

ADRC Dementia Care Training

Implementing Person-Centered
Dementia Support: Tier 1

Module 2: Communication and Behavioral Expressions

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
- Complex 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...



Opening Thoughts...

I am hungry for the life that is being taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness, and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for! Help me to be strong and free until my self no longer exists.

- James Thomas, who lived with Alzheimer's for eight years before he died at age 70

Opening Thoughts...

It's never going to be written in a prayer book, but my prayer is, "God, you gave this to me, help me deal with it."

– Cynthia, a retired schoolteacher



Opening Thoughts...

People think it's a terrible tragedy when somebody has Alzheimer's. But in my mother's case, it's different. My mother has been unhappy all her life. For the first time in her life, she's happy.

- Amy Tan, author

Opening Thoughts...

*Though those with Alzheimer's might forget us,
we as a society must remember them.*

- Scott Kirschenbaum, filmmaker



Some Facts...

- As of 2014, over 59,000 Oregonians are living with Alzheimer's disease or a related disorder.
- Approximately 1,300 people died from Alzheimer's disease in Oregon in 2010.
- The prevalence of Alzheimer's disease in Oregon is expected to rise 42% between 2014 and 2025.
- In 2014, 173,00 Oregonians provided 196 million hours of unpaid care to loved ones with Alzheimer's and other dementias = \$2,446 million dollars.

Your Work



Objectives

- Understand that behavioral expressions associated with dementia are often expressions of unmet need
- Understand how the physical and social environment can impact the well-being of persons living with dementia
- Gain knowledge about resources to assist families in addressing behavioral issues

Behavioral Expressions

- Wandering or pacing
- Repeating the same question or phrase over and over again
- Refusing care
- Trying to exit the home or other area in search of someone or something that may or may not be available
- Becoming upset, agitated, or aggressive during care or other situations

Behavioral Expressions

- Hallucinations or delusions
- Signs of depression or anxiety
- Apathy or withdrawal

Reframing Behavior Expressions

- Many terms seem to suggest that the person with dementia is the problem, is somehow at fault, or is responsible for the situation
- It's easy to focus only on how challenging behaviors affect *us* and to forget the impact of situations on *the person with dementia* who is exhibiting the behavior

Example 1



Example 2

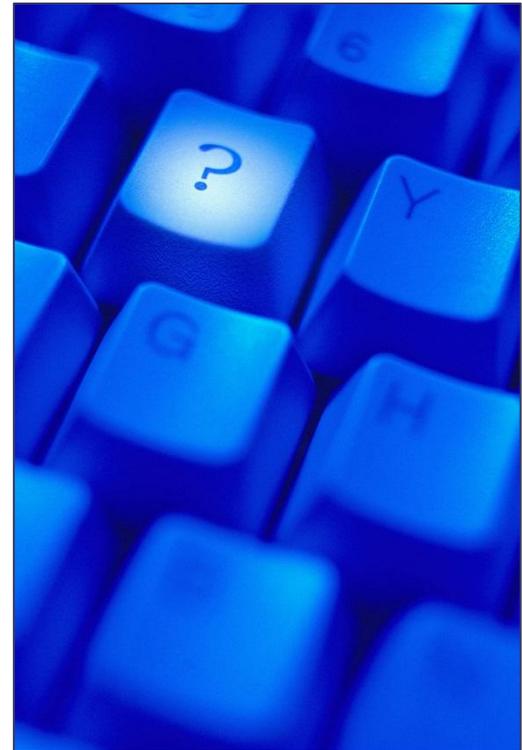


Example 3



Important Question

What is the
reason *behind*
the behavior?



Unmet Needs



Challenging behavioral expressions are almost always caused by **unmet human needs** that the person with dementia has trouble communicating.

Unmet Needs

Behavioral expressions are attempts at communicating unmet needs by a person who has trouble finding the words to express him or herself.



Pain and Discomfort



Always rule out pain and discomfort when responding to behavioral expressions.

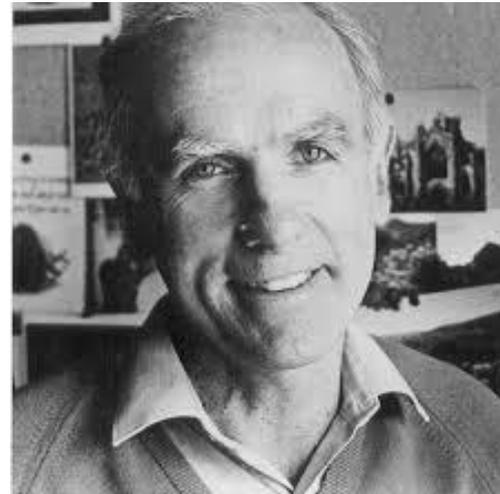
Other Causes of Behavioral Expressions

- Urinary Tract Infections (UTIs)
- Medication Reactions
- Arthritis
- Other conditions causing pain or discomfort

Back to Kitwood...

Remember from Module 1 that in addition to the basic physical needs of food, water, shelter, clothing, and security, people also have psychological needs, including:

- **Attachment**
- **Comfort**
- **Identity**
- **Occupation/Meaning**
- **Inclusion**



Knowing the Person

- Life history
- Background
- Hobbies
- Preferences



- Families and close friends know these things already, so they have an advantage!

Marietta:



Practice Empathy

- What might the person be **thinking**?
- How might the person be **feeling**?
- What might the person be **experiencing**?
- *How would I behave if I was that person?*

Why You Need to Know This

- Understanding the reasons for behavioral expressions and being able to gently educate families and other care partners is vitally important
- You cannot solve their problems, BUT you can help them to do so by offering them tools and explanations, as well as helping them to problem-solve

Importance of Activity

<http://youtu.be/GjCbIRQWwQY?list=UUkGrLDa-K4qd7MxA-k-E5g>

Environmental Factors



Environmental Factors

Size of a room



Environmental Factors

Number of people in the room



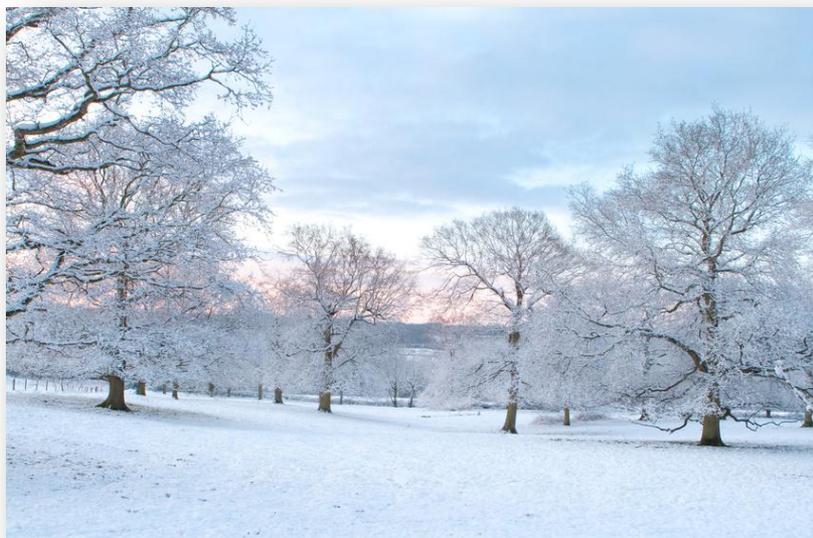
Environmental Factors

Level of light in the room



Environmental Factors

Temperature



Environmental Factors

Noise level

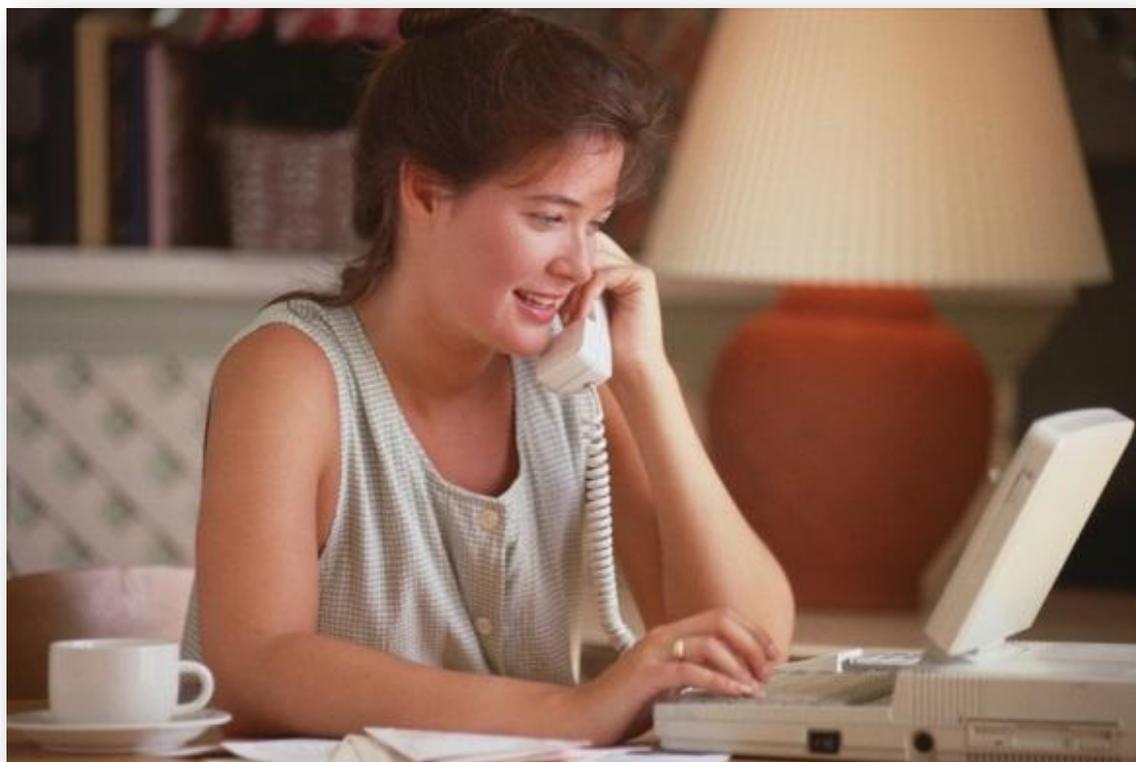


Environmental Factors

Design/obstacles



Speaking with Caregivers



Social Factors

- Who is in the room?
- What are the emotions/moods of people in the room?



Social Factors

- Is the person with dementia being included in the conversation in a way he or she can contribute?
- What is the subject/tone of the conversation?



Social Factors

- What interactions has the person with dementia had recently?



Resource Reminder

The Alzheimer's Association's free 24-hour/7 day a week helpline: **1-800-272-3900.**

- Anyone in the United States can call this number at anytime to get support with issues related to dementia
- **The type of dementia does not have to be Alzheimer's – the helpline will still help**

Caregiver Statistics

- More than 60 percent of Alzheimer's and dementia caregivers are women
- Nearly 60% of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, and more than one-third report symptoms of depression

Caregiver Emotions

- Loss, Sadness and Grief
- Anger, and Resentment
- Fear and Concern
- Guilt



Caregiver Emotions

- Confusion, frustration and helplessness
- Loneliness and isolation
- Acceptance and gratitude



Caregiver Video: Donna

ACTION NEEDED: STOP NOW AND WATCH THIS VIDEO IN YOUR BROWSER.
When you are finished please return to this presentation.

<http://www.theglobeandmail.com/life/health-and-fitness/the-long-goodbye/article4326389/>



Caregiver Video: Ric



Speaking with Caregivers

- Practice patience
- Let empathy and compassion guide you
- Take time to listen
- Offer reassurance
- There is help
 - ADRC Resources (online or by phone)
 - Options counseling



ADRC Website

<https://www.adrcforegon.org/consite/index.php>

The screenshot shows the ADRC website homepage with a dark blue header and a light blue main content area. The ADRC logo is in the top left, and a site search bar is in the top right. The main content is organized into four large white boxes with green icons: 'Explore your options' (with a star icon), 'Search for resources' (with a magnifying glass icon), 'Connect with your local ADRC' (with a person icon), and 'Plan and prevent' (with a gear icon). Each box contains a brief description and a 'Go' button. To the right of these boxes are three vertical sections: 'Planning Toolkit' (with a 'DOWNLOAD' button), 'Give feedback' (with a 'TAKE A SURVEY' button), and 'Find us on Facebook' (with a 'Like' button and a photo of three people). At the bottom, there are four columns of links for 'Explore', 'Search', 'Connect', and 'Plan', along with contact information for ADRC (1-855-ORE-ADRC) and a secondary site search bar. The browser's address bar shows the URL, and the taskbar at the bottom displays various application icons and the system clock (9:13 AM, 10/12/2014).

ADRC Website: Explore

<https://adrcforegon.org/consite/explore.php>

ADRC
Aging and Disability
Resource Connection
of OREGON

Site Search | Select Language | A A A

get connected: 1-855-ORE-ADRC
1-855-673-2372

Home | Explore | Search | Connect | Plan

Long-term services | In your community | In your home | In a facility | Alzheimer's | More options

Alzheimer's disease and related dementias

Explore your options

 It can be overwhelming to try to understand your options for [long-term services and supports](#). The ADRC of Oregon is here to help.

The information on this website will help you understand the long-term services and supports available in Oregon. You will also find steps you can take now to prepare for your future needs.

You can [contact your local ADRC of Oregon](#) through this website or our toll-free number (1-855-673-2372). You will be connected with an information and assistance specialist in your area. That person can help you find resources and refer you to services.

You may need more help planning for a safe and healthy future. A skilled professional options counselor will help you assess your strengths, needs and challenges. The counselor will also help you choose options to improve the quality of your life. The options counselor can connect you with local resources. The counselor can also help you resolve problems and help with short- and long-term planning.

ADRC of Oregon's services are free and available to anyone.

Connect with your local ADRC.

ADRC of Oregon staff are available to help you explore your options to meet your current needs or create a plan for the future.

[CONNECT NOW](#)

Search | Connect | Plan | 1-855-ORE-ADRC
1-855-673-2372

ADRC Website: Alzheimer's

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

The screenshot shows a web browser window displaying the ADRC website. The browser's address bar shows the URL: <https://adrcforegon.org/consite/explore-alzheimers-disease-and-related-dementias.php>. The website header includes the ADRC logo (Aging and Disability Resource Connection of OREGON), a site search bar, a language selection dropdown, and font size controls. Below the header is a navigation menu with icons for Home, Explore, Search, Connect, and Plan. A secondary menu highlights 'Alzheimer's' among other categories like 'Long-term services', 'In your community', 'In your home', 'In a facility', and 'More options'. The main content area is titled 'Alzheimer's disease and related dementia' and features a sub-category 'Caregiving'. It includes a photograph of a woman and an elderly woman, a search box for local resources, and a 'Connect with your local ADRC' section. The footer of the browser window shows the taskbar with various application icons and the system clock indicating 9:18 AM on 10/12/2014.

ADRC Website: Caregiving

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

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1-855-673-2372

Home Explore Search Connect Plan

Long-term services In your community In your home In a facility Alzheimer's More options

Safety Legal/financial **Caregiving** Medical Research

Caregiving

Care options

In-home care

In-home care includes a wide range of services to help a person with Alzheimer's or another dementia stay at home. It also can help caregivers.

Resources:

- ▶ IN-HOME HEALTH CARE
- ▶ HOME-CARE SERVICES
- ▶ SEARCH FOR LOCAL RESOURCES

Adult day services

Adult day centers offer social and safe activities for people with Alzheimer's and other dementias.

- ▶ LOCAL RESOURCES

Residential care settings

Does the person with Alzheimer's or another dementia prefer a communal-living environment? Or does the person need more care than he or she can get at home? If so, a residential care setting may be the best option. Different types provide different levels of care.

Connect with your local ADRC.

ADRC of Oregon staff are available to help you explore your options to meet your current needs or create a plan for the future.

▶ CONNECT NOW

ADRC of Oregon
Aging and Disability
Resource Connection
of OREGON

ADRC Caregiver Resources

- Family caregiver support program at each AAA
- Support groups (such as Alzheimer's Association)
- Workshops like *Powerful Tools for Caregivers* and *Savvy Caregiver*
- Hands-on caregiver training that may be offered by the Home Care Commission, Alzheimer's Association, Alzheimer's Network of Oregon, and others

<https://adrcoforegon.org/consite/explore-caregiver-supports.php>

Caregiver Resources

- Oregon Family Caregiver Handbook (Spanish, too)
- Caregiving Guides
- Resources for caregivers of veterans
- Caregiver Self-Assessment Questionnaire
- 10 Tips for Family Caregivers

<https://adrcoforegon.org/consite/explore-caregiver-supports.php>

Please Remember:

- In keeping with national standards that ADRCs use in providing Information and Referral services, it's a best practice to refer consumers to specialized I&R services
- For individuals and families dealing with possible or diagnosed dementia, this means ensuring that you're always letting these callers know about the 24/7 Alzheimer's Association Helpline (**1-800-272-3900**), and documenting this referral in the ADRC system

Caregiver Resources

Remember to share local resources you find with your ADRC database specialist, so everyone can benefit from the knowledge!

Summary of Module TWO

- Behavioral expressions that are challenging to caregivers are *ALSO* challenging to the person with dementia
- Behaviors are expressions of unmet needs that a person cannot communicate through words
- The physical and social environment can impact the feelings and actions of a person with dementia in many ways

Summary of Module TWO (cont'd.)

- 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

NEXT: Module 3

- Clinical aspects of dementia
- Benefits of early diagnosis
- Clues that dementia may be an issue when a consumer contacts you
- Questions to ask to help determine if dementia is an issue

Thank you for your participation!

Please **CLICK HERE** to give us your feedback on this training module.

<https://www.surveymonkey.com/s/Dementiamodule2>

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.