

Self-Care and Support for the Caregiver_Family

Caregiver Support_Family Version

Self-Care and Support for the Caregiver

For Families and Home-based Caregivers

Title Page

1/24

Slide 1: Title Page

Narration: Welcome to this course, Self-Care and Support for the Caregiver

This is the fourth in a series of courses/webinars/trainings designed to provide practical information on dementia in people with intellectual and developmental disabilities – or IDD. In this course, you'll learn more about the experience of caring for a family member with IDD and dementia. While caregiving can be stressful, there are also moments of joy and strength. This course will discuss positive aspects of caregiving as well as some of the challenges and provide resources for reducing stress - including self-care tips and seeking support from others.

Welcome!

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

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

Slide 2: Welcome and Instructions

Narration: Welcome!

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

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

Learning Objectives

- Build confidence as a caregiver
 - Recognize the positive aspects of caregiving
 - Develop self-care strategies
 - Identify challenges for caregivers
- Learn about coping strategies around grief for both the caregiver and others (other family members, house mates, peers)

Slide 3: Learning Objectives

Narration: Learning Objectives

In this training we'll shift the focus to you, the caregiver. You play a vital role in the life of your loved one and taking care of yourself will benefit you and the person you're caring for.

This training aims to help you build confidence as a caregiver including:

- Recognizing the positive aspects of caregiving
- Developing self-care strategies and
- Identifying challenges for caregivers

Also, learning about coping strategies around grief for both the caregiver and others (other family members, housemates, and peers)

Section 1:

Recognize the positive aspects of caregiving

Slide 4: Section 1

Narration: Section 1: Recognize the positive aspects of caregiving

Attitudes Towards Caregiving



Slide 5: Attitudes Towards Caregiving

Narration: Attitudes Towards Caregiving

The caregiving experience will be different for each person. You may experience positive feelings, such as satisfaction, love, and confidence, but you may also experience negative feelings, such as frustration, fatigue, and grief. We hope that as you work your way through this module, you'll recognize and strengthen the positive aspects of caring for your family member with dementia, but also learn ways to prevent or reduce stress and discomfort from more difficult situations.

Positive Aspects of Caregiving



Slide 6: Positive Aspects of Caregiving

Narration: Positive Aspects of Caregiving

While we often focus on the difficulties that caregivers face, there are many opportunities for favorable and fulfilling experiences. Watch the video to hear about one family's experience that highlights some of the positive aspects of being a caregiver.

Positive Aspects of Caregiving - Cont.

- Honoring the importance of caring for family
- Strengthening family and community bonds
- Feeling confident that you're doing something positive
- Caring for a family member makes life worth living by giving it meaning and purpose



Slide 7: Positive Aspects of Caregiving – Cont.

Narration: Positive Aspects of Caregiving – Continued

We've just heard that caring for your loved one can bring you closer as you make connections and share time together, and there's satisfaction from knowing your loved one is cared for and happy. Here are some other ways that caregiving can be a gratifying and positive experience:

- Honoring the importance of caring for family
- Strengthening family and community bonds
- Feeling confident that you're doing something positive, and
- Caring for a family member makes life worth living by giving it meaning and purpose

Think About It

Reflection on positive aspects of caregiving



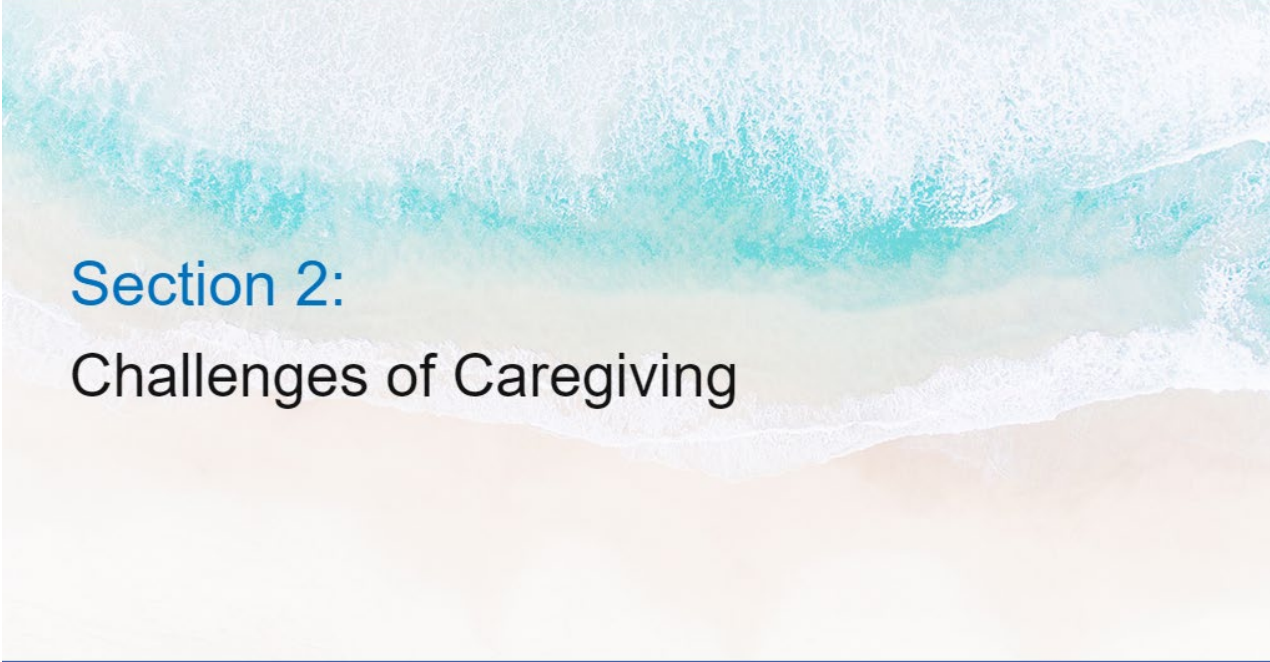
Think About It 1

8/24

Slide 8: Think About It 1

Narration: Think About It

In this section, we want you to stop for a moment and reflect on an activity that you could enjoy with your family member. Maybe it's something you do every week, such as going out to lunch. Or maybe it's just watching a favorite show on TV. Do these small moments help you feel connected?



Section 2: Challenges of Caregiving

Slide 9: Section 2

Narration: Section 2: Challenges of Caregiving

Difficulty of Caregiving



Slide 10: Difficulty of Caregiving

Narration: Difficulty of Caregiving

While caregiving can be affirming, it can also be difficult and often stressful for many reasons. Listen to one family discuss what they found difficult.

Physical

- Fatigue
- Loss of sleep
- Physical caregiving burden
- Not accessing your own health care

Social and Emotional

- Feelings of grief and loss
- Loss of personal time
- Social isolation
- Family conflict

Logistic

- Financial burden
- Future planning
- Difficulty accessing care
- Lack of training/education on how to care
- Not knowing what to expect

Slide 11: Demands of Caregiving

Narration: Demands of Caregiving

Reports from caregivers indicate that there are several aspects of caregiving that are difficult. There are physical demands of caring for someone, such as helping bathe or feed them. There are emotional demands, such as dealing with a sense of loss or managing difficult behaviors, and there are demands that are related to logistics or coordination of needs. Here are some more examples:

- Physical demands of caregiving, especially in the later stages can include:
 - Fatigue, loss of sleep, and delaying your own health care.
- Emotional demands of caregiving can include:
 - Dealing with feelings of grief and loss
 - Managing difficult behaviors and other frustrating situations
 - Feeling socially isolated
 - Experiencing fear of the unknown or not knowing what's to come, and
 - In cases where family members disagree with each other about care, the conflict can be stressful.
- And finally, there are demands and difficulties in managing the care of the person. These may include:
 - Not being able to access care for the person.
 - Even when you have access to care, it can be difficult to manage and understand the system of care.
 - Not knowing how to care for the person.
 - Financial burden
 - Planning for the future, including who can take over if you become unable to care for your loved one

Grief and Loss



Slide 12: Grief and Loss

Narration: Grief and Loss

In the previous page, we mention dealing with grief and loss. We often think of grief coming once the person has died, however with dementia you may experience grief in stages. As the disease progresses, it may seem that you are slowly losing your family member. For example, in the later stages, your loved one may not remember important memories in your history together. They may even forget who you are. These losses can be painful, and you may feel grief. Listen to one family member's story of the grief of watching someone decline.

Self-Check

Which of the following may lead to caregiver stress?

- Not knowing how to care for the person
- Family conflict over caregiving
- Behaviors of the person with dementia may be difficult to manage
- All of the above

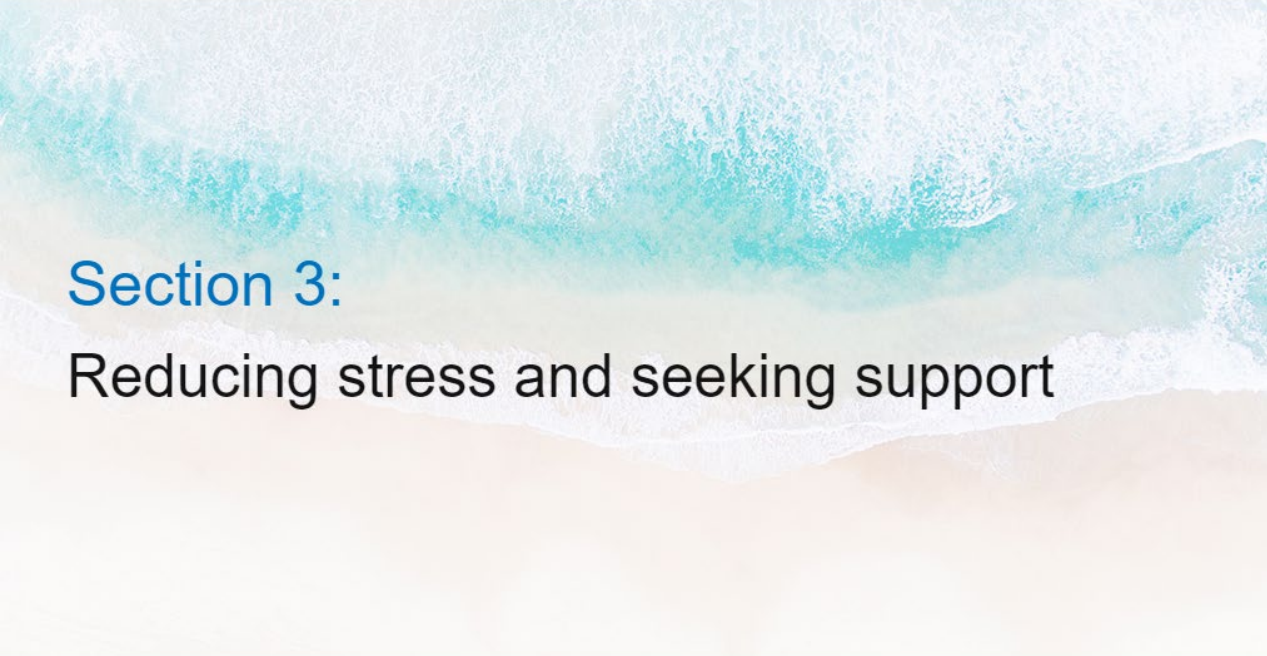
Submit

Slide 13: Self-Check

Narration: Self-check

Which of the following may lead to caregiver stress?

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



Section 3: Reducing stress and seeking support

Slide 14: Section 3

Narration: Section 3: Reducing Stress and Seeking Support

Reducing Stress in Caregiving



Slide 15: Reducing Stress in Caregiving

Narration: Reducing Stress in Caregiving

While it can be difficult and stressful to care for your loved one, there are ways to reduce the stress.

These range from learning about care to setting up plans for the future, but also personal or self-care activities and seeking support from others. Getting yourself informed and organized is one way of reducing stress.

Listen to the video for some advice on how to help manage when you first take over caring for your family member.

What is Self-Care?

Self-Care is protecting your own well-being and happiness, particularly during times of stress. It includes taking care of your own physical, emotional, mental, spiritual and social health.



Slide 16: What is Self-Care?

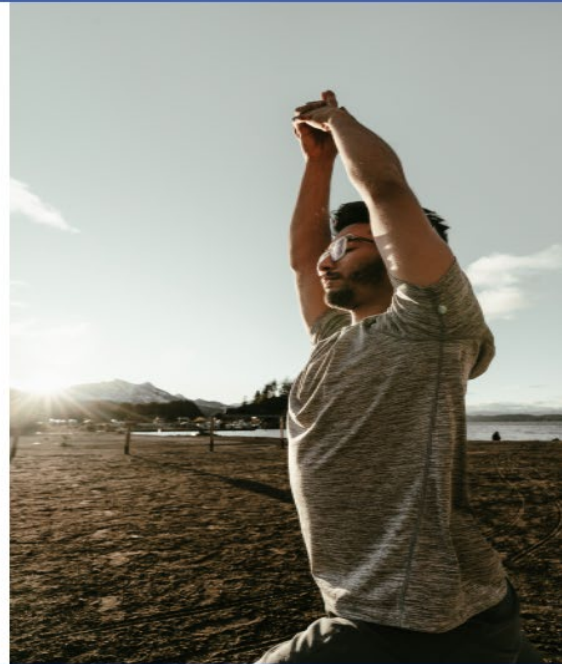
Narration: What is Self-Care?

Self-Care is protecting your own well-being and happiness, particularly during times of stress. It includes taking care of your own physical, emotional, mental, spiritual and social health.

Up until now we've talked about how getting informed about how to care for the person and putting care plans in place can reduce stress. In the next slides you'll see other suggestions for self-care.

Personal and Self-Care Tips to Relieve Stress

- Stress relief activities
- Maintain your health
- Set routines
- Take breaks and know how to calm down in the moment
- Educate yourself
- Create and seek meaningful and affirming activities, such as life story
- Don't be afraid to ask for help or seek counseling



Slide 17: Personal and Self-Care to Relieve Stress

Narration: Personal And Self-Care Tips to Relieve Stress

Here are some ways to find support and relieve stress.

- Stress relief activities such as exercise, engaging in activities that you enjoy, meditation/prayer/relaxation or mindful breathing and “green spaces.”
- It’s important to keep up with your own health care needs.
- Having a routine may help keep your day organized and running smoothly.
- Knowing how to calm down in the moment and taking breaks.
- Educating yourself will help reduce stress from the unknown and you may also learn helpful care tips – learn how to provide care, what to expect, and how to set realistic expectations.
- Engage in meaningful activity with your loved one, such as creating a life story. Search for photos and stories to create a book or other record of their life and your life together and
- Don’t be afraid to ask for help, from other family or friends, from a support group or from professionals, such as a counselor.

We’ll discuss this more in the next slide.

Stress Relief



Stress Relief

18/24

Slide 18: Stress Relief

Narration: Stress Relief

Listen to the video to hear more suggestions about ways to reduce stress.



Where to Seek Support

Seek Support From:

- Family, friends, and neighbors
- Your religious community
- Local senior center
- Case manager
- Respite services
- DDS Family Support Center
- Memory Cafe
- Support groups and grief counseling

Slide 19: Where to Seek Support

Narration: Where to seek support?

In addition to seeking support from friends, family, and neighbors, you might also turn to other groups in the community. You might find support from your religious community or from a senior center.

Speak with the case manager about respite services or about other support from DDS, such as the Family Support Center.

And look into organized support groups, such as a Memory Café or an established support group. Several communities have Memory Cafes, which are places where the person with dementia and their caregivers have the chance to socialize and engage in shared activities in a structured and supportive setting.

Formal support groups might put you in touch with other caregivers, who understand what you're going through, and some may help you deal with grief and sense of loss.

Shared Experiences



Slide 20: Shared Experiences

Narration: Shared Experiences

Listen to a professional who leads family support groups to learn about who might participate in them.

How Support Groups Work



Slide 21: How Support Groups Work

Narration: How support groups work

As you've heard, a support group may give you a way to share your experiences with people who understand what you're going through. Listen to this video to learn more on how support groups might function.

Resource Guide

Resources that Provide Support:

- [Respecting Choices](#)
- [Applying the Knowledge Webinar](#)
- [Caregiving in Action Webinar](#)
- [Family Caregiver Alliance](#)
- [Alzheimer's Caregiving: Caring for Yourself](#)
- [MA DDS, Family Support Center](#)
- [Mass Council on Aging](#)
- [Alzheimer's Association](#)
- [Your Local Aging and Disability Resource Consortia Agency \(ADRC\)](#)

Links:

- [MassOptions](#)
- [After the Diagnosis](#)
- [End of Life Planning](#)
- [MOLST Training Webinar](#)
- [Aging Information and Webinars](#)

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 22: Wrap Up

Narration: Wrap-up

If you experience stress as you care for someone with IDD and dementia, you will find your own way of relieving that stress. It may be one of the ways we've discussed or something unique to you. Take some time to explore the resources here that may help in supporting you as a caregiver.

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.

In Memoriam

John Bohan, October 1960-May 2023.

We would like to thank Patricia Bohan (John's sister) for her thoughtful contributions to this training on self-care and supporting the caregiver.



Slide 23: In Memoriam

Narration:

In Memoriam of John Bohan, October 1960-May 2023. We would like to thank Patricia Bohan (Johns' sister) for her thoughtful contributions to this training on self-care and supporting the caregiver.

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 24: 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.