ADRC Dementia Care Training

Aging Services & Supports for People Living with Dementia: Tier 1

Module 1: Understanding Person-Centered Care
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...
Those with dementia are still people and they still have stories and they still have character and they're all individuals and they're all unique. And they just need to be interacted with on a human level.

- Carey Mulligan
Volunteering makes me aware that I can still help others, despite what I have. It keeps Alzheimer’s from taking over our lives.
- Annette, a 72 year-old retired real estate agent
Listen with the ears of your heart.

– Sue Sweeny, 76 years old
If we sugarcoat, or worse yet, turn a blind eye to an issue like Alzheimer’s because it makes us uncomfortable, we will never understand its complexities.

- Scott Kirschenbaum, filmmaker
They don’t need to tell me I’m dying with Alzheimer’s disease. I know that... What they need to do – what you need to do – is help me figure out how to live with it.

- Mr. Spencer, a retired business executive
Your Work
Objectives

1. Describe person-centered dementia care and how it relates to your work or partnership with the ADRC

2. Gain insight into the experience of dementia and how stigma can negatively impact quality of life

3. Understand how people with dementia benefit from social interaction and involvement in their communities
Person-Centered Perspective

- Understanding each person’s needs, preferences, and what gives them quality of life
- Being aware of uniqueness of each human being
- Respecting each person’s experiences and perceptions of the world
Personhood Exercise

- How you were raised
- Culture/ethnicity
- Life challenges and accomplishments
- Work/career
- Hobbies/interests
- Personality and sense of humor
- Important relationships
- Spiritual and/or religious beliefs
Diversity Wheel
Personhood: Tom Kitwood
# Medical Model vs. Social Model

<table>
<thead>
<tr>
<th>MEDICAL MODEL</th>
<th>SOCIAL MODEL</th>
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<tbody>
<tr>
<td>• Treat the disease</td>
<td>• Treat the whole person</td>
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<tr>
<td>• Routines for staff efficiency</td>
<td>• Routines from life experiences</td>
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<tr>
<td>• Pharmacological interventions</td>
<td>• Non-pharmacological interventions</td>
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<tr>
<td>• Patients</td>
<td>• People</td>
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Psychological Needs - Kitwood
Imagine for a moment...
Human Needs

- **Comfort** - closeness, calmness, the feeling of security, having someone to soothe pain and/or sorrow

- **Attachment** - close relationships and bonds with others
Human Needs

- **Inclusion** - being part of a larger group and having a special place within a group

- **Occupation** - being involved in life in a way that is personally meaningful and provides deep satisfaction
Human Needs

- **Identity** - knowing who you are and having meaningful role(s) in life
Video: Jack Agueros

As you watch the video, please think about:

• The ways in which Jack still shows his personhood and sense of self
• The ways his daughter and son still honor his identity
• How his son and daughter describe loving their father for who he is now, rather than focusing on what was or what should be
Video: Jack Agueros

ACTION REQUIRED: PAUSE THIS VIDEO NOW


Click the link to watch the video in your browser. Return to this presentation when you have finished.
Video: Mary Ann Becklenberg

- As you watch the video, please concentrate on:
  - The ways Mary Ann describes living with dementia
  - Mary Ann's fears about the future
  - How her loved ones react to Mary Ann's struggles with the disease
  - What the disease has taught her
Video: Mary Ann Becklenberg

http://youtu.be/sIRb--Nauwk
Stigma and Dementia

- Relationships with family may change
- Friends may refuse to believe a diagnosis or feel helpless and withdraw from a person’s life
- People may speak to “healthy” others rather than addressing the person directly
- Reactions from others may prevent that person from seeking help or support from others or cause the person to conceal his/her diagnosis for fear of rejection.
People may unintentionally use “elderspeak,” patronizing language or tone. For example:

- “How are we doing today, Mr. Smith? Did we have a good night’s sleep last night?”
- “I love old people! They are all so cute and sweet!”
- “Come on now, Mrs. Jenkins. It’s time to go potty!”
Some Causes of Stigma

- Lack of knowledge
- Fear
- Concern
- Don’t know the consequences
Video: Facing Stigma

http://youtu.be/klz6gurnNVc
Terminology

Dementia patient

OR

Person with dementia
Terminology

- *Feeder vs. person who needs mealtime assistance*
- *Diaper vs. incontinence product*
- *Honey or Sweetie vs. the person’s preferred name*
- *Dementia unit vs. program for people with dementia or secure neighborhood*
You Can Have An Impact!

- Think about your language and what meaning it conveys to others
- Choose words that are person-centered and send the message YOU want others to hear
- How would you want others to refer to you if you had dementia?
The Experience of Dementia
Journey By Train
How You Would Want to be Treated

- Listen to you
- Recognize that you are still capable
- Are patient and empathetic
- Give you time and space to make decisions
- Give you opportunities to offer advice and opinions
How You Would Want to be Treated

- Spend time with you doing fun things
- Try to create routines that makes sense to you
- Help you stay connected to friends, family, hobbies, and other things that you enjoy
- Know you are the “same old you” as before the diagnosis.
- Acknowledge your STRENGTHS
What YOU Can Do

- Learn as much as possible about the person
- Be patient
- Speak slowly and clearly and avoid slang
- Keep dignity and respect at the forefront
- Connect on a personal level
- Don’t underestimate due to dementia
- Offer resources and supports, but don’t pressure
Importance of Socialization

- People retain social skills late into the disease process
- The need to reach out and connect with others never goes away
Importance of Socialization

- Positive social interaction is beneficial to mental and physical health.
- Social interaction helps keep the brain engaged.
- Avoid stressful interactions and conflict!
Identity

- How we see ourselves
- How others see us
- Our similarities to and differences between others
Identity Exercise: Three Words

➢ Who are you?

➢ Think about your:
  • relationships with family members and/or friends
  • career accomplishments
  • talents and hobbies
  • spiritual or religious faith
  • cultural/ethnic affiliations
  • life experiences
Identity

- Everyone has an identity and a sense of self.

- People with memory loss need our help in supporting their identities.

- Dementia cannot rob a person of his or her identity if we don’t let it happen.

- You can encourage families to support identity.
Photo Series

ACTION REQUIRED: PLEASE CLICK THE LINK BELOW TO VIEW THE IMAGES

http://www.tomhussey.com/SERIES/Reflections/3/

When you have finished viewing the content, please return to this presentation.
Identity and Conversation

- Helps people feel important and needed
- Opportunity for self-expression
- Keeps people connected; reduces isolation
- Stimulates the brain
Important Questions
Important Questions

➤ In an hour, will my correction really matter, or will it just upset the person now?

➤ Could the person be expressing a legitimate sentiment but just got the facts or the words wrong?

➤ Can address the person’s feelings or sentiment without correcting the person?

➤ What can I do to help the person express him/herself, rather than correcting him/her?
Important Questions

- How can I help this person to clarify what he or she means?
  - Can I ask a clarifying question?
  - Can I ask the person to repeat him/herself?
  - Can I ask the person for more detail?

- How can I validate the person’s feelings and concerns?
Validation

Statement: “The sky is a lovely shade of red today, isn’t it?”
Response: “I think we both appreciate a beautiful sky, don’t we?”

Statement: “I have to get to work. Which way is the bus?”
Response: “You are really committed to your work. I wish everyone was as responsible as you!”
Identity Supports

- Getting together with friends
- Maintaining group memberships
- Spiritual activities/meetings
- Volunteering
Identity Supports

- Attending events
- Getting out into the community
- Doing work around the house
- Sharing knowledge/giving advice
Summary of Module ONE

- 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
Communication and behavioral expressions

• What are behavioral expressions?
• What causes them?
• How can we help families and other care partners respond appropriately to these?
• Can we prevent them? If so, how?
Thank you for your participation!

Please type this link into your browser
https://www.surveymonkey.com/s/Dementiamodule1
to give us your feedback on this training module.

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.