the direct-care worker when working with consumers with Dementia is to calm the consumer when he or she becomes confused and upset.
- ❖ Two general approaches are used when working with a confused consumer with Dementia. "Reality orientation" is for consumers who are in early stages of dementia, or only somewhat confused. This involves giving constant reminders about time, place, and people, in the here-and-now.
- ❖ "Validation therapy" is for consumers with advanced dementia. It involves accepting whatever they are experiencing, without trying to orient them to reality. Both approaches use the technique of "redirection" – or helping the person to focus on something other than whatever is confusing and upsetting them.

Activity Steps

Interactive presentation (15 minutes)

1. Post and review the prepared flip chart page, "Alzheimer's Disease."



ALZHEIMER'S DISEASE

- Alzheimer's is a brain disease with no prevention or cure
- Alzheimer's disease is NOT "normal" aging
- Alzheimer's disease affects only:
1% of people aged 65 -75
10% of people aged 75 -85
30 -40% of people over the age of 85
- 50% of all nursing home residents have Alzheimer's or other brain-related disorders

2. Note that participants have already learned something about Alzheimer's from the discussion in Module 5, Body Systems and Common Diseases. Ask them to find Handout 5.4a, "Alzheimer's Disease," in their binders. Review the first two sections – "What Is Alzheimer's Disease?" and "Signs of Alzheimer's Disease." Note that these symptoms are sometimes referred to as dementia, and that they can be caused by other brain disorders, such as stroke, Parkinson's disease, and some brain injuries. Alzheimer's disease is by far the most common cause, however.

⇒ Teaching Tip

Some participants may not have Module 5 handouts with them. Ask them to pair up with someone who does.

Scripted role play and discussion (10 minutes)

3. Explain that, in order to better understand the effects of Dementia, we are going to have a role play about a situation that happened with Mr. Turner a few weeks ago. Ask for volunteers to help with the role play. Three volunteers are needed to read the parts of the narrator, the director of the center, and the direct-care worker. Provide each volunteer with a

copy of the script (Handout 17.1, "Role Play: Mr. Ralph Turner"). You will be reading the part of Mr. Turner. Note that all participants will be getting this handout later for their binders – for now you want them to concentrate on the role play.

4. Before beginning, ask participants to look for behaviors or thoughts of Mr. Turner's that don't seem quite "right" -- they will be discussing those later on. Remind the participants to think back to the description of Mr. Turner, written by his daughter.
5. Begin the role-play. Ask the volunteers to read dramatically, with emotion.

⇒ **Teaching Tip**

As Mr. Turner, you will need to turn to the side or otherwise indicate when you are reading the parts that are in italics, which indicate private thoughts.

6. After the role-play, debrief by asking the questions below. Affirm all correct responses and reactions to this situation:
 - *What happened in this situation?*
 - *What seemed "off" about Mr. Turner's behavior?*
 - *How do you think Mr. Turner was feeling?*
 - *How would you have felt if you were the direct-care worker in this situation?*
 - *How did the staff respond to Mr. Turner? What did they do well? What could they have done differently?*

⇒ **Teaching Tip**

Desired descriptions of Mr. Turner's behavior:

- *Confused about where he is (time and place)*
- *Thinking he is still doing his volunteer work*
- *Angry outbursts (personality change)*
- *Doesn't recognize other people/ confused about other people*
- *Restless, wandering*

7. Point out some of the symptoms of Dementia that were shown in this role-play: confusion and forgetfulness, anxiousness and agitation, wandering (or "exit-seeking"). Explain that sometimes, when someone with Dementia becomes anxious and confused, they then become angry and aggressive, like Mr. Turner became. It is important to explain that Mr. Turner has absolutely no history of being a violent man. Actually, he is a kind, generous, and sweet man. The aggressiveness is a symptom of the disease, not Mr. Turner's true personality.

Discussion (15 minutes)

8. Explain that one of the important roles of the direct-care worker is to help consumers with Dementia to calm down and avoid getting angry and aggressive. Briefly review the “Key Content” on reality orientation and validation therapy. Note that, if participants go on for further training, they will need to know these terms. However, for now, what they need to know is that the two approaches involve either trying to keep the consumer focused on reality, or going along with whatever “reality” they are experiencing in their mind. In both cases, the worker may use “redirecting,” or helping the consumer to focus on something else to take their minds off whatever is making them upset.
9. Note that, in the role play, the direct-care worker started to use validation (by saying, “it’s not time to go yet”), but mostly tried to stop him or “redirect” him by touching him. Ask:
 - *How well did that work?*[Desired response: not very well – it made him scared and angry!]
10. For the reality orientation, ask participants to suggest things the worker could say to Mr. Turner to help him stay in this reality, and also focus on something other than going to the church. After a few suggestions, ask how they think he would respond to that. Note that his response would depend on how much the disease had affected his brain, or even on the time of day when this was happening.

⇒ **Teaching Tip**

Possible responses:

- *Mr. Turner, you don't do the volunteering anymore.*
- *You spend your days with us now.*
- *You sold your car two years ago; your daughter brings you here now.*
- *That was a wonderful thing you used to do at the church – now you help us out here. Could you come help me...?*

11. Ask participants to now suggest things the worker could say that would go along with his reality (validation) but would still refocus him away from going to the church. Ask how they think he would respond to those suggestions.

⇒ **Teaching Tip**

Possible responses:

- *Mr. Turner, you're right – it is time to go to the church. Maybe you could wait over here with me while we ask someone to go get your car. While we're waiting, could you help me with this...?*
- *I think you parked your car at the back of the building. I'm walking that way right now -- why don't we walk together? Oh – look what*

these folks are doing...

- *Actually you're early today – you don't have to go to the church for another half-hour. Maybe you could help me here before you go...*

Interactive presentation (10 minutes)

12. Return to Handout 5.4a and review “How You Can Help.” Ask participants to take turns reading the tips. Briefly note how these could apply to Mr. Turner.

⇒ **Teaching Tip**

If time permits, this would be an opportunity to ask what the worker would look for under “Observe, Record, and Report” and to make notes on the flip chart page. There will be several other opportunities to do so later in the module.

13. Wrap up this activity by reminding participants how you began the module, thinking about Mr. Turner and how to best work with him or someone else with Dementia. They also explored the common emotions felt by people who have Dementia and how the anger and aggression that is often associated with Dementia is part of the disease, not the person who has it. Explain that, in the next activity, they will be looking at how to develop skills to manage challenging emotions and behaviors when they occur.

ACTIVITY 17.3 Working with Challenging Behaviors

1 hour & 35 minutes

Learning Outcomes

By the end of this activity, participants will be able to:

- Explain how to mentally separate the behavior from the person, in order to work effectively with someone who has Dementia.
- Explain the importance of “pulling back”—being aware of and controlling one’s emotions during difficult situations.
- Identify pull-back strategies that they can use in challenging situations with any consumer.
- Explain that a person with Dementia disease experiences a wide array of emotions; identifying those emotions is often useful in working with that person.
- Demonstrate the ability to use body language to help manage challenging behaviors related to having Dementia.

Key Content

- ❖ People with Dementia may at times present the direct-care worker with behavior that seems inappropriate to the situation and is difficult to control. The direct-care worker needs to understand that, while this behavior may seem strange to them, it may make sense for the consumer with Dementia.
- ❖ As a professional, it is the direct-care worker's job to stay calm and think clearly. Therefore, it is critical to learn effective techniques for maintaining emotional control and evaluating a challenging situation before responding.
- ❖ Guidelines for responding to a challenging situation with a consumer who has dementia disease include:
 - Remember: The behavior is not the person – it's the disease.
 - Pull back -- calm down.
 - Think before you act – find out what else is going on.
- ❖ "Pulling back" is a skill that provides trainees with a tool for thinking clearly before responding to a situation. Pulling back means noticing one's own initial emotional reaction to a situation (fear, anger, and frustration), but setting it aside, in order to address a situation objectively and professionally. This will help to build healthy work relationships with consumers and their family members, supervisors, and co-workers.
- ❖ Strategies for pulling back include pausing and taking a deep breath, using positive affirmations to maintain self-awareness and confidence, observing the situation, and trying to see the situation from the perspectives of the other people who are involved.
- ❖ Using supportive body language can also help to manage challenging situations with consumers who have Dementia.
- ❖ People with Dementia often have good days – or even parts of days -- when they are content, satisfied, and feeling connected. Looking at the whole person, not just the behavior, will help workers to get through challenging situations. Identifying what a person with dementia may be feeling or experiencing in a challenging situation can give clues about how to approach the person and resolve the situation.
- ❖ Working with people who have Dementia is difficult and requires time, practice, and patience. Participants should remember that no one is perfect and that their skills, attitudes, and knowledge will develop over time.

Activity Steps

Interactive presentation (15 minutes)

1. To help participants understand how to work with consumers with Dementia, explain that, for most people, new situations often bring up strong emotions. Illustrate this by asking participants:
 - *What were you feeling the day before this training started, or when you first signed up for this training?*

Get a few responses before moving on.

2. Ask participants to imagine for a moment that they couldn't make the more unwanted feelings (nervousness, anxiety, stress, fear, frustration, anger) go away. Imagine that every moment feels like a new situation, and they aren't ever able to find familiarity or relief from stress. For some people with Dementia, that's what it is like all the time. These unwanted feelings don't easily go away; and sometimes they cause people to act in strange ways compared to what we may consider normal.
3. Remind participants about Mr. Turner's behavior when he couldn't find his way out of the Adult Day Center to pick up the church people. Explain that people with Dementia may exhibit behaviors that seem strange to the outside observer because they are acting on feelings that they cannot control nor understand; or because brain cells that have been damaged by disease are "misfiring" – they may even think they are in a different place or time. These behaviors are called "challenging" because they are inappropriate to the situation, and/or because it is difficult to get the consumer to stop.
4. Distribute Handout 17.2, "Challenging Behaviors." Note that "Don's" day is full of situations that can arise when working with people who have Dementia. Ask two participants to volunteer to read the parts in the conversation between Don and Fran. Then read each bullet and ask participants for quick, one-word responses for how they would feel if they were the direct-care worker in that situation.
5. Affirm that having a strong emotional reaction to being hit by a consumer, for example, is natural. However, hitting a consumer back would be physical abuse. That's not only wrong, but it also doesn't address the situation -- or resolve what is going on for the consumer. Explain that remembering a few key rules will help in working with someone with Dementia whose behavior seems strange or aggressive. Distribute Handout 17.3, "Responding to Challenging Behaviors." Review the tips from other direct-care workers for responding to challenging situations with consumers. Note that these apply not only to consumers with Alzheimer's disease, but to any consumer.

Demonstration role plays and discussion (10 minutes)

6. Note that the tip, “Pull back – calm down,” is sometimes hard to do, but can be practiced and learned. Explain that you and another instructor (or participant volunteer – see “Advance Preparation”) will do two role plays of a difficult situation to show what it looks like when people don't pull back and when they do. Emphasize that these role plays are for educational purposes, and that nothing that is said should be taken personally.
7. Set up the role play with yourself and the other instructor/volunteer, standing or sitting where everyone can see and hear you. Describe the scenario—e.g., the volunteer is Mr. Turner, and you are role-playing a direct-care worker who has just asked Mr. Turner to come join the singing activity (see the Teaching Tip, below, for ideas on what each player might say).

⇒ **Teaching Tips**

Mr. Turner (angry):

- I will NOT go to singing! I HATE singing! You're just jealous because I have a job and you don't! You probably even stole my car – I'm calling the police!

Direct-care worker (also angry):

- Mr. Turner, I DO have a job –! ...You just go ahead and call the police! I want to tell them how you threaten to hit me every day!

8. Step out of your role by moving away from the other person. Facilitate a brief discussion by asking participants:
 - *What did you observe in this role play?*
 - *How do you think the direct-care worker was feeling?*
 - *How would you describe the direct-care worker's reaction to Mr. Turner?*
 - *What is likely to happen next?*
 - *What could the direct-care worker have done differently to get a better outcome?*
9. Explain that you are now going to repeat the situation and try a different response. Begin the same way, with the same comments from “Mr. Turner.” This time the direct-care worker will demonstrate pull-back strategies (see Teaching Tips, below).

⇒ **Teaching Tip**

Examples of “pull back” responses would be:

- Taking a deep breath.
- Waiting five seconds before responding.
- Consciously relaxing your body language.

- Saying, "I'm sorry, Mr. Turner. I understand now that you don't like singing. What else could you and I do together, besides singing?"

10. Again step out of your role by stepping away from the other instructor/volunteer. Help him or her come out of his role, too, by thanking the volunteer for doing such a good job, and asking for a round of applause (to emphasize that it was truly "acting"). Then debrief by asking participants:

- *What was different about the direct-care worker's response?*
- *What did the direct-care worker do to gain emotional control?*
- *What do you think is likely to happen next in this conversation?*

Discussion (15 minutes)

11. Post the prepared flip chart page with the description of "Pull Back" and review the goal.



PULLING BACK

The Goals –

- calm down,
- get clear, and
- focus on understanding and responding appropriately to the situation.

STRATEGIES FOR PULLING BACK:

12. Ask for ideas about *how* people can control their emotions when they're in the middle of a difficult situation. Ask them to reflect on their own experiences; or think about what they observed in the second role play that was different from the first. Write their ideas down on the flip chart page (above).

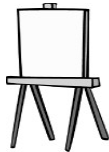
⇒ **Teaching Tip**

Pull-back strategies can include: take deep breaths; silently say a prayer, or count to five (or ten!), say an affirmation such as "I have the strength to deal with whatever is happening here."

13. Distribute and review Handout 17.4, "Pulling Back."
14. Note that their use of body language can also have an impact on managing a challenging situation. Distribute and review Handout 17.5, "Body Language Speaks¹," asking participants for examples.

Small-group work (10 minutes)

15. Now that participants have considered how to pull back from their own emotional reactions to a situation, and how to use appropriate body language, explain that they will now practice using these techniques in challenging situations. Divide participants into four groups, and distribute Handout 17.6, "How Would You Respond to Mr. Turner?" Explain that participants will look at situations that could pose a challenge to a direct-care worker, from the perspective of the emotions that Mr. Turner might be experiencing. Their goal in this role play is to help Mr. Turner to be more calm. Note that role plays in the next module will focus more on solving the problems Mr. Turner faces.
16. Assign one scenario to each group. Post and review the prepared flip chart page with instructions for group work. Ask them to take seven or eight minutes to think about the questions and prepare to do a role play for the rest of the participants, with one of their group playing Mr. Turner and another playing the direct-care worker.



**INSTRUCTIONS FOR GROUP WORK
& ROLE PLAY**

1. What might Mr. Turner be feeling?
2. What might be causing this feeling?
3. Role-play how you would respond to Mr. Turner:
 - Pull-back
 - Body language
 - Redirection

¹ Adapted from the presentation "A New Approach to Dementia Care Training" by Teepa L. Snow, Melanie Bunn, and Maureen Charlton of the Alzheimer's Association's Eastern North Carolina Chapter in Raleigh, at the World Alzheimer Congress 2000. <http://www.longtermcareprovider.com/content/news/>

Role plays and discussion (40 minutes)

17. Spend about ten minutes on each situation. Have the first group begin by reading their situation, explaining what they think Mr. Turner is feeling, and why.
18. Then they conduct their role play.
19. In the discussion, ask participants (role players first) what they thought the group did well in responding to Mr. Turner, and what could be improved. Ask for examples of pull-back, body language, and redirection that participants observed.
20. Repeat for the other three groups.

Interactive presentation (5 minutes)

21. Wrap up the session by noting that people with Dementia, such as Mr. Turner, often have good days, when they are content, satisfied, and feeling connected. And there are going to be days when a direct-care worker must use his or her skills to get that person to a happier place. Remind participants to think about the whole person, not just the behavior. Remind them about the benefits of pulling back from their own initial emotional reaction. When we identify what a person may be feeling or experiencing, this gives us a clue about how to approach the person and start to resolve the situation. Finally, reassure participants that nobody is perfect. Working with people who have Dementia is difficult and requires time, practice, and patience.

Instructor's Guide, Activity 17.1

MR. RALPH TURNER

This narrative was written by Mr. Turner's daughter, Pat.

First thing to know about my father is that he is very independent and old-fashioned! So this Alzheimer's disease has really hit him hard. Dad is a very organized person, and he has a daily routine. Ever since my mother died 10 years ago, he has been getting himself up every morning at 7 -- he takes a shower, makes coffee and breakfast, and gets dressed. Up until a year ago, he used to jump into the car to take care of whatever things were on his "to-do" list. He used to do a lot of volunteer work at the church, helping drive "old folks" to doctor's appointments and such. When he first realized he was forgetting things or getting lost, he used to get very angry with himself. Eventually, he had to give up the car and he stopped volunteering after that.

Dad had his own business for many years. He was very successful. But one day, out of the blue, he told me he was "tired of working," and he sold his business. Now I think it's because he was having trouble remembering things, and he was afraid of making a big mistake.

Besides the Alzheimer's, Dad's pretty healthy, but lately he's had several wetting accidents. I've started to talk with him about wearing Depends and you can just imagine how this really upsets him!

Dad has two sisters who visit regularly but I'm his only child. My husband and I live just down the street, so we pop in on him all the time. He's always had a lot of friends in the neighborhood, and the church, too, but it seems like he's embarrassed to see them anymore.

We brought Dad to Adult Day mostly because both my husband and I work long hours and we don't want to leave him alone during the day. We thought about home care but he doesn't need anyone to do anything around the house. Just remember, my Dad is proud of being independent. As long as you can help him feel this way, you'll do alright with him.

Module 17 Handouts

Working with a Consumer with Dementia

Activity 17.2: Understanding Dementia

Handout 17.1

Role Play: Mr. Ralph Turner

Activity 17.3: Working with Challenging Behaviors

Handout 17.2

Challenging Behaviors

Handout 17.3

Responding to Challenging Behaviors

Handout 17.4

Pulling Back

Handout 17.5

Body Language Speaks

Handout 17.6

How Would You Respond to Mr. Turner?

Handout 17.1—Role Play: Mr. Ralph Turner

Page 1 of 3

Narrator:

Here we are at Riverview Adult Day Health – and here comes Mr. Ralph Turner.

Mr. Turner (talking to himself):

I don't know why they want me to go to bingo. I don't like bingo. Besides, I have to go pick up the old folks at church. But I can't find my car keys! They keep taking things and putting them in the wrong place! If I don't leave soon, the old folks won't get to their appointments.

Narrator:

Mr. Turner walks to the front door. He wants to go out. A direct-care worker stops him.

Mr. Turner:

Get out of my way -- I'm late! I have to go now, or the old folks won't get to their appointments!

Direct-Care Worker:

It's not time to go yet. Would you like to join in The Good Old Days singing group?

Mr. Turner:

I don't sing. Birds sing. They're waiting at the church for me. And, what did you do with my car?

Handout 17.1—Role Play: Mr. Ralph Turner

Page 2 of 3

Narrator:

From behind, the direct-care worker places her hand gently on Mr. Turner's shoulder. She tries to get him to come with her to the community room, where the singing is taking place.

Direct-Care Worker:

Come on, let's go. We can sing together. How does that sound?

Mr. Turner (talking to himself):

Why is she grabbing me? I need to go. Don't these folks listen? I'm late! I've got to go!

Narrator:

Mr. Turner turns around and pushes the worker's hand from his shoulder. He tries to go out the door. The worker grabs his arm to keep him from going outside.

Mr. Turner:

Let me go! Let me go!

Narrator:

Mr. Turner starts walking back and forth. His face is getting red.

Mr. Turner:

Let me out! Help! Police! What's going on here? Why won't they let me go? Where am I? Who are these people! What's going on?

Handout 17.1—Role Play: Mr. Ralph Turner

Page 3 of 3

Narrator:

Mr. Turner keeps yelling, sounding more upset. The center director comes out of her office.

Center Director:

What is going on? He needs to calm down. Take him into the blue room.

Narrator:

The direct-care worker tries to take Mr. Turner's arm again, to guide him down the hall. Mr. Turner pulls away.

Mr. Turner:

The blue room? What's that? I don't want to go to jail. All I want to do is go to the church. No! You can't take me!

Narrator:

To be continued ...

Handout 17.2—Challenging Behaviors

Page 1 of 1

It can be hard to work with people who have Alzheimer's disease. Their behavior is sometimes inappropriate and it's hard to get them to stop. Don is a program assistant at Riverview Adult Day Health. Here he is talking with his friend, Fran, about his day at work.

Don:

I had a really tough day today.

Fran:

What happened?

Don:

Well, first Mr. Richards got upset when I tried to help him eat his breakfast. He actually smacked me! Then Mr. Gray kept wandering off down the hall during exercise class. Then Mrs. Lore yelled and cursed at me when I reminded her to take her meds. This was all before lunch! And still, even on these rough days, I like the job and the people.

Fran:

Wow, that was a hard day! I admire that you are still upbeat after all that. I guess it's because you know that people with Alzheimer's disease don't know what they are doing at times.

People with Alzheimer's disease may:

- Not let you help them
- Curse at you or say rude things
- Try to hit you
- Not want to do things with the group
- Try to get away from you

Handout 17.3—Responding to Challenging Behaviors

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Assisting people with Alzheimer's disease is an art. Read these important tips from caregivers.

Manuel's Tip — The behavior is not the person.

“If someone hits me or says something rude, I always tell myself -- That's just the Alzheimer's, not the person. People with Alzheimer's act the way they do because they are sick.”

Asha's tip — Pull back – calm down.

“If someone hits you, you may want to hit back. But it doesn't help anyone. So I step back and breathe deep, to give myself time to think before I take action.”

Kofi's tip — Think before you act – find out what else is going on.

“Sometimes Mr. Turner seems to blow up about nothing. But if I just try to find out what's happening for him, sometimes I see there's some real problem that I hadn't noticed, and he's reacting to that.”

Joyce's tip – Speak slowly and clearly.

“When I talk to people with Alzheimer's, I keep my message really simple. I use just a few words at a time and speak very slowly. That helps them follow what I'm saying.”

Handout 17.3—Responding to Challenging Behaviors

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Review:

When you're facing challenging behavior from a person with Alzheimer's disease, remember:

1. The behavior is not the person – it's the disease.
2. Pull back -- calm down.
3. Think before you act – find out what else is going on.
4. Speak slowly and clearly.

Handout 17.4—Pulling Back

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The Goal of Pulling Back:

To give you time to –

- Calm down
- Set your emotions aside
- Get clear
- Focus on understanding the situation and responding appropriately.

When you start to get upset, take these steps:

1. Stop. Take a deep breath.
2. Pay attention to how you feel. Are you mad? Sad? Worried?
3. Set your feelings aside – maybe you'll get back to them later.
4. Think clearly about what is going on.
5. Pay attention to the other person and try to see the situation from their point of view.

Pull-back tips:

- Take a deep breath
- Silently say a prayer
- Count to ten
- Silently say an affirmation – “I have the strength to deal with what is happening here”

Handout 17.5—Body Language Speaks

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Here are some ways to use body language when working with a person who has Alzheimer's disease², like Mr. Turner.

Approach Mr. Turner from the front.

Coming from behind can startle him.

Move to his side.

Mr. Turner may feel attacked when you speak to or touch him from the front.

Go slow.

Give Mr. Turner time to get used to what's happening around him before you start something new.

Get low.

Squat down so you're at eye level or lower. If you can't squat, sit in a chair. When Mr. Turner is sitting down and you stand over him, he feels powerless and trapped.

² Adapted from the presentation "A New Approach to Dementia Care Training" by Teepa L. Snow, Melanie Bunn, and Maureen Charlton of the Alzheimer's Association's Eastern North Carolina Chapter in Raleigh, at the World Alzheimer Congress 2000.

Handout 17.5—Body Language Speaks

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Give him space.

Respect Mr. Turner's personal space. Plus, stay at least an arm's length away, in case he strike out at you.

Say, "Mr. Turner."

Or call him by the name he likes.

Make eye contact.

This shows that you are listening. Plus, Mr. Turner can understand you better when he sees your lips move and the look on your face.

Offer him your hand.

Hold out your hand, palm open and up. Let Mr. Turner take your hand. This helps him make eye contact and follow your lead.

Be careful about touching.

No matter how gentle you are, touching Mr. Turner might be a bad idea when he is already upset. If you must touch him, use an open palm and a slow, steady, firm motion.

Handout 17.6—How Would You Respond to Mr. Turner?

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In the following situations:

- Try to imagine how Mr. Turner feels.
- Try to figure out what is making him feel that way and if there's anything you can do about it.
- Act out how you would respond.
 - Use pull-back if needed
 - Use at least one of the body language tips in Handout 17.5.
 - Redirect Mr. Turner

Situation A.

Mr. Turner is sitting in a chair looking down. Everyone else has gone to lunch. You go closer and see that he has wet his pants. When you try to talk to him, he yells at you to, "STAY AWAY FROM ME!"

Situation B.

Mr. Turner is sitting by himself at a table. He is the first person at the center today because his daughter dropped him off early. His head is down. When you bend over him to say good morning, he looks up and calls you by his wife's name. He reaches up to you and tries to hug you.

Handout 17.6—How Would You Respond to Mr. Turner?

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Situation C.

You are in a hurry, running to get an adult brief (Depends) in the supply room for another consumer. You see Mr. Turner walking down the hall. He is saying, “Otto, Otto, where are you?” Otto is the name of his cat that died years ago. He sits down on the couch and begins to cry. He asks you to help him find his cat.

Situation D.

You are preparing for an activity involving beads, putting beads into plastic cups for the participants. Mr. Turner is standing near you, looking anxiously at the door. When you ask if he wants to help you, he starts to put beads into cups. But suddenly he sweeps all the cups off the table with his arm, and yells, “I’m supposed to be at work – not sorting stupid beads!”