# **ADRC Dementia Care Training**

Implementing Person-Centered Dementia Support: Tier 1

# Module 3: Medical and Clinical Aspects of Dementia Aging and Disability Resource Connection 1

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...**

https://www.youtube.com/watch?v=waeuks1-3Z4





### **Your Work**







- Discuss medical and clinical aspects of dementia
- Understand benefits of early diagnosis
- Examine clues that dementia may be an issue when a consumer contacts you
- Review questions to ask to help determine if dementia is an issue and how to help



### **Dementia Defined**

### Dementia is not actually a disease itself.

# It is a **set of symptoms** that may be caused by many different diseases or conditions.



### **Dementia Effects:**

- > Memory
- Reasoning and judgment
- Thinking
- > Ability to do self-care
- Language
- Spatial orientation
- Problem-solving
- > Mood and/or personality

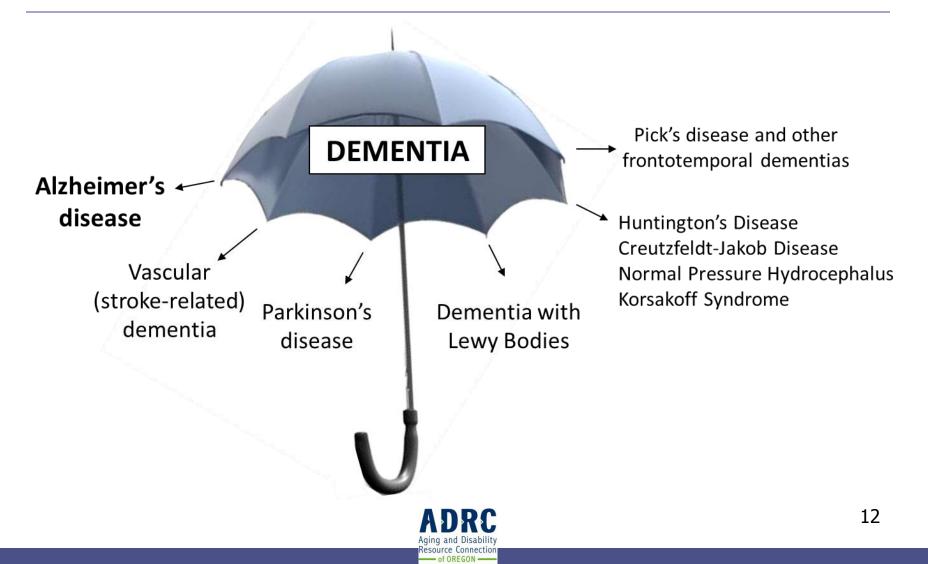


### **Dementia Terms**

- 1. Irreversible/Progressive
- 2. Reversible

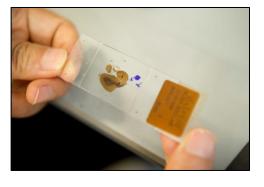


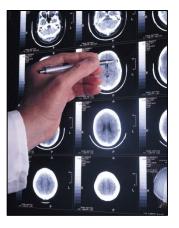
### **Dementia Umbrella**



# **Alzheimer's Disease (AD)**

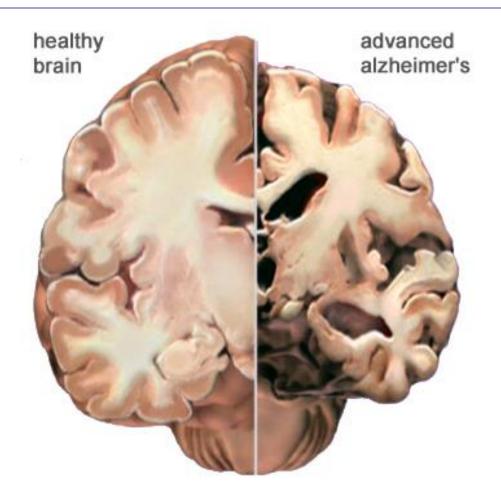
- ➤ 75% 85% of dementia
- Gradual onset
- Protein plaques and tangles
- Short-term/recent memory loss first
- > Highest risk >65
- Diagnosis of exclusion
- People live 3-20 years after diagnosis







### **Brain Comparison**





# **Young Onset Alzheimer's**

- > Often runs in families
- More rapid progression
- People with young onset are in 50s or younger
- > Unique challenges due to young age
  - Financial issues
  - Young and strong
  - Difficult placement





# Mild Cognitive Impairment (MCI)

- Intermediate stage between normal aging and Alzheimer's disease
- Not enough loss to interfere with daily functioning
- May increase risk of later progressing to AD
- Some get worse, some stabilize, some get better





# **Video: Mild Cognitive Impairment**

#### http://www.youtube.com/watch?v=k8vRubFxmwA



Janet Cellar, DNP Emory Alzheimer's Disease Research Center Administrator



### Vascular Dementia

- > One common type is called multi-infarct dementia (strokes are "infarcts")
- > Brain is cut off from blood/oxygen causing death of neurons
- Sudden onset
- Stepped progression



> May be mixed with Alzheimer's Disease



### Video: Vascular Dementia

#### https://www.youtube.com/watch?v=QTbdgHgmTgw





# **Parkinson's Disease**

> Nervous system disorder associated with:

- Trembling or shakiness in limbs
- Slowness of movement
- Muscle stiffness
- Shuffling gait
- Loss of facial expression
- Changes in voice

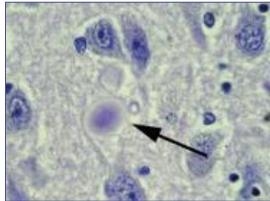


Dementia not present until late in disease process (if at all)



# Lewy Body dementia

- Named for particular type of protein clusters found in brain (Lewy bodies)
- > May progress more quickly than Alzheimer's
- Symptoms of both Alzheimer's and Parkinson's
  - Visual hallucinations
  - Movement disorders
- Increased risk for falling





# **Frontotemporal Dementia**

- Several conditions, including Pick's disease
- Relatively rare
- Impacts behavior, emotional responses, judgment, language skills
- May be misdiagnosed as psychiatric illness or Alzheimer's
- > Often occurs at younger age than Alzheimer's (40-75)



### **Other Irreversible Conditions**

- > Huntington's disease
- > Traumatic brain injury
- > HIV
- Creutzfeldt-Jakob
- > Alcohol-related dementia (Korsakoff syndrome)





# **Reversible Dementia-Like Symptoms**

- > Delirium
- Infections and immune disorders
- > Metabolic/endocrine problems
- > Nutritional deficiencies/dehydration
- Reaction to medication
- Poisoning



# **Reversible Dementia-Like Symptoms**

- Alcohol or drug use
- > Brain tumors
- Heart and lung problems
- Normal pressure hydrocephalus
- Depression



### **Important Take-Aways**

- Dementia is not a disease; it is a set of symptoms that can be caused by a number of diseases or conditions
- Alzheimer's disease is the leading cause of dementia, but not all dementia is caused by Alzheimer's
- 3. Dementia looks different depending on the person and the cause



### **Your Role**





### **Important Questions**

- In general, why is it important to ask individuals or families about dementia or possible dementia?
- What are some of the reasons you might suspect dementia could be an issue?
- What questions can you ask to help determine whether dementia may be an issue?
- What should you do if a dementia diagnosis is involved or if you suspect that dementia may be an issue?



# Why Ask about Dementia?

- Seek assistance form medical provider
- Early detection allows person and family to pursue treatment options
- Early detection allows person and family to plan
- > Helps ADRC staff make appropriate referrals

https://www.youtube.com/watch?v=my3voh-sndE



# **Importance of Diagnosis**

- Solution Ask the individual or family member if a diagnosis has been made or if the individual has been screened.
- Encourage the individual or family to make an appointment with the individual's provider, preferably at a time in which the family member can also attend (as the individual may be unaware or unwilling to share information about concerns)
- Remind individuals and families that they have the right to request a screening and proper diagnosis.



### **Diagnosis Story**

### https://www.youtube.com/watch?v=FJQXbgm8JyA



# **Reasons You Might Suspect Dementia**

The person...

- > Has trouble articulating her questions or thoughts
- Seems confused, is unable to track the conversation, or is unable to answer questions appropriately
- Cannot think of the words for common objects or concepts
  - Substitutes word such as "scoop thing" for spoon or "mouth cleaner" for toothbrush



# **Reasons You Might Suspect Dementia**

The person...

- Does not seem clear about why he called and may even ask, "Who is this again?"
- > Asks for the same thing over and over, even after you have given an answer
- Becomes easily frustrated
- Repeats the same information



### **Sample Conversation**





# **Questions for Families**

- Does he/she tell the same stories or ask the same questions over and over again?
- Have you noticed if he/she is more forgetful, such as forgetting important appointments, family occasions or holidays?
- Has he/she lost interest in his/her usual activities such as hobbies, reading or social activities?
- Have you noticed any changes in his/her moods; for example does he/she seem sad, irritable or suspicious?



# **Questions for Families**

- Does the person have any problems finding the right words, such as when finishing a sentence, or naming people or things?
- Have you noticed if he/she is having difficulty with managing finances, such as balancing his/her checkbook?
- Do you have any concerns regarding safety, such as leaving the stove on, getting lost, driving safely, taking his/her medications correctly, etc.?



## **Questions for the Person**

- > Are you having problems doing familiar tasks? For example cooking, doing laundry or shopping?
- > Do you think you have become more forgetful?
- > Are you having trouble finding the right words or names during conversation?
- Do you sometimes forget where you are, where you are going, or what you are doing?
- Have you been told that you repeat questions or say the same things over and over again?



## **Questions for the Person**

- > Have you become lost when walking or driving?
- Have you noticed (or has your family told you they see) changes in your mood or personality? For example have you experienced any sadness, irritability or frustration?
- Do you feel like you have been worrying more than usual lately?



#### **Goals and Challenges**

- People need time to develop trust
- A person may not know an answer to a question, which can cause frustration
- People may be fearful or in denial





- What's the best way to share information with you?
  - Would information in writing be helpful, is there someone else who can help in decisionmaking?



- > What do people do to help you?
  - To identify the kinds of tasks with which a person may require assistance





> Who helps you? or Who do you live with?

• To identify potential sources of further help and information





> Do I have your permission to contact them?

• Contacting a family member or other care partner may open the door to the person receiving needed services or supports



# **Clarifying Questions**

- Is there someone there with you right now who could help me understand what you are telling me?
- Can you share your (family member's) name and number with me?
- Do I have your permission to call him/her about your concern?



## **Other Recommendations**

- Refer to health care provider
- Refer to ADRC website, and walk them through the resources if you are able
- Encourage them to call back in the future
- Remember to track "dementia" in the ADRC Call Module or Care Tool to allow for future follow-up



# **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





## What You Can Do



- 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
- Recommend resources that may be helpful, both for the person with dementia AND for the caregiver



#### **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



# **Summary of Module THREE**

- 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



## **NEXT: Module 4**

- Understand the information and referral process for specific issues related to dementia, including:
  - Referral to Adult Protective Services (APS)
  - Severe or emergency behavioral expressions
- Understand when to refer consumers and families for options counseling



# Thank you for your participation! Please <u>CLICK HERE</u> to give us your

feedback on this training module.

https://www.surveymonkey.com/s/Dementiamodule3

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