

Tier 2 Companion Guide

Discussion Questions & Resources

Module 5: Honoring Personhood
through Person-Centered Decision Support

Module 6: Honoring Personhood
through Person-Centered Planning

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Advanced Care and End-of-Life Planning

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ADRC Dementia Care Training

Aging Services and
Supports for People
Living with Dementia

Tier 2 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

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Group Discussion Questions & Activities

Module 5: Honoring Personhood through Person-Centered Decision Support

1. List examples from your ADRC of using traditional planning approach & list examples of a more person-centered approach (the person with dementia and their family in the “driver’s seat”).
 - a. Generally, how might outcomes using these approaches be different?
 - b. What are the strengths of each approach? Weaknesses?
 - c. Look again at the examples of the traditional approach. Choose one example and discuss how it can be made more person-centered.

Note: *As professionals we develop routines and habits that are helpful to us in getting our work done, but these routines may not meet the unique needs of the person in front of us. The purpose of exploring traditional and person-centered planning approaches is to help participants to critically examine their own practice. Professionals often feel they are being person-centered, but many times their clients do not feel that they are – they report the professional really doesn’t know them or what is important to them. By “drilling down” into a common practice, participants in this discussion may gain insight into ways they can improve their person-centered thinking and planning skills and improve overall services offered through the agency.*

2. How can you incorporate visual tools in your meetings with families? How can you practice using these tools to gain skills?

Note: *Visual tools are helpful to those who use them regularly. It may be difficult to implement in the field because of concerns about time, the logistics of carrying a flip chart, and lack of experience using these tools. Think of ways that you can incorporate visual tools in your discussions about the Tier 2 training as well as in other staff meetings. As a group think about situations with consumers, where trying out one or more of these tools could be helpful. Get a volunteer to try a tool with one consumer. Report back to the group how it went, what was helpful, and how they could use it next time.*

3. In the story about Dennis and his daughter, Sally vents for about 2 minutes. It was important for the training purposes of helping the webinar participant to get to know Dennis, his daughter, and their unique situation. In real life situations, however, how

can the options counselor assure that both Dennis and his daughter feel heard and assure that the issues from the points of view of each person are discovered. What did the options counselor do well? What could she have done differently?

Note: *Try not to let the discussion turn into a critique of the actor portraying the options counselor. Keep the focus on person-centered thinking, that is, focusing on the person with dementia and their family or other support person.*

Link to Module 5 Feedback: <https://www.surveymonkey.com/s/Dementiamodule5>
(please encourage each participant to complete this)

Module 6: Decision Support through Person-Centered Planning

1. Select one of the cases presented in this module (Martha, Dennis, or Sarah). How can you use the tools and approaches portrayed in these cases in your own work? (Dennis: Desired outcomes based on routines, Sarah: what's working and not working; changing roles & responsibilities; Martha: Timeline.)

Note: *Many elements of the tools presented are probably already in your "tool bag." Think about how the content presented in this module can enhance your skills and abilities to use these person-centered approaches in supporting people with dementia and their families.*

2. Share a challenging situation you are dealing with right now. It may be where a family and a person with dementia are at odds, with the person focusing on maintaining preferred routines and activities, while the family is mostly concerned about health and safety. It could be a situation in which the person with dementia has limited social support. Describe this situation and then considered how you might approach person-centered planning.

Note: *Balancing the needs and preferences of the person with dementia with the needs and preferences of the family member or other caregiver can be difficult. Family needs and preferences often take precedent over the person with dementia. It is easier to achieve a balance when you know the person with dementia and can answer these questions: Who is this person with dementia? How is their past influencing their life today? What are their daily routines? What is working and not working from the point of view of the person with dementia? From the points of view of different family members?*

Link to Module 6 Feedback: <https://www.surveymonkey.com/s/Dementiamodule6>
(please encourage each participant to complete this)

Module 7: Decision Support in Care Transitions

1. A diagnosis of dementia is a usually turning point in the lives of the people with dementia and their families. What can you do to assist with the psychological transitions that accompany the diagnosis?

Note: Think about ways to preserve personhood and sense of self as the person takes on the label of “person with dementia” or the role of “family member of a person with dementia.” What are some specific resources you can share with individuals in these situations?

2. What are the difference between dementia, depression, and delirium? All of these conditions, especially depression and delirium, go undiagnosed and untreated. Those with dementia are at increased for both. What are the triggers for further evaluation and assessment of these conditions? What referrals would you make? How can you prepare family members to recognize these triggers? How can you do this without information overload?

Note: Review the websites and resources referenced in this module. Identify information you can give to individuals and families to alert them to issues. Identify information that can be readily available to agency staff.

Link to Module 7 Feedback: <https://www.surveymonkey.com/s/Dementiamodule7>
(please encourage each participant to complete this)

Module 8: Decision Support for Advance Care and End-of-Life Planning

1. Review some of the planning documents referenced in this module (slides 10, 12, 14, 15, 21). Discuss how to use these documents to encourage and support advance planning.

In your discussion, identify ways that you can introduce the need for and resources for advance care and end-of-life planning to individuals and families in a person-centered way.

Note: *Think about Joanne Lynn’s perspective on what is important to include in an advance directive (slide 22). How can this type of information be integrated into conversations between people with dementia and their family members? How can this information be integrated into the more formal advance planning documents such as Oregon’s Advance Directive or the POLST.*

Think about the importance of knowing the person, balancing what is important to and what is important for a person, and information in advance directives for the health care representative (i.e., instructions given to the health care representative).

2. Situations in which a person with dementia has no support system and has not done advance planning are particularly challenging. Discuss your experiences with obtaining guardianship and various alternatives to court appointed guardians in these situations. Issues of making decisions for others based on substituted judgment or best interests of the person (refer to resource listed in slide 21). Talk about circumstances where one approach would be chosen over. What considerations would go into making these decisions?

Note: *Discuss the resources available in your agency for obtaining guardianships. When should you pursue guardianships and when are other approaches likely to be more appropriate?*

Link to Tier 2 Assessment: <https://www.surveymonkey.com/s/Dementiamodule8-Tier2quiz>
(Participants must each complete this assessment in order to receive a certificate of completion for Tier 1 (modules 5-8) of this training.

Resources for Module 5: Honoring Personhood through Person-Centered Decision Support

Videos and media from YouTube and other sources

- “Person-centered approaches, thinking and planning” (Length - 5:47)
<http://www.youtube.com/watch?v=tvANuym5VXY>

Additional resources

- **Navigating Choice and Change in Later Life: Frameworks for Facilitating Person-Centered Planning* (2011). Patty Cotton & Susan Fox. Institute on Disability/ UCED, University of New Hampshire.
 - Book can be purchased at <http://www.iodbookstore.org/products/Navigating-Choice-and-Change-in-Later-Life%3A-Frameworks-for-Facilitating-Person%252dCentered-Planning.html>
 - PowerPoint presentation download
www.adrc-tae.acl.gov/tiki-download_file.php?fileId=28941
- *More facts about visual learning
<http://www.scoop.it/t/visual-thinking>

Resources for Module 6: Honoring Personhood through Person-Centered Planning

Videos and media from YouTube and other sources

- “4 plus 1 questions” (Length - 6:28)
- “What’s working and not working” (Length - 9:58)
<http://www.youtube.com/watch?v=M190htHcvok>

ADRC Website Tools and Resources

- Alzheimer’s Overview
<https://adrcforegon.org/consite/explore-alzheimers-disease-and-related-dementias.php>
- Safety
<https://adrcforegon.org/consite/explore-alzheimers-disease-and-related-dementias-safety.php>

- Legal resources and financial planning
<https://adrcoforegon.org/consite/explore-alzheimers-disease-and-related-dementias-legal-financial.php>
- Care options
<https://adrcoforegon.org/consite/explore-alzheimers-disease-and-related-dementias-caregiving.php>
 - Home Care Workers
<https://adrcoforegon.org/consite/explore-who-can-help.php>
- Family Caregiver Handbook
<https://adrcoforegon.org/forms/Family%20Caregiver%20Handbook%20Final.pdf?t=Family%20Caregiver%20Handbook>

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

- Alzheimer’s Association Oregon Chapter
<http://www.alz.org/oregon/>
- Support groups
http://www.alz.org/oregon/in_my_community_support.asp
- Dementia & Driving Resource Center
<http://www.alz.org/care/alzheimers-dementia-and-driving.asp>
- MedicAlert™ and Alzheimer’s Association Safe Return™
<http://www.alz.org/care/dementia-medic-alert-safe-return.asp>
- AARP: Tips for Hiring a Home Care Worker
http://www.aarp.org/relationships/caregiving-resource-center/info-08-2010/pc_home_care_worker.html
- *State Plan for Alzheimer’s Disease and Related Dementias in Oregon (SPADO)
http://www.alz.org/oregon/documents/spado_report.pdf

Resources for Module 7: Decision Support in Care Transitions

Videos and media from YouTube and other sources

- “Health Affairs' Susan Dentzer on Care Transitions” (Length - 2:20)
<https://www.youtube.com/watch?v=xZPR4ulloLM>

ADRC Website Tools and Resources

- ADRC of Oregon homepage
www.adrcforegon.com
- Facility-based services and supports
<https://www.adrcforegon.org/consite/explore-in-a-facility.php>
- Alzheimer’s Overview
<https://www.adrcforegon.org/consite/explore-alzheimers-disease-and-related-dementias.php>

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

- Alzheimer’s Association homepage for 24/7 telephone support, younger onset resources, support groups for people with dementia and caregivers, education programs, and more. www.alz.org
- Driving and dementia
http://www.alz.org/documents_custom/statements/driving_and_dementia.pdf
- Alzheimer’s and Dementia Caregiver Center: Safety
<http://www.alz.org/care/alzheimers-dementia-safety.asp>
- 10 Signs of Alzheimer’s
http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp
- Alzheimer’s Network – Caregiving Center, education, support, and outreach
<http://alznet.org/>
- Family Caregiver Alliance
www.caregiver.org
- Preventing falls at home
http://eldercare.gov/Eldercare.NET/Public/Resources/Brochures/docs/Preventing_Falls_Brochure_pagebypage.pdf

- *Transportation: driving cessation
[http://www.seniortransportation.net/Portals/0/Cache/Pages/Resources/Research to Practice-Diving Cessation Dementia.pdf](http://www.seniortransportation.net/Portals/0/Cache/Pages/Resources/Research%20to%20Practice-Diving%20Cessation%20Dementia.pdf)
- *Dementia Capability Toolkit
<http://www.aarp.org/livable-communities/learn/health-wellness/info-12-2012/Dementia-Capability-Toolkit-2011.html>
- Mayo Clinic: Delirium
<http://www.mayoclinic.org/diseases-conditions/delirium/basics/symptoms/con-20033982>
- *Information & Assessment tools including assessing pain in persons with dementia, wandering in hospitalized older adults, and assessing & managing delirium in persons with dementia.
<http://consultgerirn.org/resources>
- The Three Ds of Confusion: Delirium, Depression, Dementia. (PowerPoint presentation)
<http://www.olderadultfocus.org/Adapt/ThreeDs.ppt>

Resources for Module 8: **Decision Support for Advanced Care and End-of-Life Planning**

Selection of videos and media from YouTube and other sources

- “Planning for Your Future – Alzheimer’s Association” (Length - 1:27)
<http://www.youtube.com/watch?v=YQtDyi865AE>
- “Advance Care Planning – Palliative Care” (Length - 4:23)
<https://www.youtube.com/watch?v=OOH5hVQRxD4>
 - Joanne Lynn, Director, Altarum's Center for Elder Care and Advanced Illness
<http://altarum.org/staff/joanne-lynn#sthash.TBqV1OOS.dpuf>
- “End of Life Planning for People with Dementia” (Length - 1:33)
<https://www.youtube.com/watch?v=2a-Qm2c5VBU>
- “Dementia: End-of-life Care” (Length - 10:11)
<https://www.youtube.com/watch?v=3zKADdgcF14>
- “Late-Stage Dementia: Palliative Care and Comforting” (Length - 2:03)
<https://www.youtube.com/watch?v=M9n9sUhgF-A>

ADRC Website Tools and Resources

- Planning for Your Future: A Toolkit for Long-term Services and Supports
<https://adrcoforegon.org/consite/forms/ADRC-toolkit-web3.pdf>
- Legal help in end-of-life planning
<https://adrcoforegon.org/consite/plan-legal-and-care-planning-develop-documents.php>
- Health Care Advance Planning
<https://adrcoforegon.org/consite/plan-legal-and-care-planning.php>

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

- The Conversation Starter Kit – Having difficult conversations with your family
<http://theconversationproject.org/starter-kit/intro/>
- *Being Prepared: A Resource Guide for End-of-Life Decisions and Planning*, Governor's Commission on Senior Services
<https://apps.state.or.us/Forms/Served/msc0202.pdf>
- Legal and financial planning
<http://www.alz.org/i-have-alz/plan-for-your-future.asp>
- Financial planning – Senior Health Insurance Benefits Assistance Program (SHIBA)
www.oregon.gov/DCBS/SHIBA/
- Consumer's Tool Kit for Health Care Advance Planning (2nd Ed)
http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html
- Oregon Health Decisions – *Advance Directive: Your Life, Your Decisions*
www.oregonhealthdecisions.org
- *Making Medical Decisions for Someone Else: A How-To Guide*
http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_proxy_guide_gen.authcheckdam.pdf
- Physician Orders for Life Sustaining Treatment (POLST)
<http://www.or.polst.org/>
- Office of Adult Abuse Prevention and Investigations (OAAPI) Annual Report, 2013
<http://www.oregon.gov/dhs/spwpd/adult-abuse/Documents/2013%20OAAPI%20Annual%20Report%20093014.pdf>