ADRC Dementia Care Training

Implementing Person-Centered Dementia Support: Tier 1

Module 2: Communication and Behavioral Expressions
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...
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
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
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
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, 173,000 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
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?
Challenging behavioral expressions are almost always caused by unmet human needs that the person with dementia has trouble communicating.
Behavioral expressions are attempts at communicating unmet needs by a person who has trouble finding the words to express him or herself.
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
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?
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
ACTION NEEDED: STOP NOW AND WATCH THIS VIDEO IN YOUR BROWSER. When you are finished please return to this presentation.

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
ADRC Website: Explore

https://adrcoforegon.org/consite/explore.php
ADRC Website: Alzheimer’s

ADRC Website: Caregiving

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.
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.