

Adapting Services to Preserve Quality of Life_Staff

Quality of Life_Staff

Adapting Services to Preserve Quality of Life For Staff and Paid Caregivers

Title Page

1/37

Slide 1: Title Page

Narration: Welcome to this course, Adapting Services to Preserve Quality of Life
This is the last in a series of webinars and trainings designed to provide practical information on dementia in people with intellectual and developmental disabilities – or IDD.

This course gives you an overview of ways to adapt how you care for someone with IDD to make sure they have a good quality of life as their dementia worsens and until their passing.

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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- And the speaker button will mute the audio.

Learning Objectives

- Understand what the term *good quality of life* means
- Understand how to adapt services and care in order to preserve a person's quality of life

Slide 3: Learning Objectives

Narration: Learning Objectives

- Understand what the term *good quality of life* means.
- Understand how to adapt services and care in order to preserve a person's quality of life.

Learning Objective 1:

Understand what the term *good quality of life* means

Slide 4: Learning Objective 1

Narration: Learning Objective 1:
Understand what the term *good quality of life* means.

What is Quality of Life?

Common Themes:

- Happiness
- Comfort
- Security



Slide 5: What is Quality Life

Narration: What is Quality of Life?

What does it mean to have a good quality of life? There are many ways to define it, but across definitions there are some common themes: Quality of life is often considered a measure of a person's happiness, comfort, and security.

The Diagnosis

Just because a person has dementia doesn't mean that their quality of life will get worse.

Adapting

Adapt how you provide care to maintain the person's quality of life.

Slide 6: Maintaining Quality of Life After Diagnosis

Narration: Maintaining a Good Quality of Life After Diagnosis

Life is dynamic and we're always changing and adapting. It's important to point out that just because someone has dementia doesn't mean that you should expect their quality of life to get worse. As the person's functioning changes, caregivers will need to adapt ways of doing things with and for the person in order to maintain their quality of life. This is your main role as a caregiver. This training, like previous trainings in the series, will suggest ways of adapting how you care for someone to ensure they have a good quality of life.

Quality of Life for Someone with IDD and Dementia

For this course, we'll use six outcomes that care teams in Massachusetts consider when they create someone's individual support plan - the ISP.

Click on each outcome for a brief explanation, including how dementia might impact each one.

Rights and Dignity

Everyone has the right to be treated with dignity and respect.

- To live as they choose
- To get support they need as dementia progresses

No.1

No.2

No.3

No.4

No.5

No.6

Slide 7: Quality of Life for Someone with IDD and Dementia

Narration: Quality of Life for Someone with IDD and Dementia

For this course, we'll use six outcomes that care teams in Massachusetts consider when they create someone's individual support plan, or the ISP.

Click on each outcome for a brief explanation, including how dementia might impact each one.

Rights and Dignity: Everyone has the right to be treated with dignity and respect. Everyone in your care has the same rights as anyone not receiving care, such as visiting with friends and family, to live as they choose, in a safe place, to be part of a community, and to get services they need, including the medical care and support services they need as their dementia progresses.

Individual Control: Everyone has the right to make choices about their life as much as possible. You need to explain options in a way that the person understands and support the person's decisions about their care as much as possible. When they are unable to make decisions, a court-appointed guardian or health care proxy can make decisions for them in accordance with their wishes and preferences.

Community Membership: Everyone has the right to have experiences in their community. This means seeing people beyond family or friends, if they choose, and to visit places such as parks, restaurants, and places of worship. The person may need support to maintain engagement in the community as their dementia worsens.

Relationships: Relationships with family members and friends, housemates and co-workers are important, and every effort should be made to support these relationships as the person's memory

worsens. In early stages, supportive relationships, such as those found in a support group might be helpful.

Personal Goals and Accomplishments: Personal goals and accomplishments. In general, goals can include things like independence in self-care, learning to manage money, using transportation, and working at a job. These types of goals will change as the person's dementia progresses, and the emphasis will be on providing activities that are meaningful and enjoyable for the person, as well as supporting the person's independence in daily living skills for as long as possible.

Health, Safety, and Financial Security: It's important to provide medical care, dementia-related services, good nutrition and any other care to maintain the person's health and mobility. Their environment should be free from hazards and their physical needs should be met in order to prevent injury. Finally, they should be supported to manage their finances, and plans must be made to ensure that someone will handle finances once the person is unable to do so.

Dementia Does Not End Rights



Everyone has basic rights that must be respected, and a dementia diagnosis does not end those rights.

Slide 8: Dementia Does Not End Rights

Narration: Dementia Does Not End Rights

In the previous slide we discussed the six outcomes to consider when planning someone's supports, but in many ways each one comes back to rights and dignity. Everyone has basic rights that must be respected, and a dementia diagnosis does not end those rights. Work with the whole team, as well as the person you serve, to adapt how you maintain those rights, and at every stage, make sure the changes you make are the least restrictive options you can use and still keep the person safe, comfortable, and happy.

Let's Review!

Try these questions to check your understanding of Section One

Slide 9: Let's Review: Section 1

Narration: Let's review! Try these questions to check your understanding of Section One.

True/False

When someone has dementia their quality of life may decline if caregivers do not adapt ways to support the person.

- True
- False

Submit

Slide 10: Section 1: Question 1

Narration: True or False. When someone has dementia their quality of life may decline if caregivers do not adapt ways to support the person.

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

True/False

As the person's dementia progresses, goals should continue to reflect learning new daily living skills and increased independence.

- True
- False

Submit

Slide 11: Section 1: Question 2

Narration: True or False. As the person's dementia progresses, goals should continue to reflect learning new daily living skills and increased independence.

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

Learning Objective 2:

Understand how to adapt services and care in order to preserve a person's quality of life

Slide 12: Learning Objective 2

Narration: Learning Objective 2:

Understand how to adapt services and care in order to preserve a person's quality of life.



Protecting Rights and Dignity

Remember, through every stage of the person's dementia, you must treat the person with respect and dignity. This means making sure that they're getting the services and support they need to live a happy, comfortable and safe life.

Slide 13: Protecting Rights and Dignity

Narration: Protecting Rights and Dignity

In the previous section we learned about areas to address in giving someone a good quality of life. But how do we adapt goals, services, and our interactions to make sure we do this? We can start with Protecting Rights and Dignity.

Remember: Through every stage of the person's dementia, you must treat the person with respect and dignity. This means making sure that they're getting the services and support they need to live a happy, comfortable, and safe life.

Protecting Rights Following a Diagnosis



Slide 14: Protecting Rights Following a Diagnosis

Narration: Protecting Rights Following a Diagnosis

When you first start to notice changes in the person's functioning, behavior, or communication, it's important to keep notes and seek a medical evaluation. Not all changes are related to dementia, and a thorough evaluation will help determine possible causes.

Once the diagnosis is made, you'll support the person's involvement in their care as much as possible, by explaining information to them in a way that they understand, answer their questions, and listen to their preferences. When restrictions of rights need to be made in order to protect the person, you may need to contact your agency's human rights committee.

Protecting Rights Day to Day

On a day to day basis, honoring someone's dignity means:

- Speaking respectfully to them
- Giving them privacy - as long as it's safe
- Offer failure-free choices
 - As decision-making gets more difficult, you can adapt how you offer choice



Slide 15: Protecting Rights Day to Day

Narration: Protecting Rights Day to Day

On a day-to-day basis, honoring someone's dignity means:

- Speaking respectfully to them.
- Giving them privacy – as long as it's safe - when they're dressing, showering, or using the bathroom.
- Offering choices in things like what they wear, who they see, what activities they want to do, and what they want to eat.
- As decision-making gets more difficult for the person, you can adapt how you offer choice, by offering failure-free choices.
 - In the communication course, we described an example: if it's a chilly day, ask the person if they'd like to wear their blue or red sweater. This offers choice, yet with limited options, it's not overwhelming. It respects dignity, but also may reduce distress.

Supporting Individual Control

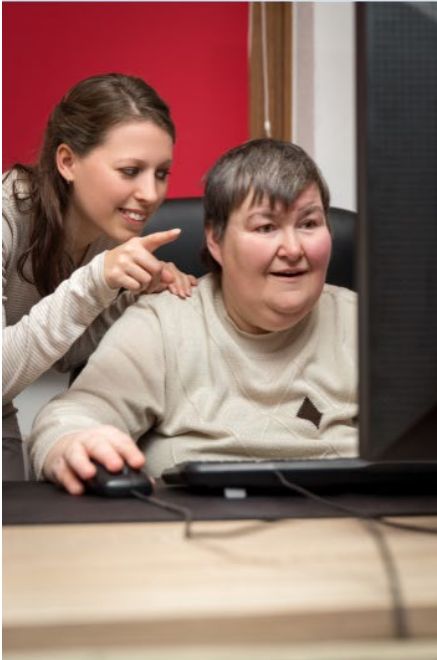
As the person becomes less able to make decisions on their own, someone will need to help the person make decisions, and eventually someone will need to take over decision-making on their behalf.



Slide 16: Supporting Individual Control

Narration: Supporting Individual Control

It's hard to separate the right of individual control from basic rights and dignity as discussed on the previous page. As the person you care for becomes less able to make decisions on their own, someone will need to help the person make decisions, and eventually someone, such as a guardian, will need to take over decision-making on their behalf.



Supporting Decision-Making

If a person understands and is capable of expressing needs and wants, support them in planning for the future:

- Discuss the person's wishes for future care
- Create advanced directives
- Appoint a health care proxy
- Consider guardianship if the person is no longer capable of making informed decisions

Slide 17: Supporting Decision Making

Narration: Supporting Decision-making

Some specific ways you can support individual control is to support their decision making.

Major decisions:

If someone is in the early stages of dementia, and they're capable of expressing their needs and wants, work with them to create care plans, make medical and financial decisions, and advanced directives – such as Five Wishes. See an agency or area office nurse or service coordinator for more information on advanced directives. Also, consider having the person name a health care proxy.

A health care proxy is a proactive action that is less restrictive and supports the person's choices and values. It needs to be done when the person can still make decisions. The person can name one or more people to make decisions on their behalf if they become incapacitated. If a health care proxy has not been named, and the person is no longer able to make informed decisions, then a guardianship may be needed.

Guardianship

1

Guardians are

Appointed by a judge

2

Authorized

to make decisions on behalf of the person

3

Family

members are not automatically appointed

Slide 18: Guardianship**Narration:** Guardianship

A guardian is court-appointed by a judge. This guardian is authorized to make major life decisions on behalf of someone who is incapable of making decisions, as determined after a court hearing. It's important to note that family members do not automatically become guardians.

A judge must issue the guardianship decree before the guardian can make major decisions on the person's behalf. Speak to the service coordinator to learn more about the process. See a link to a Guardianship webinar in the resources page.

Supporting Individual Control Day to Day

- Involve the person in day-to-day decisions
- Give the person control over their life
- Speak clearly using language the person understands when giving choices or directions



Slide 19: Supporting Individual Control Day to Day

Narration: Supporting Individual Control Day to Day

Involve the person in their day-to-day care and routines in a way that gives people some control over what they do. Make sure you use communication skills, such as speaking clearly and using language the person understands when giving choices or directions. The key point is to include the person in as much as possible.

Consider the Person's Experience



Slide 20: Consider the Person's Experience

Narration: Consider the Person's Experience

As you help the person understand their choices and make sense of the world around them, consider what the person is experiencing. Listen to this video that discusses this more in detail.



Supporting Community Membership

There's no need for the person to stop enjoying activities in the community:

- When offering opportunities for community outings consider the person's preferences
- You may need to support the person if they become overwhelmed or agitated in certain environments
- Look for dementia-friendly options for activities in your community

Slide 21: Supporting Community Membership

Narration: Supporting Community Membership

There's no need for the person to stop enjoying activities in their community.

- When offering community outings consider the person's preferences, including activities they enjoyed in the past.
- Support the person if they become overwhelmed or agitated in certain environments. For example, if the person wants to go to a favorite restaurant, you can go at a less busy time. Or perhaps a person wishes to go to mass – go on a weekday when the service tends to be shorter and less crowded.
- Look for dementia-friendly options for activities in your community. These are places where efforts are made to support the needs of people with dementia. Some examples are Memory Kits in your local library, Purple Table Reservations at restaurants. See the resource section for more information.

Supporting Relationships

- Caregivers will need to work hard to facilitate relationships
- Find alternative ways of communicating
- Help others maintain their relationship with the person



Slide 22: Supporting Relationships

Narration: Supporting Relationships

As memories fade and communication becomes more difficult, caregivers will need to facilitate relationships that are important to the person. You may need to find alternative ways of communicating, for example through music and art, revisiting the past through photographs, traditions, and preferred foods. Effective communication strategies will be key to supporting the person.

You may also need to help peers and housemates maintain their relationships. As the person changes, they may need help in understanding how to interact with their friends.

The Importance of Emotional Connections



Slide 23: The Importance of Emotional Connections

Narration: The Importance of Emotional Connections

It's very important to remember that just because communication and cognitive skills decrease doesn't mean that emotional connections become less important. Emotions are felt until the very latest stages of dementia and providing emotionally supportive care and comfort helps ensure a good quality of life for the person. Listen to the video for further explanation and ways to support emotional care.

Adapting Personal Goals and Accomplishments



The focus of goals for work, learning, and daily living will shift to maintaining skills as much as possible.

Slide 24: Adapting Personal Goals and Accomplishments

Narration: Adapting Personal Goals and Accomplishments

Goals for work, learning, and daily living skills will shift. As people enter the moderate and later stages of dementia their capacity to learn new skills gradually diminishes. This is true especially for the later stages. Some people may be able to adapt and learn new routines: For example, where their new bedroom is or how to fasten a new pair of shoes. But to expect someone to learn and accurately perform new skills, for example, how to use the computer, if they've never done that - or cook using new utensils or on an unfamiliar stove, may cause them and their caregivers a lot of frustration. At this point, the focus will shift to maintaining the skills that they do have.

Supporting Skills and Encouraging Independence

- Speak slowly and clearly
- Break tasks into small steps
- Use gestures, pictures, and assistance
 - Don't assume that a person is unable to take care of him or herself
- Have set routines
- Keep the environment quiet, calm, and free of distractions



Slide 25: Supporting Skills and Encouraging Independence

Narration: Supporting Skills and Encouraging Independence

In previous trainings, we've discussed strategies to support a person's behavior and daily living routine and behavior, as well as effective ways to communicate. Some of the ways we've discussed include:

- Speaking slowly and clearly
- Breaking tasks into small steps
- Using gestures, pictures, and assistance so that the person doesn't get frustrated as they complete a task, such as toothbrushing or getting dressed.
 - On the other hand, don't assume that a person is unable to take care of him or herself. Things may take longer, and they might need assistance, but encourage independence, as much as possible without making them discouraged.
- Setting routines will help, as will keeping the environment quiet, calm, and free of distractions.

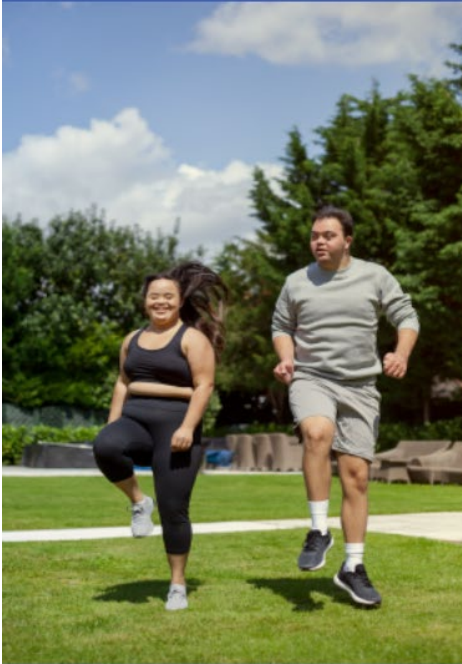
The Meaningful Day



Slide 26: The Meaningful Day

Narration: The Meaningful Day

As the person's dementia progresses, they will likely stop participating in work or in a day program. This doesn't mean that they should stop activities. Quite the opposite! The challenge for caregivers will be to find activities that the person enjoys and makes them happy. Providing engaging, pleasant activities brings joy, allows people to share experiences, and also provides mental stimulation. Watch this video to learn more about a meaningful day.



Protecting Well-Being: Health

- Keep medical appointments, vaccinations, and wellness visits
- Provide occupational, physical, and speech therapy, if needed
- Maintain vision and hearing care, including:
 - Keeping glasses clean and hearing aids in working condition
- Provide good nutrition and hydration
- Make sure the person gets good sleep
- Encourage physical activity and safe movement
- Provide mental stimulation

Slide 27: Protecting Well-being: Health

Narration: Protecting Well-being: Health

A dementia diagnosis doesn't mean that all other health care stops. A healthy life helps the person have a good quality of life.

Some specific things you can make sure to support include:

- Keeping medical appointments, vaccinations, and wellness visits
- Provide necessary allied health services to promote functioning. These include occupational, physical, and speech therapy.
- Maintaining vision and hearing care, including keeping glasses clean and hearing aids in working condition
- Providing good nutrition and hydration
- Making sure the person gets good sleep.
- Encouraging physical activity and safe movement
- Providing mental stimulation through activities that are interesting and pleasing for the person.

End of Life Care

In general, a person is the most comfortable at home, so it's important that the person remain at home as long as possible, ideally through the end of life



Slide 28: End of Life Care

Narration: End of Life Care

In general, a person is the most comfortable at home, so it's important that the person remain at home as long as possible, ideally through the end of life. This may require extra supports as the person's physical needs increase, especially toward very late-stage dementia. Keep notes about how much care the person requires, as this documentation will be helpful as your supervisor makes staffing decisions. The team might consider comfort supports such as hospice and palliative care.



Protecting Well-Being: Safety

The home should:

- Be clean
- Be free of tripping hazards
- Have adequate lighting, heating, and cooling
- Have adaptive equipment to support the person's safety and functioning

Slide 29: Protecting Well-being: Safety

Narration: Protecting Well-being: Safety

Living safely at home and in the community is important to ensuring the person's quality of life.

The person's home should:

- Be clean.
- Be free of tripping hazards, such as clutter, loose cords, or area rugs.
- Have adequate lighting, heating, and cooling.
- Have adaptive equipment to support the person's safety and functioning, for example ramps on stairs, grab bars in the bathroom, or adaptive eating utensils.

Safety: Weighing Rights vs. Risk

When restrictions are needed to protect the person, you need to weigh the loss of rights and personal choice against risk.

Consider what can be done to ensure safety with the fewest restrictions possible.

Some strategies include:

- Provide failure free choices
- Allow the person to pace in a safe, quiet area
- Maintain a calm environment
- Reduce demands, especially at the end of the day

Slide 30: Safety: Weighing Rights vs. Risk

Narration: Safety: Weighing Rights vs. Risk

When restrictions are needed to protect the person, you need to weigh the loss of rights and personal choice against risk. Some common examples include:

- Special diets due to choking risk.
- New supervision when the person can't use public transportation.
- Restricted movement due to wandering.
- Behaviors are putting others at risk.
- Consider what can be done to ensure safety with the fewest restrictions possible. In previous trainings, we've discussed how to address distressing behavior to minimize risk. Some strategies include:
 - Provide failure free choices.
 - Allow the person to pace in a safe quiet area.
 - Maintain a calm environment.
 - Reduce demands, especially at the end of the day.

Listen to a video that discusses more about risk

Appoint a Guardian

It's important that a guardian is appointed to ensure that someone will handle finances once the person is unable to do so.

Financial Decisions

Some financial decisions that will need to be managed include:

- Bank accounts and possessions
- Bills and expenses
- Medical insurance
- Social security

Remember

A judge must appoint a guardian before they can make financial decisions on the person's behalf. Speak to the service coordinator to learn more about the process.

Slide 31: Protecting Well-being: Financial Security

Narration: Protecting Well-being: Financial Security

Everyone has the right to have possessions, money, and to manage their finances. As the person loses the ability to manage their money, someone will need to support the person. If the person is capable, involve him or her in plans for their finances, including who they want to handle their financial decisions. Whether or not the person is able to participate, it's important that a guardian is appointed to ensure that someone will handle finances once the person is unable to do so. Some financial decisions that will need to be managed include:

- Assets or bank accounts and possessions.
- Bills and expenses
- Medical insurance
- Social Security

Remember a judge must appoint a guardian before they can make financial decisions on the person's behalf. Speak to the service coordinator to learn more about the process.

Let's Review!

Try these questions to check your understanding of Section Two

Slide 32: Let's Review: Section 2

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

Multiple Choice

Which of the following is NOT an example of respecting someone's dignity?

- Make day-to-day decisions for the person, such as what to wear or what to eat
- Caregivers the individual is comfortable with should assist with activities such as bathing or toileting
- Give only as much assistance as is necessary for the person to complete a task
- Speak clearly or use visual cues to help the person understand their choices

Submit

Slide 33: Section 2: Question 1

Narration: Multiple choice. Which of the following is NOT an example of respecting someone's dignity?

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

True/False

When a person is no longer capable of making major decisions for themselves, the service coordinator appoints a family member as legal guardian.

- True
- False

Submit

Slide 34: Section 2: Question 2

Narration: True or False. When a person is no longer capable of making major decisions for themselves, the service coordinator appoints a family member as legal guardian.

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

Wrap Up

- Maintaining a good quality of life for the person requires a team effort
- Keep the focus on the person
- Honor the person's feelings
- Try to understand what they're experiencing
- Respect the person and their life story, their preferences, and their dignity

Slide 35: Wrap Up

Narration: Wrap up

Maintaining a good quality of life for the person will require a team effort involving the family, agency staff, peers, the community, and the person. And yet, remember to keep the focus on the person, keeping them at the center of the planning. As we've stressed throughout these trainings, good communication will be key to smooth planning as the person's dementia transitions from stage to stage. Honor the person's feelings, try to understand what they're experiencing, and honor their experience. Most importantly respect the person and their life story, their preferences, and their dignity.

Resource Guide

Links:

- [Purple Tables](#)
- [Adapting to Age-Related Changes](#)
- [Aging Information and Webinars](#)

Guardianship Webinars

- [Part 1](#)
- [Part 2](#)

Resources that Provide Support:

- [MA DDS, Family Support Center](#)
- [Dementia Friendly America - MA](#)
- [Mass Council on Aging \(MCOA\)](#)
- [JFCS Memory Resources](#)

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 36: 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 37: 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.