

ADRC Dementia Care Training

Implementing Person-Centered
Dementia Support: Tier 1

Module 4: Information and Referral Issues

ADRC

Aging and Disability
Resource Connection

— of OREGON —

WELCOME!

➤ Tier 1:

- Understanding Person-Centered Care
- Communication and Behavioral Expressions
- Medical and Clinical Aspects of Dementia
- **Information and Referral Issues**

➤ Tier 2:

- Honoring Personhood through Person-Centered Decision Support (orientation & building trust)
- Decision Support through Person-Centered Planning
- Decision Support in Care Transitions
- Decision Support for Advanced Care and End-of-Life Planning

Training Philosophy

- The person comes first
- Treat the person, not the disease
- Strengths-based approach

Important Reminders

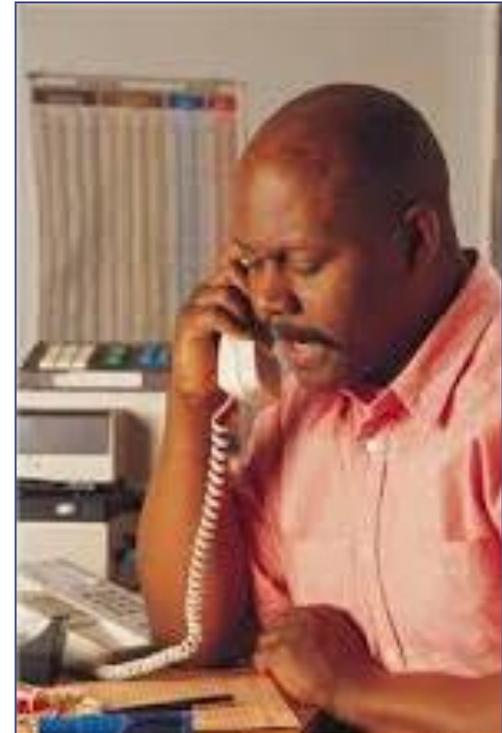
- Please view trainings in order
- Feedback surveys:
 - Following each Module (both Tiers)
 - These will help us determine where to focus or provide more training
- Knowledge Assessments
 - following Tier 1 and Tier 2

Let's Get Started...



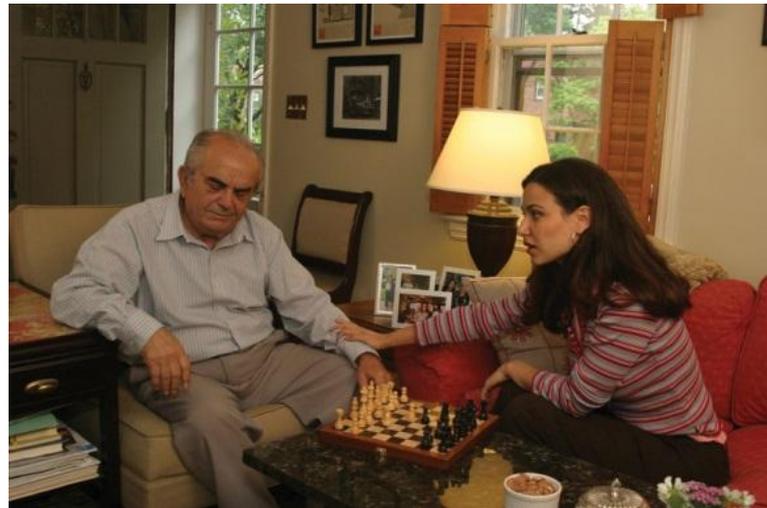
Sample Calls

“I don’t know what to do about my mother. She’s forgetting things more and more, and she’s just not the person she has been.”



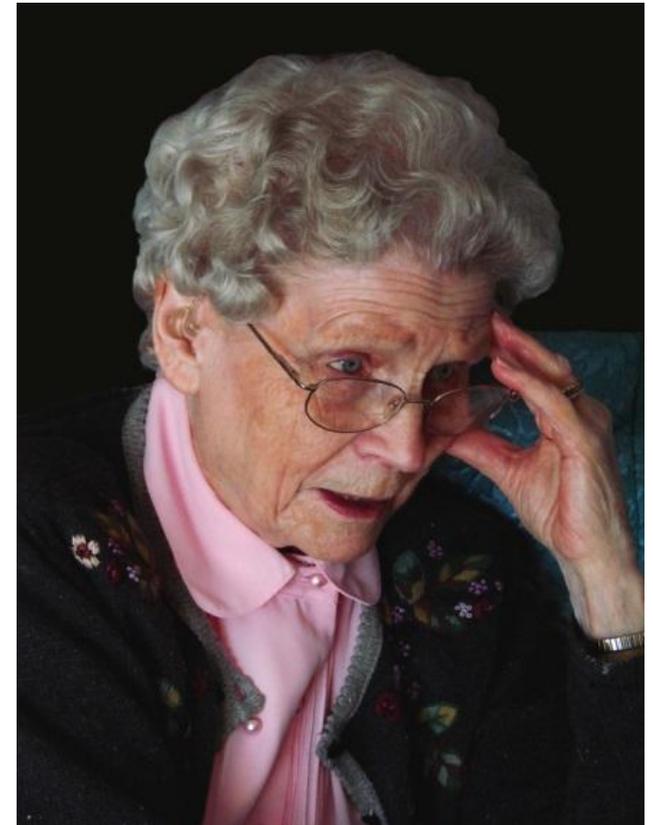
Sample Calls

“My dad has started wandering and he refuses to stay at home. I don’t know what to do, and I can’t leave the house without worrying.”



Sample Calls

“I went to the doctor because I’ve been forgetting things. My memory was not so good anymore. He told me I have dementia, and to get some more tests, but he didn’t say much more than that. He told me the name of a specialist, but I can’t get an appointment for about 3 weeks and it’s driving me crazy. Do I have Alzheimer’s?”



Sample Calls

“My kids are lazy, good for nothing moochers! They are stealing everything from me. They even stole my glasses, and now I can’t see a damn thing. Can you help me put them in jail and get my money back?”



Sample Calls



“I am at my wits end. I love my husband, but he won’t listen to anything I say. He wakes up at night and he won’t go back to sleep. I’m exhausted, and I don’t know what to do!”

Sample Calls



“My grandma used to be so busy. Now, she’s quit her bowling league, she doesn’t play cards, and she doesn’t want to get together with the family or our friends. She keeps saying she’s tired, and all she does is stay home. And I’m not even sure she’s getting enough to eat.”

Sample Calls

“I’m worried about my Aunt. She and my Uncle were always so happy, but now she forgets things, and he gets frustrated. Sometimes, he really yells at her. He just seems angry at her all the time.”



Your Work



Objectives

- Be familiar with ADRC and national resources to help those with dementia and families
- Understand the information and referral process for issues related to dementia, including:
 - Referral to Adult Protective Services
 - Wandering and severe behavioral expressions
- Understand when to refer consumers and families for options counseling

Review of Resources

Alzheimer's Association 24/7 Helpline

1-800-272-3900

Review of 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>

Review of Resources

ADRC Website - Medical Section

<https://adrcoforegon.org/consite/explore-alzheimers-disease-and-related-dementias-medical.php>

Review of Resources

Alzheimer's Association site:

“I Have Alzheimer's Disease.”

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

Review of Resources

Driving Issues:

The Alzheimer's Safety section of ADRC website

<https://adrcforegon.org/consite/explore-alzheimers-disease-and-related-dementias-safety.php>

Review of Resources

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

Review of Resources

Veterans Administration (VA) has a 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/>

Review of Resources

ADRC website:

Learn More About Dementia section

<https://adrcoforegon.org/consite/explore-alzheimers-disease-and-related-dementias.php>

Review of Resources



Local Resources

- Start a list of resources unique to your own community
- Share the resources you learn about with your ADRC database specialist
- These may include resources related to transportation, support groups, senior centers and meal programs, medical equipment and supplies, and others

Need for More Support

- Calls may not always go smoothly
- Do your best to assist
- Reminder to try and obtain contact information for the person and his or her family, with permission
- You may not be able to provide the actual support, but you can connect them to resources that will help them get what they need
- Leave the door open for future interactions

Is Options Counseling an Option?

➤ Need for:

- More information and support
- Individualized planning
- Person-centered resources
- Complex family issues
- Try to include a family member



Information & Referral Issues

- Possible Abuse
- Person who is lost or missing
- Challenges due to behavioral expressions



APS Abuse Types

1. Physical
2. Wrongful chemical or physical restraint
3. Abandonment
4. Verbal/emotional
5. Financial
6. Neglect
7. Sexual
8. Involuntary seclusion
9. **Self-neglect**



Intervention Without Capacity

- Determine areas of retained capacity and allow for autonomy in those areas
- Use the principles of:
 - Substitute judgment
 - Least restrictive alternatives
- Must benefit the person

Voluntary vs. Involuntary Interventions

➤ Substitute judgment

- Attempt to determine the preferences of the person
- Attempt to reach the decision the person would make if they were still able
- Allows for decisions to be made in accord with the person's own definition of well-being

When to Refer to APS Screener

- Significant harm or negative outcome due to another's conduct
- Threat of serious harm
- Person's conduct is excessively improper
- Person's adverse conduct persists
- Patterns of maltreatment
- Injuries not accidental
- Possible sex abuse, sexual consent
- Violence and physical threats
- **When in doubt, refer to an APS screener!**

Where to Report Suspected Abuse

Adults 65+ and Adults with Physical Disabilities

1-855-503-SAFE

Not Abuse But Not Okay

- Not all adverse conditions and bad behavior rises to the level of abuse
- Not rising to abuse does not mean it is acceptable and nothing should be done
- It means that steps other than an APS referral should be considered



What Doesn't Meet APS Criteria

- Home care worker (HCW) signs a voucher for hours not worked
- Showing up late to work once in a while
- Caregiver and consumer both agreeably cuss
- Worker keeping the change the first time
- Not doing the laundry right
- Family squabbles



ADRC Elder Abuse Resource

ADRC Website:

<https://adrcoforegon.org/consite/explore-elder-abuse-prevention.php>

Wandering



Person Who is Lost or Missing

- Alzheimer's Association MedicAlert Safe Return Program (preventative)
 - Jewelry with individualized number
 - 24-hour nationwide response
 - Wandering or medical emergency
- Call 9-1-1 immediately if person is already lost
 - Inform operator that person has (or may have) dementia



<http://www.alz.org/care/dementia-medic-alert-safe-return.asp>

Calls about Behavioral Expressions

- Behaviors are the way people with dementia communicate their unmet needs
- The actions and behaviors of a person with dementia are that person's way of communicating
- Every behavior is a form of communication, and every behavior has meaning

Calls about Behavioral Expressions

You can help caregivers to realize that understanding and meeting the person's needs is the best way of responding to behavioral challenges, and that by doing so, they will also improve the person's quality of life – and probably their own, too.

What You Can Do

1. Ask some simple questions to try and determine what assistance the caregiver may need right away, as well as on an ongoing basis, in order to safely care for the person with dementia
2. Recommend resources that may be helpful, both for the person with dementia AND for the caregiver

Immediate Questions

- Are you in immediate danger?
- Is the person in immediate danger?
- Do you feel like you need assistance right away to stay safe or to keep the person safe?



Fact-Finding Questions

- What does the behavior look like when it happens? or Can you describe the behavior to me?
- Can you think of anything that might be causing the behavior (sights, smells, tastes, sounds)?
- Is there anything you have found that helps lessen or prevent the behavior?

Fact-Finding Questions

- Has the person been diagnosed with frontotemporal dementia or another condition that may cause or aggravate the behavior?
- Have you found anything that lessens the behavior?
- Is there a certain time of day when the behavior usually happens?
- Is there anything the person does or says before the behavior begins that gives you warning it is about to occur?

Ongoing Assistance Questions

- What is your biggest challenge in taking care of (person with dementia)?
- What is the hardest thing for you to deal with?
- What is a typical day like for you?
- Does anyone help you? What do people do to help you?

Ongoing Assistance Questions

- What do you do to take care of yourself?
- Can you leave (person with dementia) alone for more than one hour?
- If the family reports a diagnosis of dementia, ask: Have you had any information about dementia or Alzheimer's disease?

Courses of Action - #1

1. Neither the person nor the caregiver is in danger; however, both could benefit from resources, information, and assistance. In these cases, provide information that's helpful based on their specific needs, and determine whether options counseling may be beneficial. Note your course of action in the ADRC Call System.

Courses of Action - #2

2. The person with dementia may be in some danger if certain issues are not dealt with. Provide as much information and as many resources as possible, and suggest specific plans of action. If you suspect abuse, contact APS right away. Note your course of action in the ADRC Call System, and alert your supervisor if an APS call is warranted.

Courses of Action - #3

3. In the unlikely situation that the caregiver or the person with dementia is in immediate danger, call 9-1-1. Note your course of action in the ADRC Call System, and alert your supervisor.

Reminders

- Stay calm
- Try to get contact information
- Learn as much as possible
- Listen for signs of dementia

Reminders

- Offer whatever applicable resources the person will accept
- Refer to options counseling when warranted
- Involve APS if you suspect any possible abuse

Review of Tier 1



Review: Module 1

- Each person with dementia is still a whole and complete person
- Focus on the person's remaining abilities and strengths
- Honor the person's identity, and encourage his or her involvement in the community in meaningful ways
- Families and friends can help ease the feelings of loss that accompany dementia and replace them with feelings of normalcy and hope

Review: Module 2

- Behavioral expressions that are challenging to care-givers are ALSO challenging to the person w/ dementia
- Behaviors are usually expressions of unmet needs that a person cannot communicate through words
 - Some forms of dementia cause damage to parts of the brain that control behavior, so unsettling behavior is part of the illness and not necessarily an unmet need
- The physical and social environment can impact the feelings and actions of a person with dementia in many ways

Review: Module 2 (continued)

- Caregivers experience a variety of emotions, and although caregiving can be a tough job, there are resources available
- The ADRC website has a variety of information and resources for caregivers that is easily accessible

Review: Module 3

- It is important to determine if dementia is an issue when a consumer or a family calls the ADRC
- Early diagnosis allows consumers and families peace of mind and the ability to plan for the future
- Asking specific questions can help you to determine if dementia may be an issue
- There are many resources available for people with dementia and their families and caregivers
 - Start with the ADRC website and the Alzheimer's Association Helpline

Review: Module 4

- There are many resources available to help and support people with dementia and their families
 - Start with the ADRC website and the Alzheimer's Association Helpline
- If you even *suspect* abuse could be occurring, refer the situation to an APS screener
- Provide resources according to each person's individual needs and preferences
- If someone needs more than information and referral services, refer for options counseling.

Being Dementia Capable

- Information and assistance services have a method to identify people with possible dementia
- Individuals with possible dementia receive a recommendation for follow-up with a physician
- Workers who interact with persons with dementia and their caregivers have appropriate training in identifying:
 - A possible dementia in persons that they serve
 - The symptoms of Alzheimer's disease and other dementias
 - The likely illness trajectory, and services needed

Thank you for your participation!

Please **[CLICK HERE](#)** to give us your feedback on this training module.

<https://www.surveymonkey.com/s/Dementiamodule4-Tier1quiz>

This training was developed by Portland State University on behalf of Oregon Department of Human Services – Aging & 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.