

Adapting to Behavior Changes_Family

Adapting to Behavior Changes_Family Version

Adapting to Behavior Changes For Families and Home-based Caregivers

Title Page

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Slide 1: Title Page

Narration: Welcome to this course, Adapting to Behavior Changes for Families and Home-based Caregivers.

This is the second in a series of courses/webinars/trainings designed to provide practical information on dementia in people with intellectual and developmental disabilities – or IDD. This course gives you an overview of behavior changes that may occur as your family member’s dementia develops and progresses, as well as practical suggestions for how to manage challenges that may arise because of these changes.

Welcome!

The buttons underneath the slides will help you navigate through the course:

- The “Play” button will play or pause the slide
- The left arrow will bring you back to the previous slide
- The right arrow will bring you to the next slide
- The speaker button will mute the audio

Slide 2: Welcome and Instructions

Narration:

Welcome! The buttons underneath the slides will help you navigate through the course.

- The “Play” button will play or pause the slide.
- The left arrow button will bring you back to the previous slide.
- The right arrow button will move to the next slide.
- And the speaker button will mute the audio.

IDD

This stands for Intellectual and Developmental Disabilities.

Limitations in:

- Learning, thinking, problem solving
(*intellectual functioning*)
- Practical everyday skills (*adaptive behaviors*)
- Before 22

ADRD

You may see or hear people talk about ADRD. It stands for Alzheimer's Disease and Related Disorders. And those diseases and disorders are what this course will explain further.

Slide 3: Definitions

Narration: Definitions

Throughout this course you'll hear us refer to IDD and ADRD. What do these acronyms - or letters - stand for?

IDD

This stands for Intellectual and Developmental Disabilities

What does that mean?

It means that a person with IDD has significant limitations with intellectual functioning – in other words - things like learning, thinking or problem solving. And they also have significant limitations in adaptive behavior or using practical everyday skills– things like job skills, self-care, using transportation, using money, cooking, knowing how to ask for help, getting along with other people, or knowing their rights.

When these limitations happen before the age of 22, then the person has an intellectual or developmental disability. And again - we shorten that to IDD.

ADRD

You may see or hear people talk about **ADRD**. It stands for Alzheimer's Disease and Related Disorders. And those diseases and disorders are what this course will explain further.

Learning Objectives

- Understand that behavior and mood may change over time
 - Be aware of the ways that a person with ADRD might behave
- Understand that behavior is a form of communication (verbal/non-verbal)
- Introduce ways to anticipate and respond to behavior of someone with ADRD

Slide 4: Learning Objectives

Narration: Learning Objectives

- Understand that behavior and mood may change over time.
 - Be aware of the ways that a person with ADRD might behave.
- Understand that behavior is a form of communication - verbal (or spoken) and non-verbal (or non-spoken)
- Introduce ways to anticipate and respond to behavior of someone with ADRD

Learning Objective 1:

Understand that behavior and mood may change over time

Slide 5: Learning Objective 1

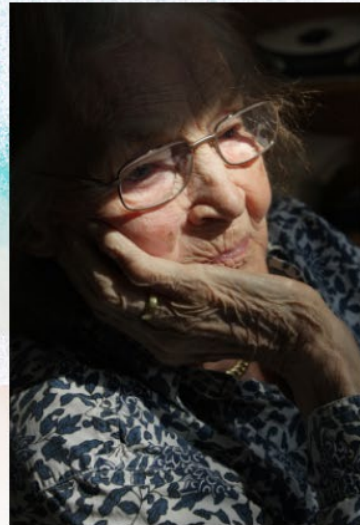
Narration:

Learning Objective 1: Understand that behavior and mood may change over time.

How might behavior and mood change over time?

Behavior and mood will change over time:

- “Not their usual self”
- Behaviors may continue to change and affect the person’s life
- Some behaviors may be harmful or dangerous



Slide 6: Behavior and Mood Change Over Time

Narration: Section 1: How might behavior and mood change over time?

One of the changes you’ll notice in your family member with dementia is that their behavior and mood – the way they act - will change or become inconsistent over time.

- At first you may notice that they’re “not their usual self”. For example, someone who is usually cheerful may become anxious or angry.
- As the dementia progresses, the behaviors may continue to change or affect the person’s life more and more.
- The behaviors may even become harmful or dangerous for the person – for example, they may wander outside the home, not dress properly for the weather, or forget to take medication

Keep Notes About Changes

Describe:

- **What** happened before and during
- **When** it occurred
- **Where** it occurred
- **How** you reacted

Tell Someone

Tell your family member's health care provider about behaviors that are out of the ordinary.

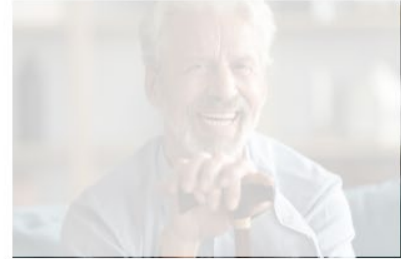
This helps with the diagnosis and care plan for the person.

Slide 7: Keep Notes About Changes

Narration: Keep Notes About Changes

- It's important to keep notes about changes and concerns you have. Describe:
 - What happened before and during a significant incident.
 - When it occurred, how it related to what was going on at the time or how it differed from the usual routine.
 - Where it occurred – especially what was going on in the setting (was it noisy, for example?)
 - How you reacted to the incident
- The notes will allow you to tell your loved one's health care provider details about behaviors that are out of the ordinary. This will help the health care provider make a diagnosis and care plan for the person.

What Might You Notice?



Changes in Early and Moderate Stages The person might become:



Withdrawn, depressed or seem to lose motivation for activities they once enjoyed. They may also be sad, anxious, or tearful.



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Slide 8: What Might You Notice?

Narration: What Might You Notice?

In the early and moderate stages of Alzheimer's disease and dementia you may notice some of these changes in the person's mood and behavior.

- For example, they might become more withdrawn, depressed, or seem to lose motivation for activities they once enjoyed.
 - They might become sad, anxious or tearful.
 - Click on the little blue left or right arrows to see some more examples.
- They might become overly excited – almost overly happy or giddy with excitement.
- It's not uncommon for the person to become easily upset, agitated, or frustrated, because as their brains change, they're less able to understand the world around them.
- They might develop obsessive behaviors – behaviors that they insist on and which cannot be easily changed. For example, they might start hoarding things – tucking items in drawers or closets.
- They might refuse to participate in activities or act in a way that seems stubborn– for example they may refuse to bathe.
 - Remember – they're not trying to be stubborn. It's the changes in their brain that causes them to act this way.
- As the dementia progresses the person may act out, yelling and having verbal outbursts or even becoming aggressive.

What Might you Notice - Continued



Slide 9: What Might You Notice – Cont.

Narration: What Might You Notice, Cont.

Let's listen to a dementia expert talk about what you may see, especially early on. Kathy Service is a nurse practitioner with more than 40 years' experience working with people with IDD

Changes in Moderate to Late Stages

Sundowning

Wandering

Seizures

Hallucinations and Delusions

As the dementia progresses to the Moderate and Late stages the person may experience some of these symptoms.

Click on the topics on the left to hear more.

Slide 10: Changes in Moderate to Late Stages

Narration: Changes in Moderate to Late Stages

As the dementia progresses to the Moderate and Late stages the person might experience some of these symptoms. Click on the topics on the left to hear more.

- Sundowning
 - Sundowning is a term that's used when a person's agitation and confusion increases later in the afternoon and evening. And they may seem to become depressed. This may be due to decreasing sunlight and fatigue.
- Wandering
 - Wandering is used to describe movement of a person with dementia. This can be a significant safety hazard when the person leaves the residence. There is a risk that the person can get lost or injured in an unfamiliar place.
- Seizures or seizure like activity
 - Seizures may vary from "spacing out" to small tic-like jerkiness to shaking and large jerky movements followed by complete loss of muscle tone or becoming limp.
 - Note that in people with Down syndrome, seizures may develop earlier in the disease.
- Hallucinations and Delusions
 - Hallucinations are categorized as seeing someone or something that isn't there.
 - While delusions are believing something that isn't accurate

On the next slide, you will hear some examples from an expert.

Hallucinations and Delusions



Slide 11: Hallucinations and Delusions

Narration: Hallucinations and Delusions

Click on the video below to hear an expert talk about examples of hallucinations and delusions

Let's Review!

Try these questions to check your understanding of Section One

Slide 12: Let's Review: Section 1

Narration:

Let's Review! Try these questions to check your understanding of Section One.

Choose the Best Response

You open a drawer in Janice's room. It is stuffed with used napkins. Which is the correct response?

- You have Janice throw all the napkins away because she needs to learn to keep her room clean.
- You clean the drawer without calling attention to it because you know hoarding is not unusual in someone with dementia

Submit

Slide 13: Section 1: Question 1

Narration: Choose the best response. You open a drawer in Janice's room. It is stuffed with used napkins. Which is the correct response?

Select your answer then click Submit, click it again to go to the next slide.

Choose the Best Response

Jim puts his coat on and tells you he's waiting for his grandmother to take him to lunch. His grandmother passed away many years ago. Which is the best response?

- Jim, take that coat off now! Don't you remember that your grandmother passed away?
- I know you were excited to see Grandma, but she can't come today, so please take your coat off and have some lunch with me.

Submit

Slide 14: Section 1: Question 2

Narration: Choose the best response. Jim puts his coat on and tells you he's waiting for his grandmother to take him to lunch. His grandmother passed away many years ago. Which is the best response?

Select your answer then click Submit, click it again to go to the next slide.

Learning Objective 2:

Understand that behavior is a form of communication

Slide 15: Learning Objective 2

Narration:

Learning Objective 2: Understand that Behavior is a Form of Communication

Why is This Behavior Happening?



Slide 16: Why is This Behavior Happening?

Narration: Section 2: Why is This Behavior Happening?

There are several reasons why behavior and mood changes occur. The video below will provide some examples.

Reactions to Health-related Issues and Physical Needs

- Possible medical or physical needs:
 - Medication side effects
 - Pain or physical discomfort
 - Illness not associated with the dementia
 - Loss or worsening of hearing or vision
 - Fatigue, hunger, thirst
- Some changes may have underlying causes that you can address



Slide 17: Reactions to Health Issues, Physical Needs

Narration: Reactions to Health-related Issues and Physical Needs

Remember that the person's behavior may be telling you that there might be a medical or physical need that should be considered or addressed, such as:

- Medication side effects
 - If someone is showing unusual behavior after starting a new medication, this could indicate a serious medication side effect. Contact the person's medical provider immediately or call 911 if it is a medical emergency.
- Pain or physical discomfort
 - Perhaps they have a headache or toothache, or maybe they're chilly. Maybe a chair is uncomfortable.
- Illness not associated with the dementia, such as an infection.
- Loss or worsening of hearing or vision.
- Fatigue or tiredness, hunger, or thirst

While some behavior and mood changes are the result of changes in the brain that cannot be cured, some changes may have underlying causes that you can address or take care of. So, it's important to raise concerns with your family member's health care provider.



Reactions to Surroundings

Possible things in the surroundings or environment that may affect behavior and mood include:

- Noise or many sounds happening at the same time
- Fading light of day
- Clutter
- Changes in routines

Slide 18: Reactions to Surroundings

Narration: Reactions to Surroundings

Your loved one might react to their environment or surroundings. For example, their living spaces, social settings, and routines and schedules.

Things like:

- Too much noise or too many sounds happening at the same time.
- Fading light of day
- Clutter
- Changes in routines

In just a few slides, we'll talk about ways to make the person's surroundings more comfortable for them

Reactions to Surroundings - Continued



Slide 19: Reactions to Surroundings, Cont.

Narration: Reactions to Surroundings, Cont.

Click on the video below for an example of how something in the environment triggered fear in a person with dementia.

Confusion

Especially in the earlier stages of dementia, your family member may be upset or confused by what's happening within them.

They may feel a sense of loss or frustration as they struggle to remember things.

Fear and Anxiety

They might become fearful and anxious in situations that they have trouble understanding

- A new residence, change in routine, or new people
- Things that were familiar become unfamiliar, and the person may also become confused, agitated or anxious.

Slide 20: Reactions to Having Dementia

Narration: Reactions to Having Dementia

Especially in the earlier stages of dementia, your family member may be upset or confused by what's happening within them.

- They may feel a sense of loss or frustration as they struggle to remember things – for example, names, words, or how to do something or ask for something they want.

They may become fearful and anxious in situations that they have trouble understanding.

- A new residence, change in routine, or new people.
- As things that were once familiar become unfamiliar, the person may also become agitated, confused, or anxious.

Reactions to Having Dementia - Continued

The person may not recognize:

- Family members, friends, or long-time helpers
- Familiar places
- Themselves in a mirror

Slide 21: Reactions to Having Dementia, Cont.

Narration: Reactions to Having Dementia, Cont.

- They may not always recognize you, or other family members, friends or long-time helpers and may view them with fear.
 - They may not recognize a familiar place and become disoriented and confused.
 - They may not recognize themselves in a mirror.

Click on the video for an example of someone who no longer recognized themselves in the mirror, and the creative way the staff responded.

In the next section, we'll discuss even more strategies to help calm someone.

Let's Review!

Try these questions to check your understanding of Section Two

Slide 22: Let's Review: Section 2

Narration:

Let's Review! Try these questions to check your understanding of Section Two.

Multiple Choice

Your family member is sleeping a lot during the afternoon. Which of the following may explain it?

- People with dementia may become easily fatigued or tired
- The person may be ill and have no energy
- The person may be reacting to having less light as the daylight fades (this is known as *sundowning*)
- All of the above

Submit

Slide 23: Section 2: Question 1

Narration: Multiple choice. Your family member is sleeping a lot during the afternoon. Which of the following may explain it?

Select your answer then click Submit, click it again to go to the next slide.

Choose the Best Response

At dinnertime, the family is home and talking about their day. Pots are clattering in the kitchen, the TV is on, and it's noisy. You ask your family member to get washed up for dinner, they refuse and start to cry. Which is the best explanation?

- They are overwhelmed by the noise and activity and react by getting frustrated.
- They must be angry with you for some reason and are being stubborn to upset you.

Submit

Slide 24: Section 2: Question 2

Narration: Choose the best response. At dinnertime, the family is home and talking about their day. Pots are clattering in the kitchen, the television is on, and it's noisy. You ask your family member to get washed up for dinner and they refuse and start to cry. Which is the best explanation?

Select your answer then click Submit, click it again to go to the next slide.

Learning Objective 3:

Introduce ways to anticipate and respond to behavior of someone with ADRD

Slide 25: Learning Objective 3

Narration:

Learning Objective 3: Introduce ways to anticipate and respond to behavior of someone with ADRD.

What Can You Do?

In the previous section we said that people's behavior might be a reaction to having a health-related issue or unmet need, reacting to something in their surroundings or even something happening within them.

In this next section we'll discuss some ways to help prevent behaviors from occurring, and offer some tips to calm someone who's in distress.



Slide 26: What Can You Do?

Narration: Section 3: What Can You Do?

In the previous section we said that people's behavior might be a reaction to having a health-related issue or unmet need, or they might be reacting to something in their surroundings or even something happening within them. In this next section we'll discuss some ways to help prevent behaviors from occurring and offer some tips to calm someone who's in distress.



Take Care of Health-Related Issues and Physical Needs

Make sure that physical and medical needs are met:

- Clean glasses
- Hearing aids are in and working
- Maintain well-visits
- Review medication interactions and side effects
- Offer a healthy diet, including fluids
- Make sure they're getting enough rest

Slide 27: Take Care of Health-Related Issues

Narration: Take Care of Health-Related Issues and Physical Needs

Make sure that physical and medical needs are met:

- Make sure that glasses are clean.
- Make sure that hearing aids are in and working.
- Maintain well-visits with the person's health care provider.
- Review medication interactions and side effects with the health care provider
 - Make sure that you understand possible side effects or medication interactions could occur and then monitor for those. Alert the health care provider immediately if you notice adverse reactions or call 911.
- Make sure your family member is eating a healthy diet, including fluids.
- Make sure they're getting enough rest.

What Can You Do To Prevent Some of These Behaviors?

- The person's home should not have clutter and should be brightly lit.
- Keep noise down to reduce distractions
- Offer soothing objects
- Monitor your own mood and behavior around your family member



Slide 28: What can you do to Prevent Behaviors?

Narration: What can you do to help prevent some of these behaviors?

Let's start by looking at how you can make your loved one's surroundings comfortable for them, which in turn can help them remain calm:

- Your home should not have clutter and should be brightly lit.
 - This will minimize distractions, keep the person from feeling overwhelmed, and will eliminate hazards, such as tripping over area rugs or stray electrical cords.
- Keep noise down to reduce distractions.
- Offer soothing objects – such as a soft blanket, a stuffed animal, or quiet music.
- It will also help you pay attention to your own mood and behavior around the person – they may sense how you're feeling and mirror or copy it.



Routines and Schedules

Remember that a person may react to the dimming light at the end of the day.

It helps to:

- Schedule activities for earlier in the day when the person is more alert
- Establish routines

Slide 29: Routines and Schedules

Narration: Routines and Schedules

Remember that a person may react to the dimming light at the end of the day. And they may get tired more easily. It helps to:

- Schedule activities for earlier in the day when the person is more alert.
- It helps to structure the day with routines that the person can rely on

Communicate Clearly and Calmly

- Use a calm and respectful tone of voice
- Ask one question at a time
- Limit choice
- Help the person through a task or activity one step at a time
- Don't argue when the person says something that is incorrect
 - "Go with it!"
 - Validate their experience



Slide 30: Communicate Clearly and Calmly

Narration: Communicate clearly and calmly

- Use a calm and respectful tone of voice.
 - Make sure you use an even tone of voice and a relaxed body position.
- Ask one question at a time and give the person time to respond.
- And Limit choice – the idea is that you don't want to overwhelm the person by asking them to respond to too much information at once.
- Help the person through a task or activity one step at a time.
 - Use cues – such as pictures, color coding of objects or places in the residence, pointing or gestures. These types of supports may help the person complete a task more independently.
- Don't argue when the person says something that is incorrect.
 - "Go with it!"
 - Validate their experience.
 - If they seem bothered by someone they see, you validate their concern and then distract their attention away from what seems to be concerning them. For example, say something like, "you seem to be bothered by that man over there. Let's go to the kitchen and I'll make you some tea."

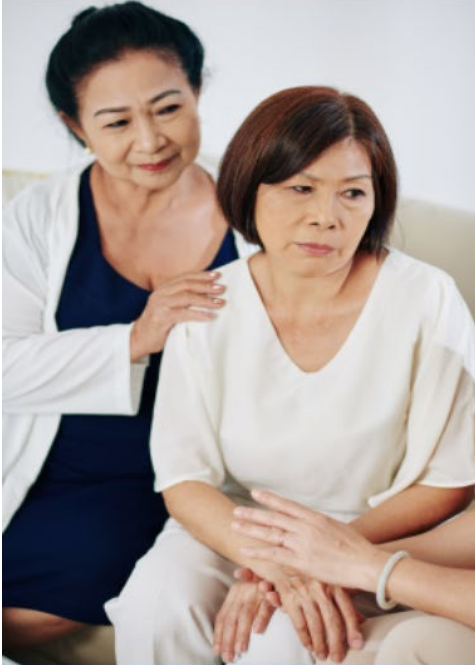
Validating Someone's Experience



Slide 31: Validating Someone's Experience

Narration: Validating Someone's Experience

Click on the video below for more on validating someone's experience.



Calming Someone Who Is Upset

Here are a few things you can try:

- Offer a soothing activity
- Reassure the person when they become frightened by a hallucination, but **remember that for them, the situation is real**
- Allow them to pace in a quiet safe spot
- Allow them time to calm down
- Keep a positive, upbeat attitude

Slide 32: Calming Someone Who Is Upset

Narration: Calming Someone Who Is Upset

Sometimes, even with your best efforts, your family member may become agitated, upset, or act out. When this happens, here are few things you can try:

- Deflect or redirect your family member by offering a soothing activity that you know they enjoy.
- Reassure them when they become frightened by a hallucination, but **remember that for them, the situation is real**. Offer to take care of whatever it is that is upsetting them.
- Allow them to pace in a quiet safe spot in the house.
- Give them time to calm down.
- Keep a positive, upbeat attitude because the person will pick up on it if you're upset

Calming Someone



Slide 33: Calming Someone

Narration: Calming Someone

Click the video below for further discussion and tips about calming a person who's upset.

Remember!

The important message is that the behaviors are not on purpose. The person is not trying to hurt, insult, or manipulate you.

Look at the person's behavior as a form of communication: *What are the behaviors telling you?*

Slide 34: Remember!

Narration: Remember!

The important message is that your loved one is NOT doing these behaviors on purpose. They are not trying to hurt, insult or manipulate you.

- Instead look at their behavior as a form of communication: *What are the behaviors telling you?*

Click on the video below to listen to an expert discuss this in more detail.

Finding Support



Finding Support - Video

35/40

Slide 35: Finding Support

Narration: Finding Support

The person will need more care as their dementia progresses. It will take more and more time and hard work to support their needs. At some point, they may need more support than you can easily provide. When this happens there are many places you can go to get the support they need.

Click on the video for a discussion on finding support.

Prevent Burnout and Stress

In another module, we'll talk about finding support for you as the person who gives care, including where you might find respite care for times when you need a break or have something you must do outside your home.

Talking to a Service Coordinator

You can always start with the service coordinator, who you can contact through the Area Office.

The service coordinator can help you find resources.

Slide 36: Finding Support, Cont.

Narration: Finding Support, Cont.

Prevent Burnout and Stress: In another module, we'll talk about finding support for you as the person who gives care, including where you might find respite care for times when you need a break or have something you must do outside your home.

Talking to a Service Coordinator: You can always start with the service coordinator, who you can contact through the Area Office. The service coordinator can help you find resources.

On the next slide, we'll share some links to these and other types of resources.

Resource Guide

Links:

- [NTG Screening Tool](#)
- [Dementia Screening and Diagnosis](#)
- [MassOptions](#)
- [After the Diagnosis](#)
- [Creating a Memory Cafe](#)
- [End of Life Planning](#)
- [MOLST Training Webinar](#)
- [Aging Information and Webinars](#)

Resources that Provide Support:

- [MA DDS, Family Support Center](#)
- [Mass Council on Aging](#)
- [Alzheimer's Association](#)
- [Your Local Aging and Disability Resource Consortia Agency \(ADRC\)](#)

The resource links on this slide are current as of 7/1/23 but may change over time as pages are updated. Please visit the organization site for the most current information.

Slide 37: Resource Guide

Narration: Resources

On this slide you will see the resource links that we have mentioned throughout this course. The Links will bring you to specific sites or documents that we referenced. The Resources that Provide Support will bring you to the websites listed.

The resource links on this slide are current as of July 1, 2023, but may change over time as pages are updated. Please visit the organization site for the most current information.

Let's Review!

Try this question to check your understanding
of Section Three

Slide 38: Let's Review: Section 3

Narration:

Let's Review! Try these questions to check your understanding of Section Three.

Multiple Choice

Even tasks that your family member used to do on their own may now be difficult. Which of the following is NOT helpful?

- Break the activity into smaller steps
- Use pictures or gestures to guide them through the activity
- Offer them a treat if they can remember how to do the task without any help

Submit

Slide 39: Section 3: Question 1

Narration: Multiple choice. Even tasks that your family member used to do on their own may now be difficult. Which of the following is NOT helpful?

Select your answer then click Submit, click it again to go to the next slide.

Congratulations! This is the end of the training.

Please click the “Exit Activity” button above to leave the training and go to the course homepage.



Slide 40: Course End

Narration: Congratulations! This is the end of the training.

Please click the “exit activity” button above to leave the training and go to the course homepage.