

Communication with a Person Living with IDD and Dementia_Family

Communication_Family Version

Communication with a Person Living with IDD and Dementia

For Families and Home-based Caregivers

Title Page

1/40

Slide 1: Title Page

Narration: Welcome to this course, Communication with a Person Living with IDD and Dementia. This is the third 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 communication in a person with dementia, and how communication will change as dementia progresses. You'll also learn practical steps to make communication easier for you and the person, as well as how to use various communication tools to ensure that the person has a good quality of life.

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!

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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

- Learn ways of communicating and their importance in caregiving
- Understand how communication changes as dementia progresses
- Using communication strategies to create a good quality of life

Slide 4: Learning Objectives

Narration: Learning Objectives

- Learn ways of communicating and their importance in caregiving
- Understand how communication changes as dementia progresses.
- Using communication strategies to create a good quality of life

Learning Objective 1:

Learn ways of communicating and their importance in caregiving

Slide 5: Learning Objective 1

Narration: Learning Objective 1:

Learn ways of communicating and their importance in caregiving

Communication is About Connection

- Communication is the key to all of our relationships
- In someone with ADRD the connections become more and more damaged within the brain
- It's the connections outside the person that allow them to maintain their relationships
- It contributes to a sense of meaning and well-being



Slide 6: Communication is About Connection

Narration: Section 1: Communication is About Connection

Communication is the key to all of our relationships whether with friends and family or with a store clerk or a person we care for. It's how we share information to let others know what we think and feel, what we want or need. And it allows us to understand what others think, feel and what they want or need.

Communication is about connecting with each other, and in someone with ADRD the connections become more and more damaged within the brain. It's the external connections – connections outside the person that allow them to maintain their relationships with you and other family members, as well as with other important people in their life. It contributes to a sense of meaning and well-being.

Listening

Use listening and observation skills to understand what someone is trying to tell you with words or actions

Words and Actions

Use words and actions to give information, ask questions or give directions in a way that the person understands

Other Methods

Communication is more than words; it includes facial expressions, gestures, and tone of voice as well

Slide 7: Communication and Caregiving

Narration: Communication and Caregiving

When caring for your loved one with dementia, good communication skills are essential. This means that you need to:

- Use listening and observation skills to understand what your family member is trying to tell you with words or actions.
- Use words and actions to give information, ask questions or give directions in a way that your family member understands.
- Communication is more than words; it includes facial expressions, gestures, and tone of voice because as the disease progresses words lose their meanings

Communication is Essential



Slide 8: Communication is Essential

Narration: Communication is Essential

Click on the video below to hear more about why Communication is so important.

Communicate with Respect



Slide 9: Communicate with Respect

Narration: Communicate with Respect

Before continuing, it's always worth a reminder that when interacting with your loved one – as with all aspects of caregiving – treat them with respect, compassion, patience, and understanding

Behavior as Communication

What is the person's behavior telling you?



Slide 10: Behavior as Communication

Narration: Behavior as Communication

In the training on behavior, you learned that the way a person acts tells you how they're feeling.

- It may seem obvious, but think about a person who is sitting calmly, in a relaxed position, with a smile on their face. This person is telling you with their body language that they are comfortable and content.
- But now think about a person who is pacing, grimacing, yelling, or refusing to participate in an activity. Their body language and actions are letting you know that something is wrong. Perhaps they're in pain, or afraid, or confused.



Interpreting the Behavior

- Dementia can affect someone's ability to communicate their needs
- They are more likely to use non-verbal - or non-speaking - ways to let you know that something is wrong
- Using good communication skills will help you maintain a good quality of life for the person by meeting their needs and wants

Slide 11: Interpreting the Behavior

Narration: Interpreting the Behavior

- As a caregiver, you need to read your loved one's behavior and try to figure out what's wrong - or at the very least try to reassure them or make them comfortable.
 - This can be challenging in someone with limited verbal – or speaking – skills.
 - This is true even in people who had good speaking skills in the past. Since dementia can affect someone's ability to speak and communicate their needs, they are more likely to use non-verbal – or non-speaking – ways to let you know that something is wrong. For example, they may become agitated or upset if something is bothering them.

This course will give you some practical steps you can use to make sure that you are communicating as effectively as you can with your loved one. Using good communication skills will help you maintain a good quality of life for the person, by meeting their needs and wants.

Let's Review!

Try this question to check your understanding
of Section One

Slide 12: Let's Review: Section 1

Narration: Let's Review! Try this question to check your understanding of Section One

Multiple Choice

Which of the following are examples of communication in a person with dementia?

- Crying
- Arguing or yelling
- Smiling
- All of the above

Submit

Slide 13: Section 1: Question 1

Narration: Multiple choice. Which of the following are examples of communication in a person with dementia?

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

Learning Objective 2:

Understand how communication changes as dementia progresses

Slide 14: Learning Objective 2

Narration: Learning Objective 2:

Understand how communication changes as dementia progresses

What to Expect as Dementia Progresses

Early Stage

Moderate Stage

Late Stage

Click on each tab to learn about the changes you may see in the way a person communicates as the dementia progresses.

This information is adapted from a table from the Alzheimer's Association.

Slide 15: What to Expect

Narration: Section 2: What to expect as the dementia progresses

Click on each tab to learn about the changes you may see in the way a person communicates as the dementia progresses. This table is adapted from information from the Alzheimer's Association.

Early Stage: In the early stages of dementia, you may notice the person has:

- Difficulty finding the right word.
- They may substitute other words or descriptions for the word they can't find.
- Difficulty following a conversation.
- Struggles to answer questions.
- Frustration may lead the person to become less talkative.
- And finally, a person who is bi-lingual may start using their first language.

Moderate Stage: In the moderate stages of dementia, you may find the person has:

- Further loss of vocabulary, or increased struggle to find the right word.
- Repeating questions and stories
- Difficulty understanding what is being said.
- Distressing physical behaviors may occur more often.

In the late stages of Alzheimer's disease, you may find that the person has:

- Little or no ability to express themselves in obvious or typical ways.
- Very little ability to understand and follow verbal instructions.

How can you Facilitate Communication?

As the person's dementia becomes worse, you will need to change the way you communicate with them.



Slide 16: How can you Facilitate Communication

Narration: How can you facilitate communication?

As the person's dementia becomes worse, their ability to communicate also becomes more and more difficult. You will need to change the way you communicate with them. In the next several slides, we'll discuss ways to do that.

Adapting Communication in the Early Stages of Dementia

Engage the person as much as possible. You can make communication easier and more effective in the early stages of dementia by:

- Asking how you can support the person's conversation and understanding
- Engaging the person directly
- Speaking clearly and waiting for responses
- Taking time to listen and understand the person's thoughts and feelings
- Reducing distractions as much as possible



Slide 17: Adapting Communication

Narration: Adapting Communication in the Early Stages of Dementia

Throughout the continuum and particularly in the early stages of dementia, it's important to engage the person as much as possible. Just because they have a diagnosis of dementia doesn't mean that they can't understand concepts, provide informed consent, or take part in decisions. You can make communication easier and more effective in the early stages of dementia by:

- Asking how you can support the person's conversation and understanding.
- Engaging the person directly and not through another person, such as another staff or family member
- Speaking clearly, and waiting for responses
- Taking time to listen and understand the person's thoughts and feelings.
- Reducing distractions as much as possible

These last two points are important at every stage but will become even more important for someone with moderate dementia.

Taking Time



Slide 18: Taking Time

Narration: Taking Time

Click on the video to get a better understanding of why it's important to be patient and take time to wait for responses.

Adapting Communication in the Moderate Stage of Dementia

To have a better chance of understanding the person, it always helps to:

- Reduce noise, commotion, and distractions
- Use visual supports that are easy to see
- Provide options for making the person comfortable



Slide 19: Adapting Communication

Narration: Adapting Communication in the Moderate Stage of Dementia

In order to make communication smoother once your loved one's dementia progresses, you'll use some of the strategies listed in the previous section – but you'll also need to provide even more support.

Let's start with a reminder about the environment - or setting.

As we learned in the Behavior course, your loved one will be more comfortable and will have a better chance of understanding what's going on around them if it's calm and quiet. It always helps to:

- Reduce noise, commotion, and distractions in the person's surroundings.
- Visual supports, such as pictures or symbols, should be clear and use contrasting colors that are easy to see.
- Provide options for making the person comfortable, such as keeping the room at a temperature that the person prefers, provide clothing or other comfort objects that you know the person prefers

Body Language and Tone of Voice



- Approach the person from the front
- Speak to them at eye level
- Position your body so that you appear calm and relaxed
- Use a calm tone of voice

Slide 20: Body Language, Tone of Voice

Narration: Body Language and Tone of Voice

How we speak to someone conveys as much information as the words we say. Body language – or the way we position our body and how loud or soft we speak, for example, can affect how our words come across.

- Some tips to help make communication easier include:
 - Approach the person from the front, speak to them at eye level, and position your body so that you appear calm and relaxed.
 - Use a calm tone of voice

Communication Tips



Slide 21: Communication Tips

Narration: Communication Tips

Click on the video to hear more tips about using body language and tone of voice to help you communicate.



Adapting your Language

- Speak slowly and clearly
- Use short sentences
- Use language and words that may be unique to the person.
- Adapt how you ask questions:
 - Short answer - yes/no questions
 - Ask one question at a time
 - Wait for an answer before moving on

Slide 22: Adapting your Language

Narration: Adapting Your Language

In general, it helps to speak slowly and clearly, and use short sentences, but you'll also need to adapt the way you ask questions and give instructions.

Use language and words that may be unique to the person. For example, if the person calls the bathroom "the john" that's the word you should use.

When you ask questions:

- Use short answer questions with simple answers, such as yes or no.
- Ask one question at a time.
- And as you've already heard, wait for an answer before moving on.

Giving Instructions

- Break task into small steps
- One step at a time
- Use visual cues, such as:
 - Picture cards or photos
 - Written steps
 - Gestures
 - Assistance



Slide 23: Giving Instructions

Narration: Giving instructions

When you give instructions, break down the task into small steps, and go one step at a time.

It helps to use visual cues or communication aids, such as:

- Picture cards or photos that are large enough for the person to see and understand.
- If your loved one can recognize words, you can try using written steps.
- And you can use gestures, like pointing or demonstrating, or give assistance with getting a task started.

Gestures and Demonstrations



Slide 24: Gestures and Demonstrations

Narration: Gestures and Demonstrations

For more information and examples, click on the video.

In Later Stages

The person may become less consistent in their ability to speak or understand sentences and words.

Use gestures and physical assistance to help them through tasks.

Sensorimotor

Sensorimotor based actions have more meaning. That means using things people can see, hear, feel, smell, or taste.

Helpful Tips

Observe closely to see what the person wants or needs.

Consider using DisDat, a tool that helps communicate distress.

Slide 25: Late Stage

Narration: Late Stage

- In the later stages of dementia your loved one may become less consistent in their ability to speak in sentences or recall words.
- They will also start to lose their ability to follow directions or understand what you say. You will likely rely on gestures and physical assistance to help them through tasks.
 - Sensorimotor based actions have more meaning. That means using things people can see, hear, feel, smell or taste.
- And you will need to become a careful observer to see what they want or need. Discomfort is an important sense to be communicated. Use the Life Story to understand what's normal for the person and consider using DisDat, which is a tool that uses a person's baseline to communicate distress. See the link on the resources page for more information about this tool.



Continue to Make Connections

Remember:

- Continue to speak to the person respectfully, calmly, and clearly
- Seek alternative ways to make connections
- The part of our brain that governs our emotions is intact until very late
- Connection on an emotional level through a feeling tone is how we keep connected

Slide 26: Continue to Make Connections

Narration: Continue to Make Connections

Even throughout the latest stages of dementia, personal connections will remain important. Continue to speak to your loved one respectfully, calmly, and clearly. And seek alternative ways to make a connection with them.

The part of our brain that governs our emotions is intact until very late in the continuum. Connection on an emotional level through a feeling tone (voice, pace, compassionate expression in your whole body) is how we keep connected.

We'll discuss some more ways to do this in the next section.

Let's Review!

Try these questions to check your understanding of Section Two

Slide 27: Let's Review: Section 2

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

True/False

When a person first receives a diagnosis of dementia, it means they are no longer able to provide informed consent.

- True
- False

Submit

Slide 28: Section 2: Question 1

Narration: True or False. When a person first receives a diagnosis of dementia, it means they are no longer able to provide informed consent.

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

Multiple Choice

Alice is not responding when you call her for dinner. It could be because

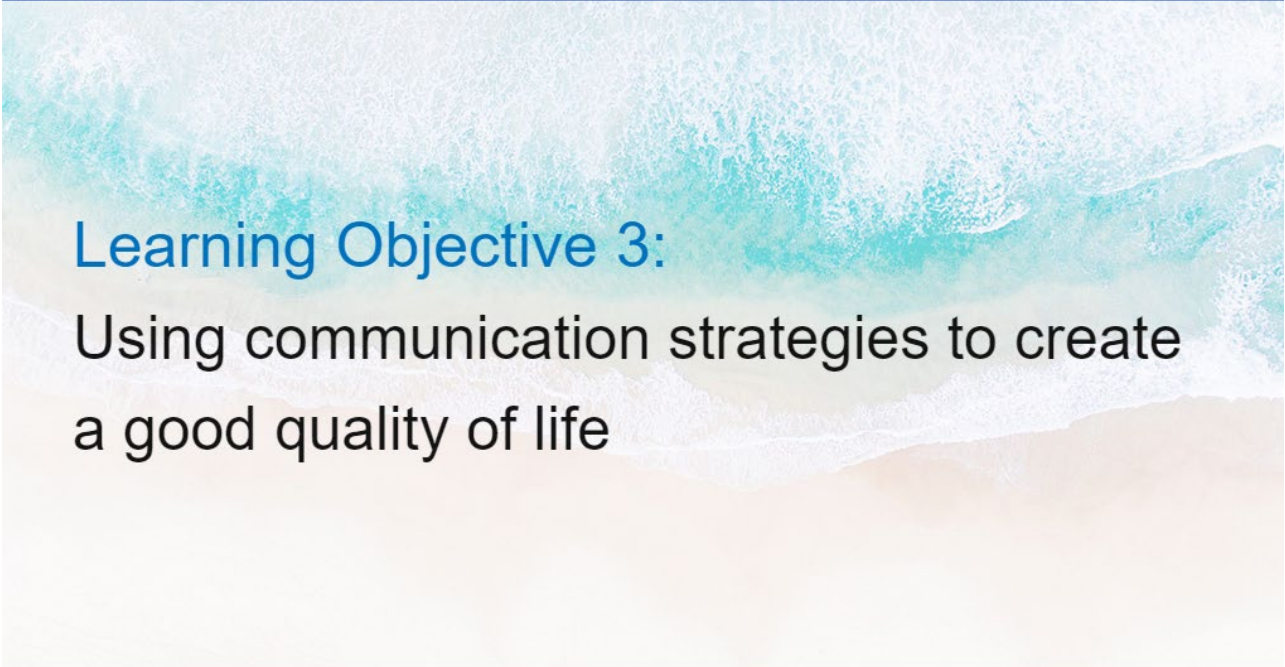
- Her hearing aids are not in correctly
- The room is too noisy
- You aren't facing directly in front of her
- All of the above

Submit

Slide 29: Section 2: Question 2

Narration: Multiple Choice. Alice is not responding when you call her for dinner. It could be because...

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



Learning Objective 3:

Using communication strategies to create a good quality of life

Slide 30: Learning Objective 3

Narration: Learning Objective 3: Using Communication Strategies to Create a Good Quality of Life

The Bigger Picture



Making connections with the person is one of the most fundamental things you can do to facilitate a meaningful day and good quality of life.

Slide 31: The Bigger Picture

Narration: Section 3: The Bigger Picture

Beyond the practical steps you can take to facilitate communication at every stage, consider the bigger picture. One of your roles is to create a meaningful life for your loved one. Making connections with them (or on their behalf) is one of the most fundamental things you can do to facilitate a meaningful day and good quality of life. When speaking and understanding skills start to decline, there are many other ways to communicate with someone, and bring them joy and meaning.

Connections with Peers

Choose shared activities that:

- Are encouraging and upbeat or happy
- That everyone will be able to participate in - like music and art
- Are preferred activities



Slide 32: Connections with Peers

Narration: Connections with Peers

The activities mentioned above are great for connecting with your loved one, but they're also good ways to help your loved one to remain connected with other family members or friends.

You should choose shared activities that are positive, encouraging and upbeat, or happy and that everyone will be able to participate in – like music and art or a special food.

And choose preferred activities for your family member – that is do things that you know they once enjoyed, and hopefully still enjoy.

Memory Cafes



Slide 33: Memory Cafes

Narration: Memory Cafés

Many communities offer Memory Cafés, which are regular meetings for caregivers and their loved ones. Art, music, food and other activities are offered, and are meant to provide a way for you to connect in a supportive group setting.

See the link in the Resource Section for more information.

Other Ways of Making Connections



Slide 34: Other Ways of Making Connections

Narration: Other Ways of Making Connections

There are many ways you can connect with the person beyond just words we may not necessarily think of as communication. But things like art activities, music, food, or movement are very effective ways to reach the person with dementia. Click on the video to learn about some creative options that encourage connections with the person.

Life Story



Slide 35: Life Story

Narration: Life Story

Telling a story about someone's life is one of the most powerful ways to tell others about who the person is. It paints a complete picture of what they've done, where they've been, their experiences, and their personality – really – it tells who they are. It's also a powerful way to revisit parts of the person's life with the person and be both calming and affirming.

Click on the video to learn more about Life Stories.

Let's Review

Instead of a quiz, try this Think About It Activity for Section 3



Slide 36: Think About It

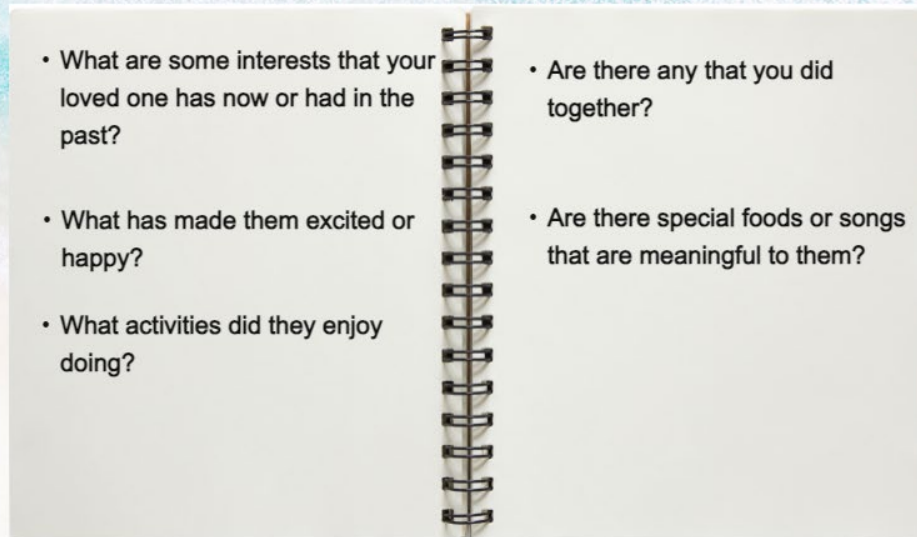
Narration: Let's Review

Instead of a quiz, try this Think About It Activity for Section 3

Finding ways to connect with someone with dementia helps to ensure a good quality of life. And as we've just discussed, that doesn't have to be through speaking. For this last review, you'll think about some of the ways you can communicate with your loved one beyond using words.

On the next page, use the questions to help you think about ways to make connections.

Think About It Activity



Slide 37: Think About It

Narration: Think About It Activity

What are some interests that your loved one has now or had in the past? What has made them excited or happy?

What activities did they enjoy doing? Are there any that you did together?

Are there special foods or songs that are meaningful to them?

Using some of these ideas, think of activities that you could share with your loved one that could help you create a meaningful connection.

When you've thought of some ideas, click on the arrow to the next page, where you'll see some suggestions for what might be included in your answer.

Think About It: Answer



Slide 38: Think About it: Answer

Narration: Think About It: Answer

There are so many possibilities that you might have included in your answers.

Click the little blue left and right arrows to scroll through some of the ideas that you may have thought of, and maybe you'll get ideas about some others.

- Consider activities that they once enjoyed, such as gardening, art or cooking. Offer the opportunity to create simple art projects, plant a garden, or cook a meal together.
- Perhaps a walk outside to look at flowers and nature.
- Think about things that come from family and cultural traditions that are familiar and important to you and your family member. Honoring the person's religious or spiritual traditions and practices may also bring comfort.
- Offer favorite foods. Texture and smell are two senses that can be engaged through food.
- Play favorite songs or music from when they were young.
- Look at photos of friends, family and familiar places.

Many of these failure free activities can be easily modified as the person's dementia progresses.

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](#)
- [DisDAT Comparison Tool](#)

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 39: Resource Guide

Narration: Resource Guide

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.

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.