

ADRC Dementia Care Training

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

Module 1: Understanding Person-Centered Care

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...

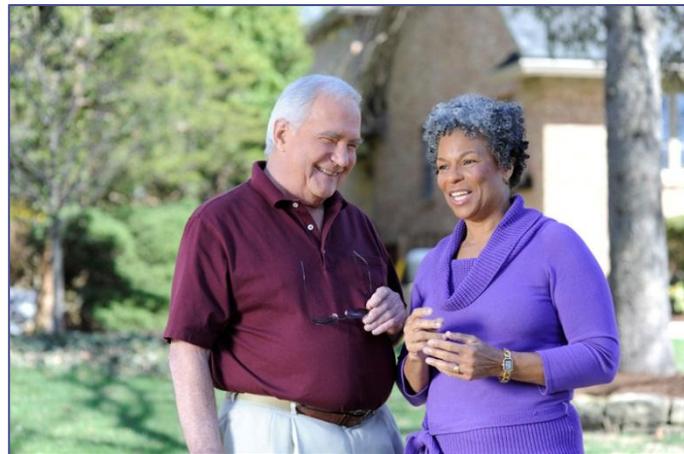
Those with dementia are still people and they still have stories and they still have character and they're all individuals and they're all unique. And they just need to be interacted with on a human level.

- Carey Mulligan

Opening Thoughts...

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



Opening Thoughts...

Listen with the ears of your heart.

– Sue Sweeny, 76 years old



Opening Thoughts...

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

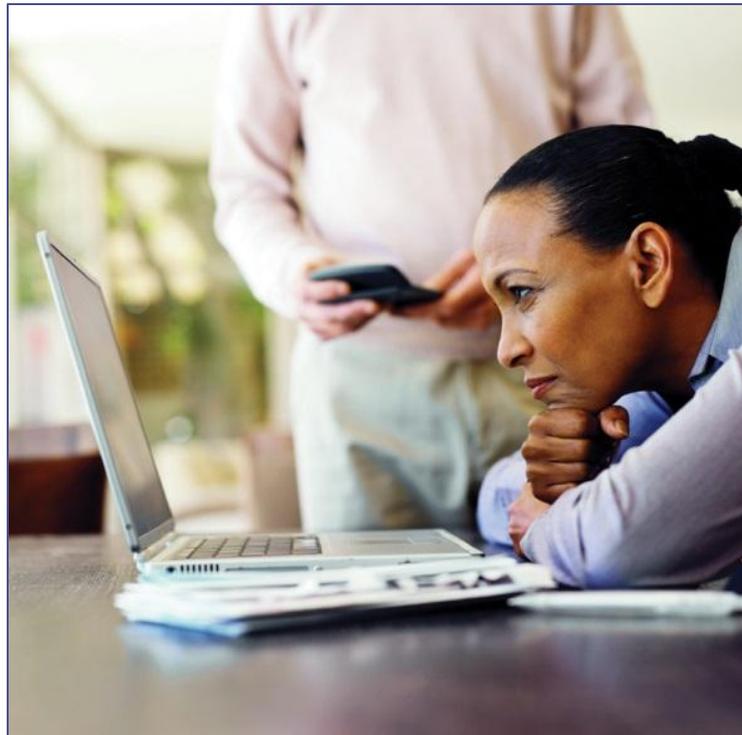
Opening Thoughts...

*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

Fear



Depression



Loss

Forgetfulness



Isolation



Kindness



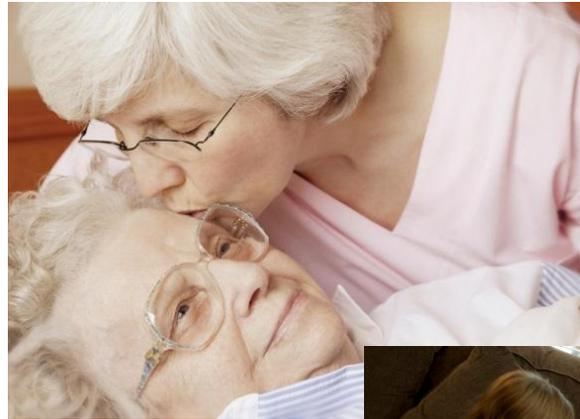
Safety



Humor



Security



Love



Hope

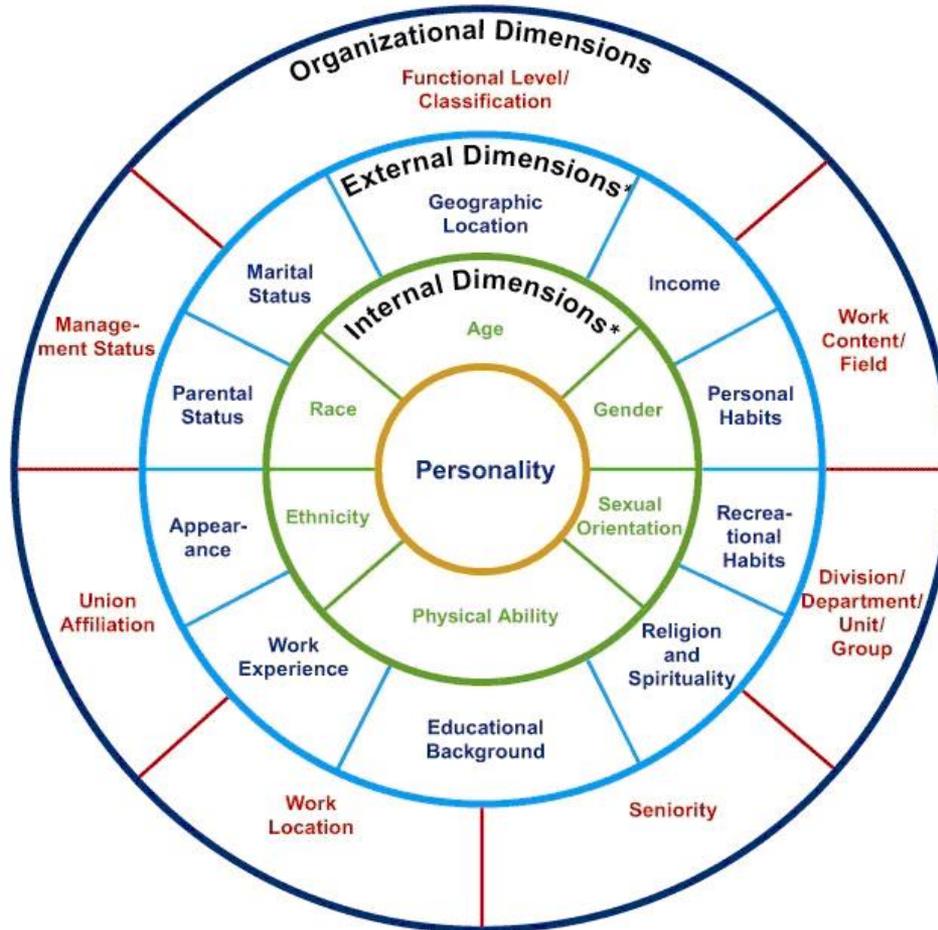
Person-Centered Perspective

- 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

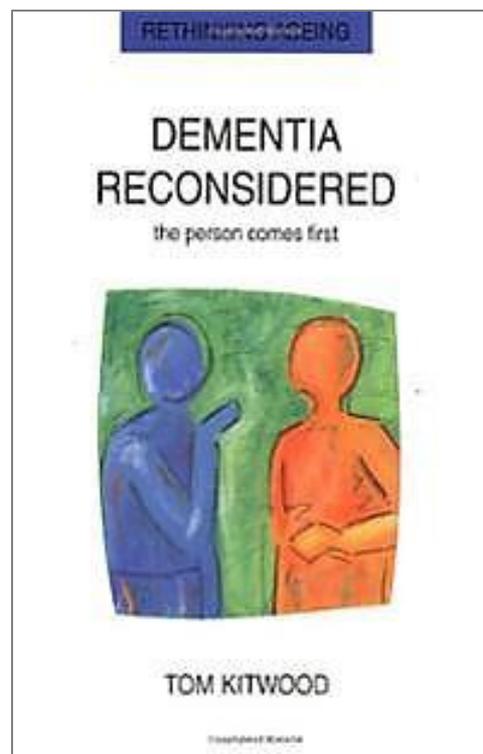
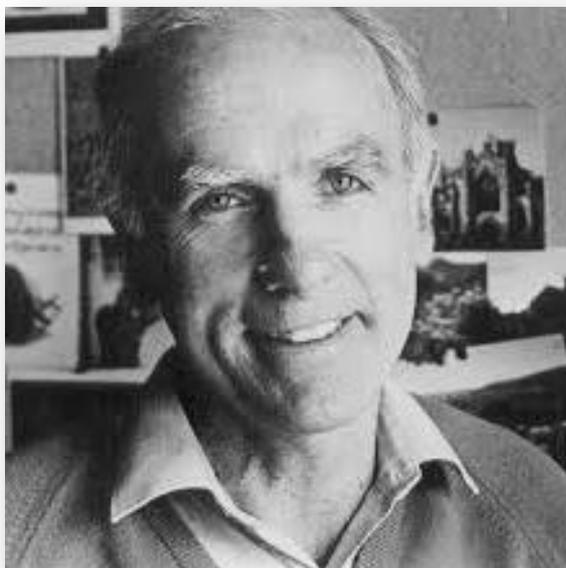
Personhood Exercise

- 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



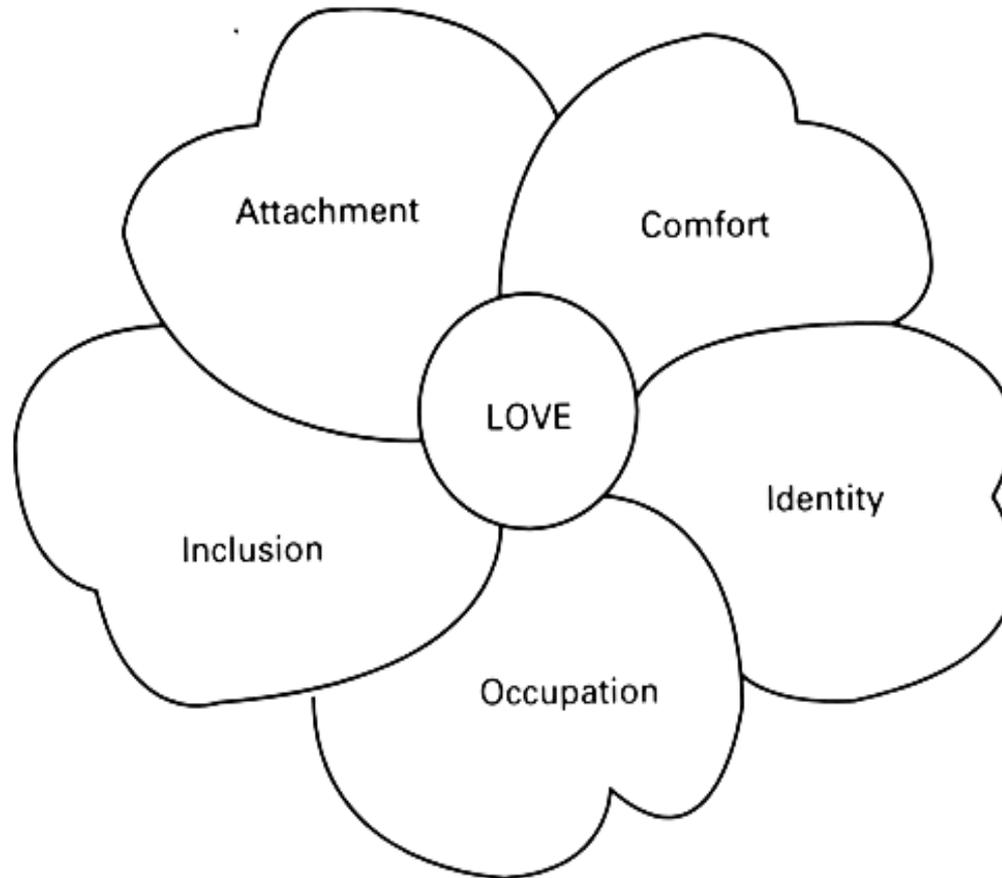
Personhood: Tom Kitwood



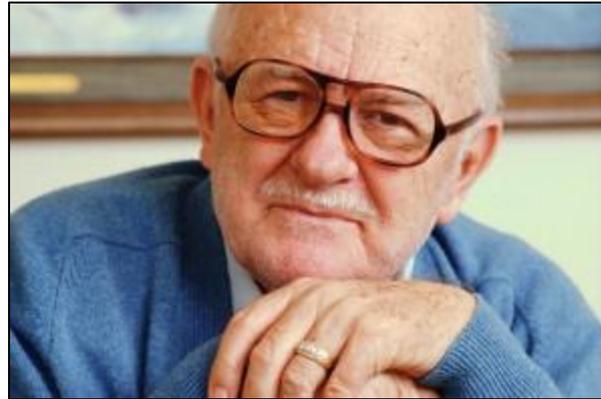
Medical Model vs. Social Model

MEDICAL MODEL	SOCIAL MODEL
<ul style="list-style-type: none">• Treat the disease	<ul style="list-style-type: none">• Treat the whole person
<ul style="list-style-type: none">• Routines for staff efficiency	<ul style="list-style-type: none">• Routines from life experiences
<ul style="list-style-type: none">• Pharmacological interventions	<ul style="list-style-type: none">• Non-pharmacological interventions
<ul style="list-style-type: none">• Patients	<ul style="list-style-type: none">• People

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

<http://www.nytimes.com/video/nyregion/10000000870254/without-words.html?emc=eta1>

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.

Stigma and Dementia

- 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

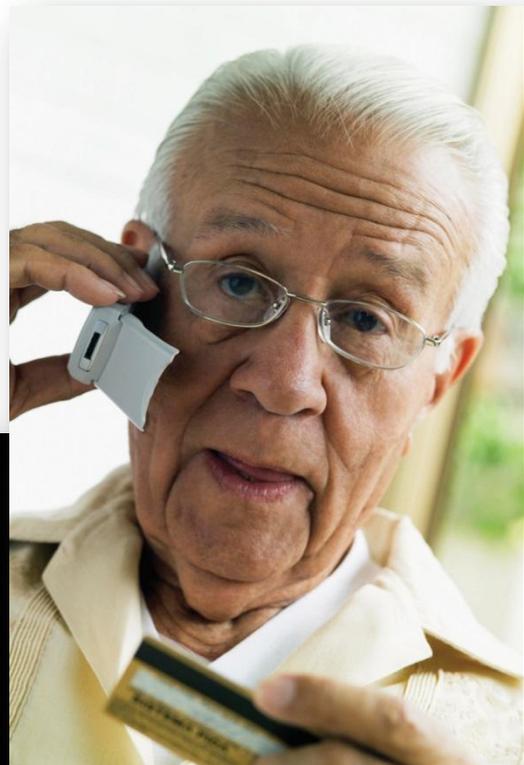
Terminology

- *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

NEXT: Module TWO

- 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.