

Understanding and Recognizing Dementia and IDD_Family

Understanding and Recognizing Dementia_Intro_Famil

Understanding and Recognizing Dementia in IDD

For Families and Home-based Caregivers

Title Page

1/43

Slide 1: Title Page

Narration:

Welcome to this course on Understanding and Recognizing Dementia in IDD for families and home-based caregivers. This is the first in a series of courses, webinars, and trainings designed to provide practical information on dementia in people with intellectual and developmental disabilities – or IDD.

The purpose of this first course is to give you an overview of what dementia is – what to look for, what you can expect, and a few tips on how to help you and your family member or person you care for adapt to 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.
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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 is 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 use 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 your 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

- Increase knowledge about ADRD in individuals with IDD
- Learn to recognize changes in individuals with IDD
- Introduce strategies for caring for a person with IDD and ADRD

Slide 4: Learning Objectives

Narration: Learning Objectives

The learning objectives for this course are as follows:

- Increase knowledge about ADRD in individuals with IDD.
- Learn to recognize changes in individuals with IDD.
- Introduce strategies for caring for a person with IDD and ADRD

Learning Objective 1:

Increase knowledge about ADRD in individuals with IDD

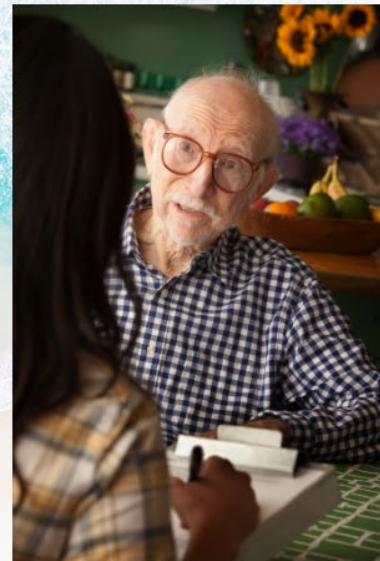
Slide 5: Learning Objective 1

Narration:

Learning Objective 1: Increase knowledge about ADRD in individuals with IDD

What is Dementia?

Dementia is a word that describes several diseases and disorders that occur in the fully formed adult brain.



Slide 6: What is Dementia?

Narration: What is Dementia?

Dementia is a word that describes several diseases and disorders that occur in the fully formed adult brain. The one we usually think of is Alzheimer's disease, but there are other types of dementia. Some of the more common types you might hear about are: Vascular dementia, Lewy body dementia, or Frontotemporal dementia. It's possible for a person to have more than one type of dementia, and in the early stages it's difficult to know which type of dementia the person has.

Most dementias are due to diseases. Other causes of dementia may be due to trauma to the brain such as a head injury or chronic alcoholism.

What difference does it make to know what type of dementia your family member has? It helps you understand what to expect as the disease or disorder progresses, but it also will help health care providers give the correct care to the person.

Common Types of Dementia

Please click on each of the buttons below to read about the most common types of dementia.

| | |
|---------------------|-------------------------|
| Alzheimer's Disease | Vascular Dementia |
| Lewy Body Dementia | Frontotemporal Dementia |

Alzheimer's Disease Symptoms include:

- Memory loss
- Confusion
- Language difficulty
- Anxiety
- Mood changes

Individuals with Down syndrome have an increased risk of developing Alzheimer's

Slide 7: Common Types of Dementia

Narration: Common Types of Dementia

Please click on each of the buttons below for a description of four of the more common types of dementia.

- Alzheimer's disease
 - Symptoms include memory loss, confusion, language difficulty, anxiety, and mood changes. Individuals with Down syndrome have an increased risk of developing Alzheimer's.
- Vascular dementia
 - Sometimes called 'post-stroke' dementia. Symptoms include memory loss, impaired judgment, loss of motivation and planning skills, and difficulty with language.
- Lewy Body dementia
 - Symptoms include sleep disruption, changes in alertness, confusion, difficulty with language and numbers, and having hallucinations. Later the person may have memory loss and movement problems.
- Frontotemporal dementia
 - Symptoms include emotional and behavioral changes, rather than memory loss. A person will not have memory or cognitive loss until the disorder progresses to the later stages.



Common Signs and Symptoms

The key symptom is CHANGE from how the person usually is.

- Changes in how a person
 - Acts
 - Thinks
 - Speaks
 - Moves
- Memory Loss

Slide 8: Common Signs and Symptoms

Narration: Common Signs and Symptoms

Each type of dementia has different symptoms, but they also have some symptoms in common. The key symptom is CHANGE from how the person usually is.

- The most common symptoms are changes in how a person behaves or acts, changes in the way a person thinks or speaks, and even changes to the way a person moves, such as how a person walks.
- In most dementias, there will also be memory loss, but that's not the main symptom in every type of dementia.



Dementia is Progressive

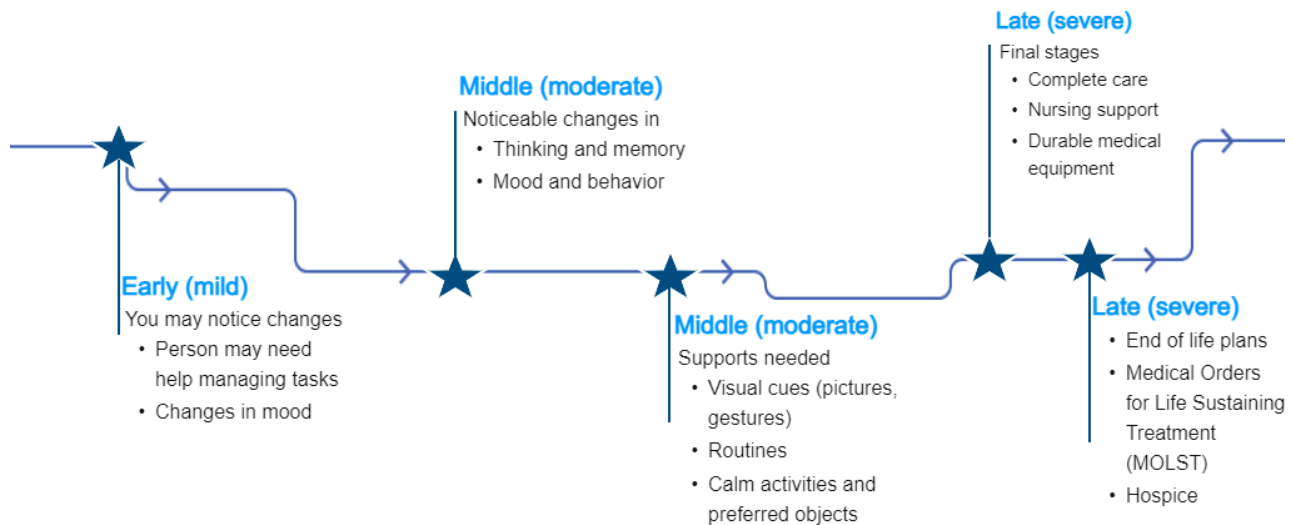
- Progressive
 - Loss of functioning over time
- There are no cures
- The most effective treatment we currently have is the way we provide care
- There are stages of Alzheimer's disease
 - Understanding what to expect at each stage will help in planning

Slide 9: Dementia is Progressive

Narration: Dementia is Progressive

- Each disease is progressive. This means that the person will lose functioning over time. You can expect to see them lose some of the skills they once had – skills like managing their own medication, using public transportation, or getting dressed – just as a couple of examples.
- There are no cures for dementia.
 - Some medications might slow the progression.
 - The most effective treatment we currently have is the way we provide care - by understanding how dementia can affect someone and using that understanding to guide care that is specific to that particular person.
- The progression of Alzheimer's disease is broken down into different stages. While there will be good days and bad days, remember that it will continually get worse over time.
- Understanding what to expect at each stage can be helpful for planning – and anticipate the supports the person is likely to need and when they'll need them.

Stages of Alzheimer's Disease



Slide 10: Stages of Alzheimer's Disease

Narration: Stages of Alzheimer's Disease. What can you expect at each stage?

Early or mild Alzheimer's Disease

- This is when you might start noticing changes, and your family member may need help in managing everyday tasks that they used to do independently. You may also start seeing mood changes— especially as your family member senses something is changing within them – something doesn't feel right - but they can't figure out what it is.

Middle or moderate Alzheimer's Disease

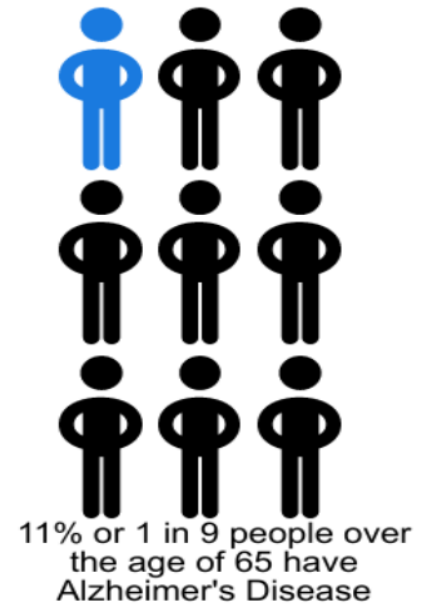
- At this stage, changes in thinking and memory become very noticeable, and the person will need more support in managing daily tasks. This is also when you'll notice more behavior changes. They may get upset more easily as they become increasingly confused. Supports that the person needs at this stage may include visual cues to help them complete an activity (some examples would be using picture cards or using gestures like pointing or acting out a step in an activity), setting routines or schedules, offering calming and pleasant activities or objects when the person is upset.

Late or severe Alzheimer's Disease

- In the final stages of Alzheimer's disease, the person will require complete care. At this stage, nursing support and (durable) medical equipment may be needed. You and the person's medical team may discuss end-of-life plans, such as Medical Orders for Life Sustaining Treatment (MOLST), or hospice.

Age and Dementia

- In Massachusetts, about 6% of people served by the Department of Developmental Services (DDS) have a diagnosis of ADRD in their health care record.



Slide 11: Age and Dementia

Narration: Age and Dementia

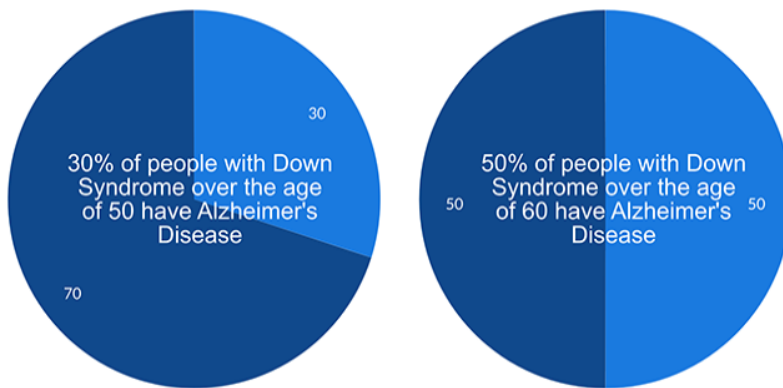
Dementia is a disease of older age.

- According to the Alzheimer's Association, over 11% of people over 65 years old currently have Alzheimer's disease.

In Massachusetts, about 6% of people served by the Department of Developmental Services have some form of dementia.

From what the research shows, dementia doesn't appear to affect people with IDD at any greater rate than people without IDD. The exception is people with Down syndrome.

Down Syndrome and Alzheimer's Disease



- People with Down syndrome are more likely to have Alzheimer's disease than someone without Down syndrome
- Age of onset happens at an earlier age

Slide 12: Down Syndrome and Alzheimer's Disease

Narration: Down Syndrome and Alzheimer's Disease

Assessment and care strategies for any person with IDD and dementia is based on the specific needs of that person, so whether or not your family member has Down syndrome doesn't matter as much as what their individual needs are. That being said, we'll spend a moment to take a closer look at Alzheimer's disease in people with Down syndrome, because they are at a higher risk of developing Alzheimer's disease.

Down syndrome is caused by genetic changes that occur in the earliest stages of development before birth. It is these same genetic changes that make a person with Down syndrome more likely to get Alzheimer's disease.

- The Alzheimer's Association estimates that:
 - 30% of people with Down syndrome over the age of 50 have Alzheimer's disease.
 - 50% of people with Down syndrome over the age of 60 have Alzheimer's disease.

For people with Down syndrome, the age of onset – when it begins – can happen when the person is in their early 50s. This is earlier than for most other people.



Risk Factors for Dementia

Other than age, factors that may raise a person's risk include:

- Smoking
- Drinking heavily
- Health factors, such as obesity, high blood pressure, and diabetes
- Having a traumatic brain injury
- And as we've said, genetic issues which includes Down syndrome

Slide 13: Risk Factors for Dementia

Narration: Risk Factors for Dementia

Scientists are trying to determine what may put someone at risk for developing dementia. Other than age, factors that may raise a person's risk include:

- Smoking
- Drinking heavily
- Health factors, such as obesity, high blood pressure, and diabetes
- Having a Traumatic Brain Injury
- And as we've just said, genetic issues which includes Down syndrome

Ways to Keep Healthy

Speak to the person's health care provider about ways to keep healthy

- Eat nutritionally healthy food and drink and maintain healthy weight
- Screen and maintain healthy blood pressure
- Screen and control diabetes
- Stop smoking and limit alcohol
- Speak to a health care provider about physical activity
- Get adequate sleep
- Encourage social interactions and meaningful activities
- Manage stress
- Keep well visits up to date



Slide 14: Ways to Keep Healthy

Narration: Ways to Keep Healthy

Although dementia is a progressive condition, people are living with it for sometimes many years. We need to help the person with dementia live as healthy a life as possible. None of these will cure dementia, but they may help relieve some symptoms and will promote a better quality of life.

Speak to the person's health care provider about ways to keep healthy, for example.

- Eat nutritionally healthy food and drink and maintain a healthy weight.
- Screen and maintain healthy blood pressure.
- Screen and control diabetes
- Stop smoking and limit alcohol.
- Speak to a health care provider about physical activity such as exercise, which is known to relieve some symptoms.
- Get adequate sleep.
- Encourage social interactions and meaningful activities that you know the person enjoys and reduces their stress.
- Keep well visits up to date.

Let's Review!

Try these questions to check your understanding of section one

Slide 15: Let's Review: Section 1

Narration: Let's Review!

Try these questions to check your understanding of Section One.

True/False

Dementia is a disease that forms in the brain before birth.

- True
- False

Submit

Slide 16: Section 1: Question 1

Narration: True or False? Dementia is a disease that forms in the brain before birth.

Press the Submit button after you select your answer, then click it again to go to the next slide.

True/False

There is currently no cure for dementia, and it will get worse.

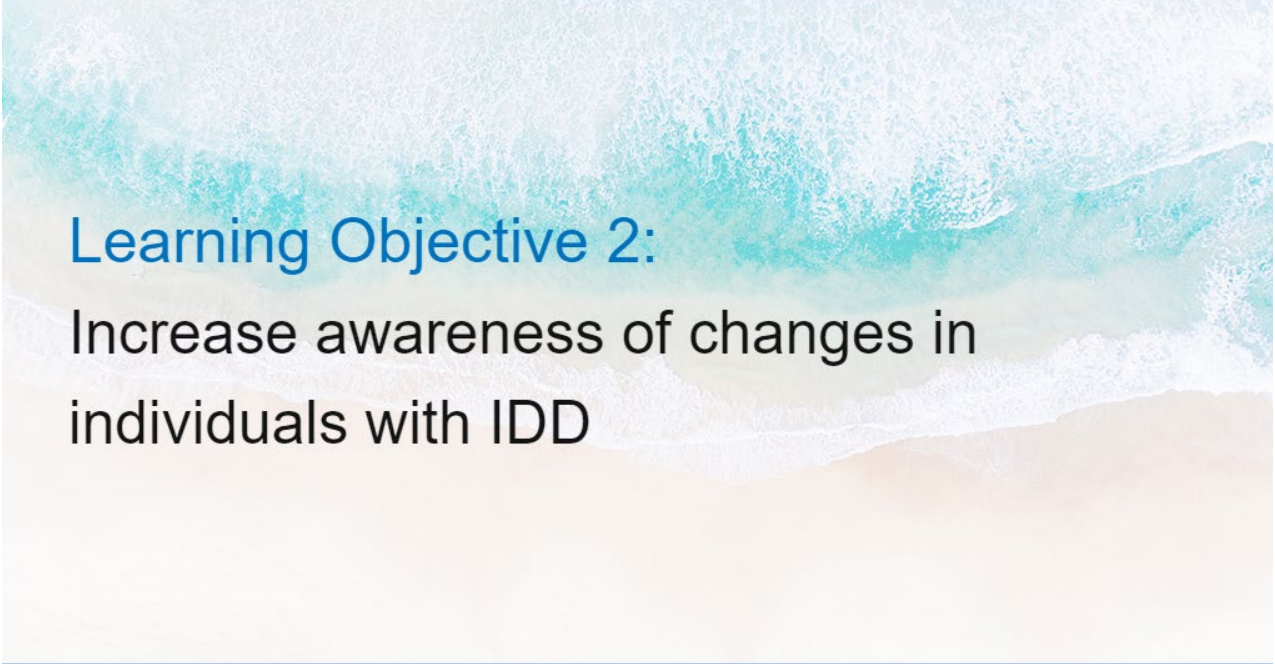
- True
- False

Submit

Slide 17: Section 1: Question 2

Narration: True or False? There is currently no cure for dementia, and it will get worse over time.

Press the Submit button after you select your answer, then click it again to go to the next slide.



Learning Objective 2:

Increase awareness of changes in individuals with IDD

Slide 18: Learning Objective 2

Narration:

Learning Objective 2: Increase awareness of changes in individuals with IDD

Noticing Changes



Everyone will experience changes as they grow older.

Take note and follow-up:

- Sudden changes not typical for the person
- Interferes with quality of life
- NTG - Early Detection and Screen for Dementia (NTG-EDSD) tool

Slide 19: Noticing Changes

Narration: Noticing Changes

Everyone will experience changes as they grow older, and people with IDD are no different than anyone else in this way.

When should you be concerned?

- It's time to take note and follow up with the person's medical provider or service coordinator when changes are:
 - Sudden
 - Not typical for the person
 - Some things you may notice include unusual behavior, changes in mood, loss of memory or forgetfulness, or changes in physical functioning – or how they use their body to do things like walk or eat, for example.
 - Interfering with the person's quality of life, which means that the person is no longer able to do the things they once were able to do or enjoyed.
- When life becomes difficult for the person or they are unhappy, it is time to seek help. Especially when the changes are sudden. There are tools that may help you measure how someone is doing or functioning. See the NTG screening tool in the resource section.
- The more information you can provide to the health care provider, the better they can figure out what's causing the problem.

Make Notes About Changes

1

WHAT

What specific behaviors do you notice? Just the facts of what you observed.

2

WHEN

When did you first start to notice the change?

3

HOW

How are new behaviors different from what you know about the person?

Slide 20: Make Notes About Changes

Narration: Make Notes About Changes

As we said in the earlier slide, it's important to make notes about changes that concern you. Your observations will help the health care provider in making a diagnosis.

- **WHAT:** What specific behaviors do you notice? Just the facts of what you observed.
- **WHEN:** When did you first start to notice the change?
- **HOW:** How are new behaviors different from what you know about the person?

This is especially important when your family member is being seen – or assessed - for dementia by a new health care provider. A health care provider may not be aware of how the person usually acts, how they speak, or what their typical mood was before any changes.

Sudden Changes

Any changes that occur abruptly or suddenly should be reported right away.

Not all changes are due to dementia. Some may be caused by a condition that can be treated, so it's very important to talk to the medical provider about sudden changes.

Gradual Changes

Changes that occur gradually will be harder to notice at first, but it's important to remember how the person was typically.

Take Note

Make a note of when you first started noticing changes.

Slide 21: Sudden Changes

Narration: Sudden Changes

- We can't emphasize enough that any changes that occur abruptly or suddenly should be reported right away.
 - Not all changes are due to dementia. Some may be caused by a condition that can be treated, so it's very important to talk to the medical provider about sudden changes.
 - Some things as simple as a buildup of ear wax could make someone appear to be non-responsive, and yet it's easily treatable. Not all changes would be this simple, and this is just one example.
- Changes that occur gradually will be harder to notice at first, but it's important to remember how the person was typically.
- Make a note of when you first started noticing changes

Changes you may notice

Behavior and Mood

Memory and Cognitive Function

Physical Function

Late Stage Alzheimer's Disease

Changes in **behavior and mood** (How the person acts or seems)

- You may notice new sadness
- The person may become unusually excited or overly happy or giddy
- The person may become hostile or angry when you don't expect it
- The person may become easily agitated and act out
- They may lose motivation for activities they usually enjoy

Slide 22: Changes you may notice

Narration: Changes You May Notice

What are some changes that you might observe in someone with possible dementia? Click on each of the topics below to see more examples.

Changes in behavior and mood (How the person acts or seems). In the early stages you may see some mood changes as your family member is sensing some of the changes happening within them. The more significant changes won't appear until the moderate stage of dementia.

- You may notice new sadness.
- The person may become unusually excited or overly happy or giddy.
- The person may become hostile or angry when you don't expect it.
- The person may become easily agitated and act out.
- They may lose motivation for activities that they usually enjoy.

Changes in memory and cognitive function (How the person remembers, thinks, or understands things). Some of these changes could be signs of the aging process, but when they begin to interfere with the person's life, you should take note.

- The person may forget names or recent events or even things they've started to do or work on
- They may struggle to find words that they usually know.
- They may repeat questions and stories.

In the moderate stage of dementia, in addition to the changes above, you may also see the following:

- They may become easily confused and have difficulty following routines.
- They might “hear” or “see” things that aren’t there.
- They may require support with performing tasks, including ones that were once familiar.
- Their capacity to learn new skills may diminish in the later stages of dementia.

Changes in physical function (How the person moves or uses their body). Many of these changes won’t appear before the moderate stage of dementia.

- You may notice changes in the way the person moves or walks.
- They may have difficulty performing physical tasks, such as laundry, eating, or bathing.
- The person’s sleep patterns, or schedule may change.

Changes you’ll notice in late-stage Alzheimer’s disease:

- They may have difficulty speaking or understanding what is said.
- They may be unable to walk independently.
- They may be unable to feed, dress, and bathe themselves.
- They may have accidents as they lose control of their bladder and bowels.
- Their mood may become withdrawn.

Now What?



Talk to:

- Case Manager or Service coordinator
- Area office nurse
- Agency nurse
- Health Care Provider
- Department of Developmental Services (DDS)

The person's health care provider can evaluate and refer to a specialist, if necessary. In the Resource Guide, you'll find a link to an additional resource:

- [Dementia Screening and Diagnosis](#)

If the person is not connected to the DDS system, you can call MassOptions

Slide 23: Now What?

Narration: Now What?

You've noted concerns and talked to the person's health care provider, case manager or service coordinator. What can you expect to happen next?

Every program and agency will have its own guidelines. In addition, the Massachusetts Department of Developmental Services (DDS) has guidelines. Your case manager or service coordinator, area office nurse or agency nurse can help start the process of referral and evaluation. The person's health care provider can evaluate the person for conditions that may be causing the symptoms, and they can also make a referral to a specialist. You can also reach out to DDS.

See the link in the resource section for more information on Dementia Screening and Diagnosis

If the person is not connected to the DDS system, you can call MassOptions. The link for that is also in the resource section.

Let's Review!

Try these questions to check your understanding of section two

Slide 24: Let's Review Section 2

Narration: Let's Review!

Try these questions to check your understanding of Section Two.

Multiple Choice

Lenny misplaces his keys every now and again. What is a reasonable response?

- Some forgetfulness may be expected as a person ages, so ignore it.
- Some forgetfulness may be expected as a person ages, but make a note to see if it happens more and more often
- Make an appointment with a specialist because all forgetfulness is a concern

Submit

Slide 25: Section 2: Question 1

Narration: Multiple Choice. Lenny misplaces his keys every now and again. What is a reasonable response?

Press the Submit button after you select your answer, then click it again to go to the next slide.

True/False

Any changes that occur abruptly or suddenly should be reported right away.

- True
- False

Submit

Slide 26: Section 2: Question 2

Narration: True or False? Any changes that occur abruptly or suddenly should be reported right away.

Press the Submit button after you select your answer, then click it again to go to the next slide.

Learning Objective 3:

Introduce caring strategies for a person with IDD and ADRD

Slide 27: Learning Objective 3

Narration:

Learning Objective 3: Introduce caring strategies for a person with IDD and ADRD

How to Support a Person with Dementia

- Create meaningful and comfortable life experiences
- Support brain and physical health with a healthy lifestyle

It's equally important to remember that a person diagnosed with dementia doesn't lose their rights as a result of the diagnosis. You'll need to protect the person's dignity and make sure they have a good quality of life

How do you Protect the Person's Dignity?

Person-centered planning:

- Support plans are written with as much participation of the person as possible
- Provide activities that are meaningful and enjoyable
- Don't focus on new skills, but on maintaining current skills and comfort
- After the Diagnosis - see link in the Resource Guide

Slide 28: How to Support a Person with Dementia

Narration: Section 3: How to support a person with dementia.

While the person with dementia continues to live at home, it's important to create meaningful and comfortable life experiences with activities they usually enjoy, positive social interactions, and a healthy lifestyle that supports brain and physical health.

It's equally important to remember that a person diagnosed with dementia doesn't lose their rights as a result of the diagnosis. You'll need to protect the person's dignity and make sure they have a good quality of life.

Person centered planning means that the person is involved in their support planning, and their wishes and preferences are honored to the greatest extent possible. Planning, specifically regarding dementia needs, should start when a dementia is suspected.

- The service coordinator will make sure that the support plans are written with as much participation of the person as possible.
- Provide activities that are meaningful and enjoyable.
- Focus on supporting and maintaining skills they currently have, rather than on learning new ones.
- And have goals that maintain a good quality of life and makes the person feel comfortable.

See the link After the Diagnosis in the resource section for more information on planning.

Relationships Matter



Slide 29: Relationships Matter

Narration: Relationships Matter

The relationship between you and the person will be a source of comfort and support. You can also encourage relationships with other extended family, friends and people in the community. There are a number of practical actions you can take. Click on the blue buttons on the slide for some suggestions.

- Make Connections. Find creative ways for you and the person to connect, such as through art, music, or familiar foods.
 - If the person is comforted by and accepts gentle touch from you, that may be reassuring also.
- Life story album. Create a “Life Story” album or photographs and stories from your family member’s life that will:
 - Encourage conversations.
 - Help calm the person by remembering familiar people or experiences.
 - Help any new helpers coming into the home get to know the person.
- Memory Café. See if there is an inclusive Memory Café that serves people with IDD and dementia in your area. Memory Cafés are regular social meetings where people with dementia share activities with friends and family in a dementia friendly social setting.

REMEMBER that just because the person's brain is increasingly unable to make connections, we are making connections with the person - and those connections matter!

Slide 30: Remember

Narration: Remember

Remember that just because the person's brain is increasingly unable to make connections, we are making connections with the person – and those connections matter!

Health and Safety



Protect the person's health, comfort, and safety

- The home is free from hazards
- Eyeglasses are clean and the correct prescription
- Hearing aids are used correctly
- Keep all health care appointments
 - Get clear instructions
- Install helpful supports in the home
- Safely store medications

Slide 31: Health and Safety

Narration: Health and Safety

Protect the person's health, comfort, and safety.

- Make sure your home is free from hazards, such as poor lighting, clutter, and loud noise.
- Make sure that eyeglasses are clean and are the correct prescription, and hearing aids are used correctly, if needed
- Make sure that you keep health care appointments, including allied health services such as OT, PT and Speech services.
 - Make sure your health care provider gives you clear instructions on medications and care.
 - Have them write down instructions so you have them on hand.
- Install helpful supports such as handrails, and try using shower chairs, or utensils that are easy to grip.
- Safely store medications so that your family member doesn't accidentally take more than they should

Supporting Derek



Slide 32: Supporting Derek Video

Narration: Supporting Derek

Please watch the video below from the United Kingdom. It gives you a sense about what your family member's experience might be like in a busy environment.

Video Discussion



Slide 33: Video Discussion

Narration: Video Discussion

In the video, did you notice how Derek was feeling? What did it look like to you? What was Derek hearing? Seeing? Feeling? And how did he respond?

Now think about what would have made things easier.

Reducing noises. Reducing clutter and busy patterns in the room. Speaking calmly and directly to the person. Giving limited choices. Supporting the person with cues. These are all ways to help the person understand what you are trying to say.

On the next slide, you will see some more guidelines.

Ways to Support Communication



Slide 34: Ways to Support Communication

Narration: Ways to Support Communication

Use the little left and right arrows below to go through some different examples.

Ways to communicate. To help the person understand conversations and directions, it helps to:

- Provide visual supports, such as pictures or diagrams and
- Break tasks into small steps.

The environment – your home, the room, the place where the person lives and works.

- Minimize distractions in the environment.
 - Reduce clutter and objects or patterns that will distract the person.
 - For example, in the video, there were bright patterns on the rug that Derek found distracting. If you have area rugs, try having solid or soft colors.
 - Reduce noise.
 - Don't have the TV and radio going at the same time.
 - Try to reduce loud noises.
 - Don't try to talk over lots of background noise.

Speaking to the person. How you talk to the person is really important

- Speak to the person calmly and with respect.
 - Approach the person from the front and make eye contact.

- Use a calm tone of voice.
- Use clear and simple language.

Giving choices. Make choices easy for the person:

- Ask only one question at a time.
- Give failure free choices. What is that? This means that whichever choice the person makes, it will be the correct one.
- Here are a couple of examples:
 - Example 1: It's important for the person to drink fluids, and you should offer drinks during the day. But instead of asking, "Are you thirsty? Or "What would you like to drink? Instead ask, "Would you like orange juice or apple juice?"
 - Example 2: You're going out on a chilly day, instead of asking the person to choose something warm to wear, show them two coats and have them choose one

Provide support. Support the person when they need to complete a task. Even things they used to be able to do, like brushing their teeth, may become difficult for them.

- Provide visual supports, such as pictures or diagrams.
 - These are things like picture cards, posters, or photographs or pointing, demonstrating an activity.
- Break tasks into small steps
 - It helps to give specific directions in small steps – here's an example.
 - Instead of asking someone to "go wash your hands" you would walk them to the sink and ask them to turn on the water. Then you would tell them to get their hands wet, put soap on their hands and lather, then ask them to rinse, turn the water off – and so on. You give step-by-step directions from start to finish. You might even have to give more help by pointing to the soap or imitating lathering your hands for example.



Providing Comfort and Assurance

- Schedule activities earlier in the day
- Reinforce predictable routines
- Don't question or argue with the person when they say something that is incorrect
- Reassure the person when something frightens them
- Distract the person with a pleasant activity using a calm voice

Slide 35: Providing Comfort and Assurance

Narration: Providing Comfort and Assurance

To help relieve the discomfort or danger of behavior distress, it helps to:

- Schedule activities earlier in the day
- Reinforce predictable routines, including daytime routines and bedtime routines.
- Don't question or argue with the person when they say something that is incorrect.
- Reassure the person when something frightens them – even if it's only an imagined fear or vision.
- When the person becomes agitated or upset, distract them with a pleasant activity using a calm voice.

Plan for the Future



Protect the person's rights and financial interests

- Health care proxy and health care agent
- Guardian or conservator
- Discuss end-of-life care
 - Hospice
 - Advanced directives, such as Five Wishes
 - Service Coordinators and Area Office Nurses have these forms
 - End of life medical orders, such as Medical Order for Life Sustaining Treatment (MOLST)
 - End of Life planning - link in the Resource Guide

Slide 36: Plan for the Future

Narration: Plan for the Future

Plan for the person's future so that you're protecting their rights and financial interests. Talk to the service coordinator to see what might be the most appropriate options, but here are options you may need to consider.

- Use a health care proxy to appoint a health care agent if that's an appropriate option.
- Talk to the service coordinator to see if it's necessary to appoint a guardian or conservator if a health care proxy is not already in place.
- While it can be difficult to think about, it's important to plan ahead and discuss end-of-life care. Speak to your provider, the Service Coordinator, or Area Office Nurse about options, such as:
 - Hospice
 - Advanced directives, such as Five Wishes. Service Coordinators and Area Office Nurses have these forms.
 - End of life medical orders (in Massachusetts, work with the medical provider to put a Medical Order for Life Sustaining Treatment - or MOLST - in place)

See the Resource Guide for more information on End-of-Life Planning

It may help to remember that it's the dementia that causes the changes in the person. They're unable to control their behavior and mood. They're not deliberately trying to annoy or hurt you.

Slide 37: Taking Care of You

Narration: Taking Care of You

It can be physically and emotionally demanding to take care of a person with dementia. There are resources available to you that we'll list in the resource section of this training.

It may help to remember that it's the dementia that causes the changes in the person. They're unable to control their behavior or mood. They're not deliberately trying to annoy or hurt you.

Seek Support

Organizations that can
Provide Support

Prevent burn out and stress

Talking to service coordinator

Organizations that can Provide Support

- Massachusetts Executive Office of Elder Affairs, Family Resource Support Program through MassOptions
- Massachusetts Department of Developmental Services, Family Support Center
- Mass Council on Aging
- Alzheimer's Association
- Your local Aging and Disability Resource Consortia agency (ADRC)

Slide 38: Seek Support

Narration: Seek Support

Seek supports from both formal and informal sources. It's important to manage your stress. By taking care of yourself, you'll be able to better care for your family member. Click on the blue boxes on the left to learn more.

- There are organizations that can provide support, such as information on referrals, or respite services. We'll provide links to these organizations, as well as other resources in the Resource Guide for this course. We'll also talk more about this in future trainings.
 - Massachusetts Executive Office of Elder Affairs, especially the Family Resource Support Program through MassOptions
 - Massachusetts Department of Developmental Services, Family Support Center
 - Mass Council on Aging
 - Alzheimer's Association
 - Your local Aging and Disability Resource Consortia agency
- There are informal ways to help prevent burn out and stress, such as reaching out to other family and friends, or your religious community, if you have one, for help and support.
- Make sure you feel comfortable talking to the service coordinator, health care providers and anyone else helping to care for the person.

Let's Review!

Try these questions to check your understanding of section three

Slide 39: Let's Review Section 3

Narration: Let's review!

Try these questions to check your understanding of Section Three.

True/False

It's not important to do social activities with a person with dementia because they won't remember it anyway.

- True
- False

Submit

Slide 40: Section 3: Question 1

Narration: True or False? It's not important to do social activities with a person with dementia because they won't remember it anyway.

Press the Submit button after you select your answer, then click it again to go to the next slide.

Multiple Choice

What is a good way to support communication so that the person can understand you better?

- Make eye contact
- Use visual cues
- Give the person simple choices
- Speak in a calm voice
- All of the above

Submit

Slide 41: Section 3: Question 2

Narration: Multiple Choice. What is a good way to support communication so that the person can understand you better?

Press the Submit button after you select your answer, then click it again to go to the next slide.

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 42: 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 43: 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.