

Tier 1 Companion Guide

Discussion Questions & Resources

Module 1: Understanding Person-Centered Care

Module 2: Communication and Behavioral Expressions

Module 3: Medical and Clinical Aspects of Dementia

Module 4: Information and Referral Issues

ADRC Dementia Care Training

Aging Services and
Supports for People
Living with Dementia

Last updated November 2014

Tier 1 Companion Guide: Discussion Questions & Resources

This guide serves as a supplement to the Tier 2 Dementia Training Modules. Where possible, ADRCs are encouraged to have staff view these modules as a group, and the Discussion Questions in this guide are provided to help encourage discussion of each module. Links and resources from the presentations are provided, as well as additional sources for further information on these topics. Some resources may be repeated in this guide as they are in the modules. The majority of these resources are likely to be helpful to families and caregivers; resources that are more technical or appropriate for ADRC staff are marked with an asterisk (*). Remember: the Alzheimer's Association's free 24/7 helpline is 1-800-272-3900 and Oregon's ADRC website section on Alzheimer's is www.HelpforAlz.org

This training was developed by Portland State University on behalf of Oregon Department of Human Services – Aging and People with Disabilities. Funding for this project was provided by an Administration for Community Living grant (#90DS2001) and funding provided by the Oregon Legislature for mental health training.

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Last updated December 2014

Group Discussion Questions & Activities

Module 1: Understanding Person-Centered Care

1. In your own words, describe the meaning of the word **personhood**.
 - Why do you think the concept of personhood is important to discuss in relation to people living with dementia?
 - Do you think someone can have personhood without memory? Why or why not?
 - What are three ways you can support the personhood of people with dementia in your work?
2. In the video Without Words, discuss two specific examples of how Jack Agueros's children support his personhood.
 - View a slightly longer version of this video that includes some additional reflections by his children on how they're trying to support their father:
<http://www.nytimes.com/video/nyregion/10000000870254/without-words.html?emc=eta1>
3. If you were diagnosed with dementia, what are some ways you would want those around you to honor your personhood and identity?
4. Describe an example from your personal experience in which a person with dementia has been stigmatized.
 - View a powerful set of photos reflecting aging and people's perceptions at
<http://www.tomhussey.com/SERIES/Reflections/3/>

Link to Module 1 Feedback: <https://www.surveymonkey.com/s/Dementiamodule1>
(please encourage each participant to complete this)

Module 2: Communication and Behavioral Expressions

1. Why do you think the term "behavioral expressions" is a preferred term to use rather than "problem behaviors" or "disruptive behaviors?"
2. In your own words, what do you think causes most behavioral expressions that are challenging to care partners?

- If a family member of a person with dementia contacted you asking about how to respond to a loved one's behavioral expressions, what are some questions you might ask and/or things you might discuss with that person?
3. Why is it important to try and determine if dementia might be an issue when you receive questions from family members or other care partners?
 4. What are some of the resources of caregivers in the community? How do you share this information in ways that supports them (doesn't overwhelm them, but lets them know support is available)?

Link to Module 2 Feedback: <https://www.surveymonkey.com/s/Dementiamodule2>
(please encourage each participant to complete this)

Module 3: Medical and Clinical Aspects of Dementia

1. If someone asked you to define **dementia** in your own words, what would you say?
2. What is the difference between dementia and Alzheimer's disease? Why do you think it is important to be able to distinguish between the two?
3. Why do you think it's helpful to get an early diagnosis?
 - If you believed you might have dementia, would you seek an early diagnosis? Why or why not?
4. What might an I&A staff person say to a caller who themselves seems to have some memory loss, or who has a family member showing early signs of dementia, to encourage them to see a healthcare provider to get a full assessment and diagnosis?

Link to Module 3 Feedback: <https://www.surveymonkey.com/s/Dementiamodule3>
(please encourage each participant to complete this)

Module 4: Information and Referral Issues

1. If you received a call from a person who claimed her nephew was stealing her money, but she could remember her address or phone number, how would you handle the situation?

2. What are some challenging calls you've received relating to dementia? Think about these situations, what are questions you might have asked, what resources did you/could you have offered, and how do you offer support to both the person with dementia and the caregiver?

Note: If no one in the group has an example, you could offer the following:

If a woman contacts you in tears because her husband's wandering and waking up at night is keeping her awake, and she doesn't know what to do, how would you respond?

- What questions might you ask?
- What resources might you offer?
- How might you help the caregiver handle her emotions while speaking with her?

3. What are two resources you've learned about in this training that you think you will find helpful and why?

Link to Tier 1 Assessment: <https://www.surveymonkey.com/s/Dementiamodule4-Tier1quiz>
(Participants must each complete this assessment in order to receive a certificate of completion for Tier 1 (modules 1-4) of this training.)

Resources for Module 1: Understanding Person-Centered Care

Videos and media from YouTube and other sources

- “Without Words” (Length - 4:51)
<http://www.nytimes.com/video/nyregion/10000000870254/without-words.html?emc=eta1>
- “The New Face of Alzheimer’s” (Length - 6:30)
<http://youtu.be/sIRb--Nauwk>
- “Person-centered care: Dignity” (Length - 4:02)
<http://www.youtube.com/watch?v=bM3YmkFFzME>
- “Person-Centered Matters” (Length - 15:48)
<http://www.ccal.org/person-centered-matters-video/>
- “Overcoming Stigma” (Length - 2:00)
<http://youtu.be/klz6gurnNVc>
- Photo series: “Reflections” © Tom Hussey
<http://www.tomhussey.com/SERIES/Reflections/3/>
- National Public Radio (NPR) story about conversations with people with dementia (Length - 5:45)
<http://www.npr.org/templates/story/story.php?storyId=104181619&ps=rs>

Alzheimer’s Association, national and state, and other resources

- *Elderspeak’s Influence on Resistiveness to Care: Focus on Behavioral Events
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2836897/>
- Alzheimer’s Association – Brochure on Communication and Dementia
https://www.alz.org/national/documents/brochure_communication.pdf

Resources for Module 2: Communication and Behavioral Expressions

Videos and media from YouTube and other sources

- “AAIC 2014 Ask the Expert Series: How Can I Deal With Aggressive Behavior?” (Length - 0:44)
<http://youtu.be/GjCbIRQWwQY?list=UUkGrLDa-K4qd7MxA-k-E5g>
- “The Long Goodbye” (Length - 4:27)
Audio slideshow telling a woman’s story caring for her husband with dementia.
<http://www.theglobeandmail.com/life/health-and-fitness/the-long-goodbye/article4326389/>
- “Extended Interview with Alzheimer’s Caregiver, Ric Gomez” (Length - 2:47)
Video interview with a man caring for his father with Alzheimer’s.
<http://www.youtube.com/watch?v=iTeXqE6slXY&feature=youtu.be>

ADRC Website Tools and Resources

- Homepage: <https://adrcforegon.org/consite/index.php>
- Explore: <https://adrcforegon.org/consite/explore.php>
- Alzheimer’s: <https://adrcforegon.org/consite/explore-alzheimers-disease-and-related-dementias.php>
- Caregiving: <https://adrcforegon.org/consite/explore-alzheimers-disease-and-related-dementias-caregiving.php>
 - Caregiver supports: <https://adrcforegon.org/consite/explore-caregiver-supports.php>

Resources for Module 3: Medical and Clinical Aspects of Dementia

Videos and media from YouTube and other sources

- “Alzheimer's Association Alzheimer's Disease Facts and Figures 2014” (Length - 1:45)
<https://www.youtube.com/watch?v=waeuks1-3Z4>
- “What is Mild Cognitive Impairment?” (Length - 2:51)
<http://www.youtube.com/watch?v=k8vRubFxmWA>
- “Vascular Dementia” (Length - 2:43)
<https://www.youtube.com/watch?v=QTbdgHgmTgw>
- “Getting a dementia diagnosis – People with dementia speak out” (Length - 2:45)
<https://www.youtube.com/watch?v=my3voh-sndE>

Resources for Module 4: Information and Referral Issues

ADRC Website Tools and Resources

- Alzheimer’s Section – www.helpforAlz.org
- Medical Section
<https://adrcoforegon.org/consite/explore-alzheimers-disease-and-related-dementias-medical.php>
- Learn More About Dementia
<https://adrcoforegon.org/consite/explore-alzheimers-disease-and-related-dementias.php>
- Safety
<https://adrcoforegon.org/consite/explore-alzheimers-disease-and-related-dementias-safety.php>
- Elder Abuse
<https://adrcoforegon.org/consite/explore-elder-abuse-prevention.php>

Alzheimer’s Association, national and state, and other resources

- National Institutes of Health – *Caring for A Person with Alzheimer’s Disease*
<http://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide>
- Alzheimer’s Association – “I Have Alzheimer’s Disease” (Length - 0:55), web page with resources for the person living with dementia.

<http://www.alz.org/i-have-alz/i-have-alzheimers-dementia.asp>

- National Institute on Aging (NIA) booklet – *So Far Away: Twenty Questions and Answers About Long-Distance Caregiving*
http://www.nia.nih.gov/sites/default/files/so_far_away_twenty_questions_about_long-distance_caregiving.pdf
- Veterans Administration (VA) support line for caregivers, as well as a website:
 - **1-855-260-3274** (support line)
 - M-F 8am-8pm EST (5am-5pm Pacific Time)
 - <http://www.caregiver.va.gov/>
- Adult Protective Services (APS) to report suspected abuse of adults 65+ and adults with physical disabilities
 - **1-855-503-SAFE (1-855-503-7233)**
- Alzheimer’s Association MedicAlert Safe Return Program
<http://www.alz.org/care/dementia-medic-alert-safe-return.asp>
- **Call 9-1-1** if a person with dementia or caregiver is in immediate danger.