

# 2023 Forum on Aging in Rural Oregon

## Dementia in Rural Oregon: Envisioning Support Across the Care Continuum

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Thank you to our partners:





# Dementia in Rural Oregon: Policies, Systems, and Supports

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DATE: May 16, 2023 PRESENTED BY: Walter Dawson, DPhil, Assistant Professor, OHSU School of Medicine, OHSU-PSU School of Public Health and Portland State University, Institute on Aging

# Disclosures

All comments and opinions expressed here are mine alone and not necessarily those of any funder, employer, or organization with which I hold leadership positions.

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Nearly 25 years ago, at the age of 10, I wrote a letter that changed my life.



Walter Dawson with his father, Cecil | Credit: Courtesy of Walter Dawson

The letter explained how I was just 8 years old when I learned my father, Cecil Dawson, was living with Alzheimer's disease. It shared how my mother

# What is Dementia?

**A Group of Disorders – Not One Disease**

Multiple types of dementia

- Alzheimer's disease (over 60%)
- Vascular
- Lewy body
- Frontotemporal dementia (FtD)
- Korsakoff's (Alcohol-related)
- Mixed dementia – co-occurring types

Note: Dementia is not a normal part of aging





# A Few Oregon Data Points

**Oregon is a large state with significant rural/fronter areas**

18.2% of Oregon's population is 65+

Percentage of Oregon's older adults who live in rural areas is higher than national average of 26.8% (U.S. Census Bureau, 2019).

All 7 Health Professional Shortage Areas (HSPAs) in Oregon in rural areas (Zhu et al., 2022).



# Rural Disparities in Dementia

According to Arsenault-Lapierre et al., 2023:

## **Strong Evidence for:**

- Higher mortality among people living with dementia and care partners in rural areas

## **Moderate Evidence for:**

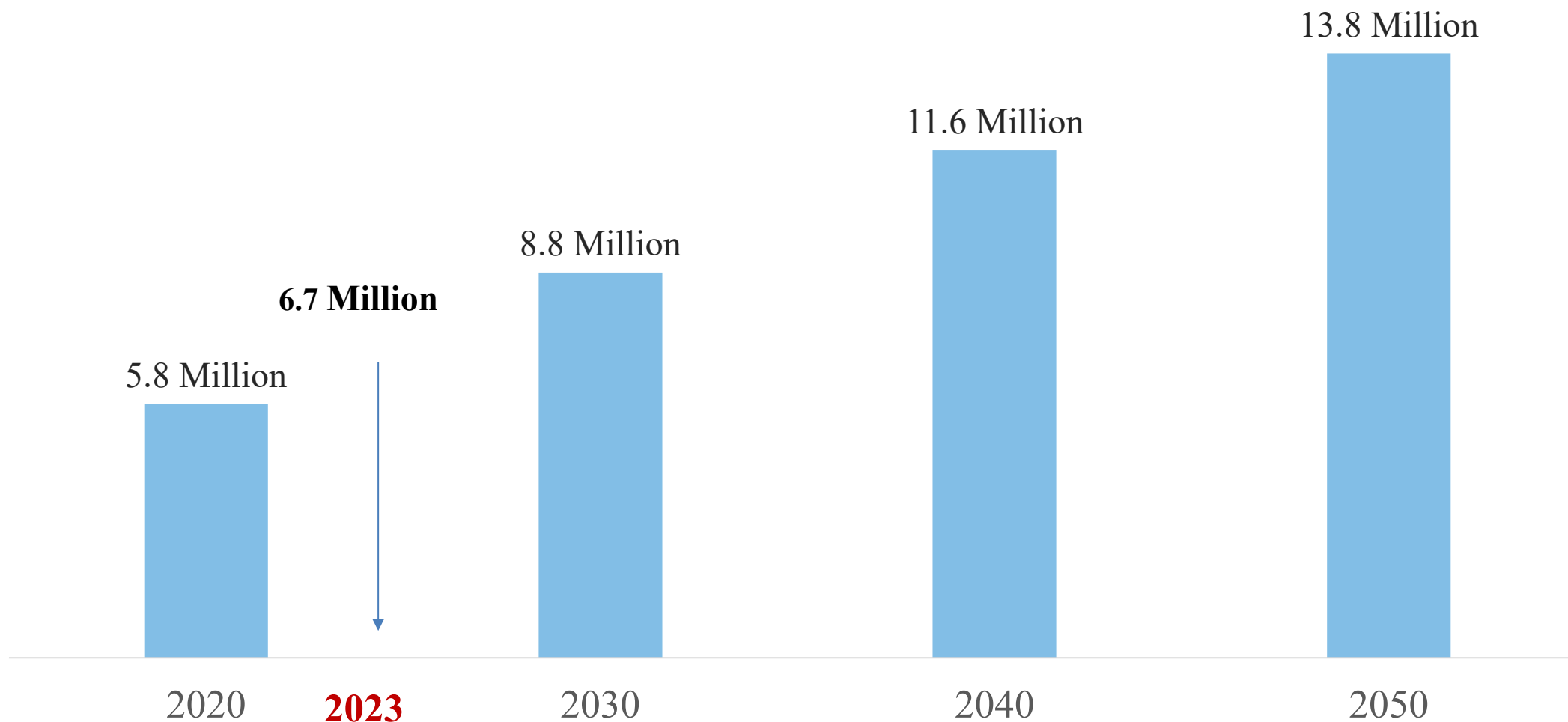
- Fewer visits to any physicians
- Higher hospitalizations but shorter stays
- Higher anti-dementia medications
- Higher antipsychotic medications
- Lower use of home care and higher use of nursing home

Source: Arsenault-Lapierre, G., Bui, T.X., Le Berre, M. et al. 2023.



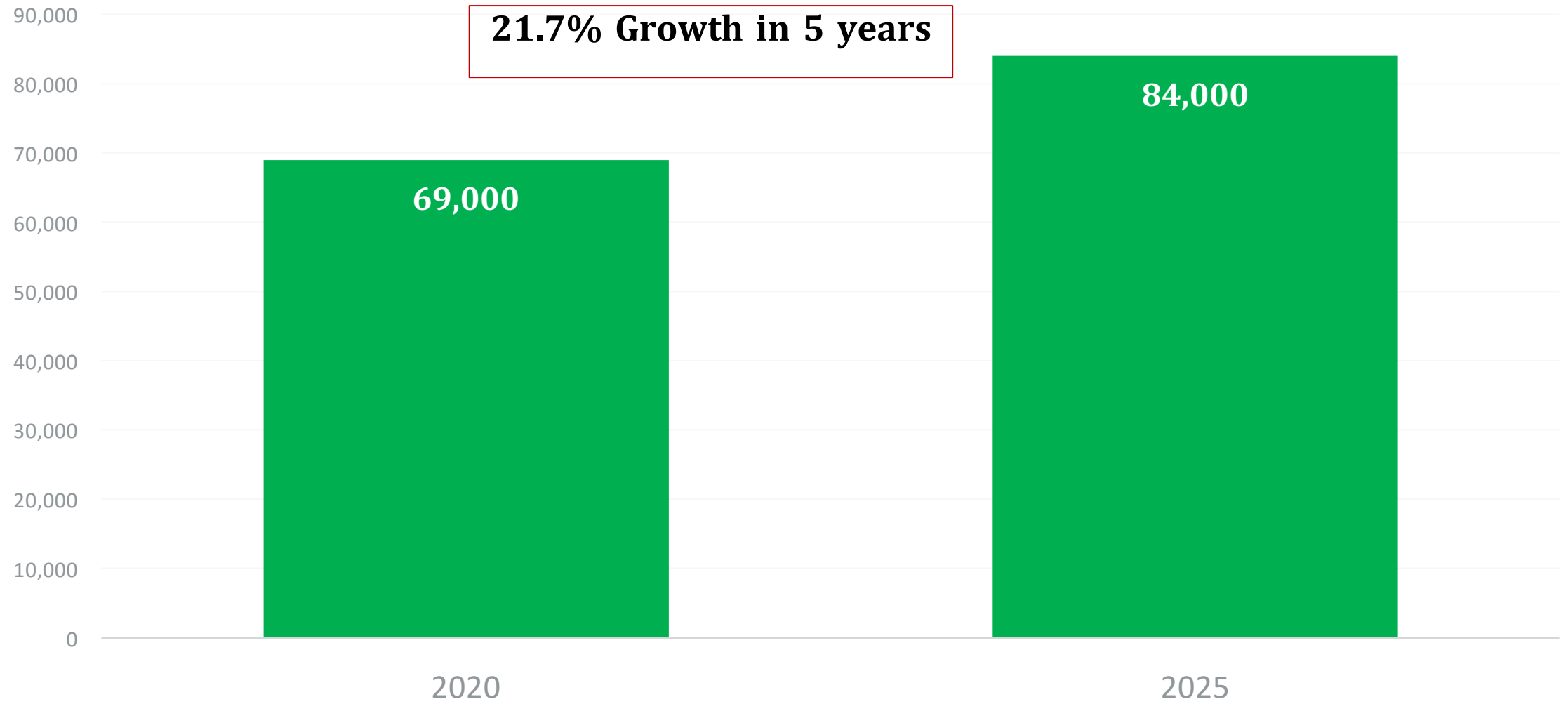


# U.S. Adults Living with Alzheimer's Disease & Dementia: 2020-2050



Source: Alzheimer's Association, 2018 and 2023.

# Oregonians Living with Dementia



Source: Alzheimer's Association, 2023.

# Caregiving in Oregon



**168,000** Dementia care  
partners



**317,000,000** Hours of  
unpaid care annually



**\$7,212,000,000** Value  
of unpaid care

# Underdiagnosed Dementia



**50% of people living with  
dementia in the US never**

**formally diagnosed**

Source: Office of the Assistant Secretary for Planning & Evaluation, 2012; World Health Organization, 2012.

# Caregiving in Oregon

**60%** - CPs w/ at least one chronic condition

**29%** - Care partners reporting depression

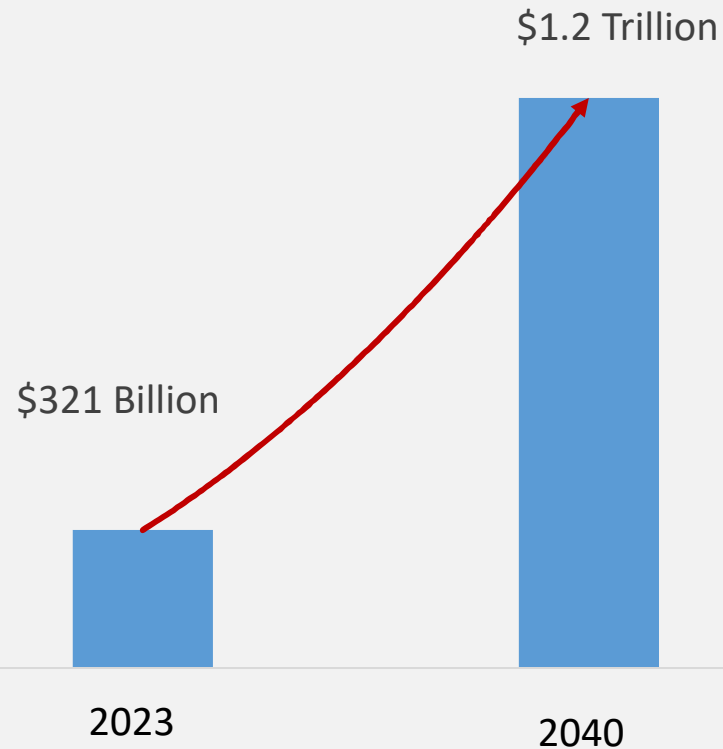
**15%** - Care partners reporting frequent poor physical health





# Dementia: Financial Impacts on U.S. Health Care System

**Projected Growth of U.S. Dementia Care  
Costs: 2023-2040**



Source: Alzheimer's Association, 2023.

## **U.S. National Dementia Care Costs**

**\$321 billion** Total health care system impact

**\$222 billion** Total Medicare & Medicaid impact

## **Individual Dementia Care Costs**

**\$48,977** Average annual cost per person

**\$10,798** Average annual out-of-pocket costs

## **Rising Costs of Dementia Care**

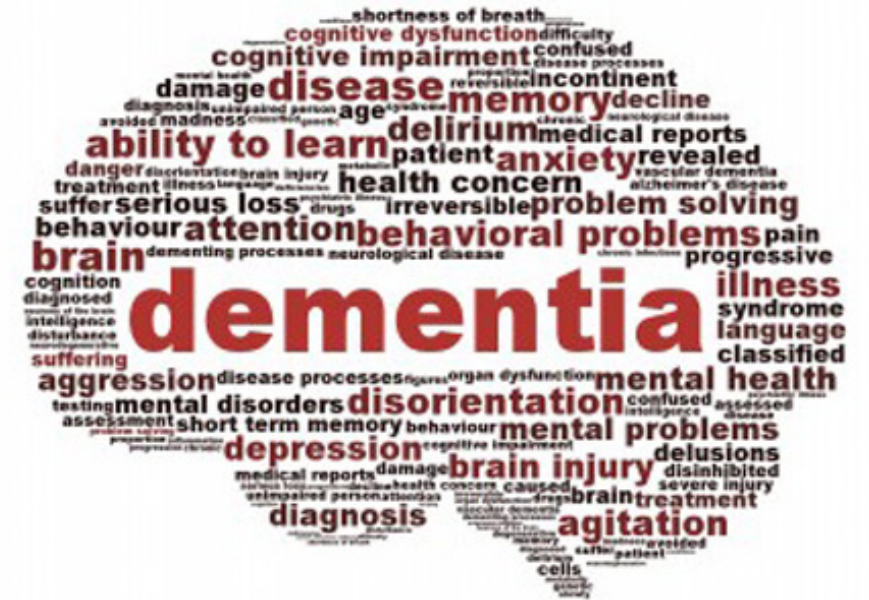
# Costs of Dementia: Oregon

2020: \$253 million Medicaid

2025: \$317 million Medicaid



# Dementia – A Policy Issue



# Optimizing brain health across the life course:

WHO position paper



## Global Actions to Advance Brain Health via Policy

Source: World Health Organization, 2022.



# Joining a research study

## Why join a study?

- Connect with staff who have a vast knowledge of aging, memory loss, and brain health
- Help scientists learn more about aging and memory loss (research can't move forward without your help)
- Help the next generation (those in your family and in the larger population)
- Be empowered and take an active role in society
  - Together we can add years to life and life to years

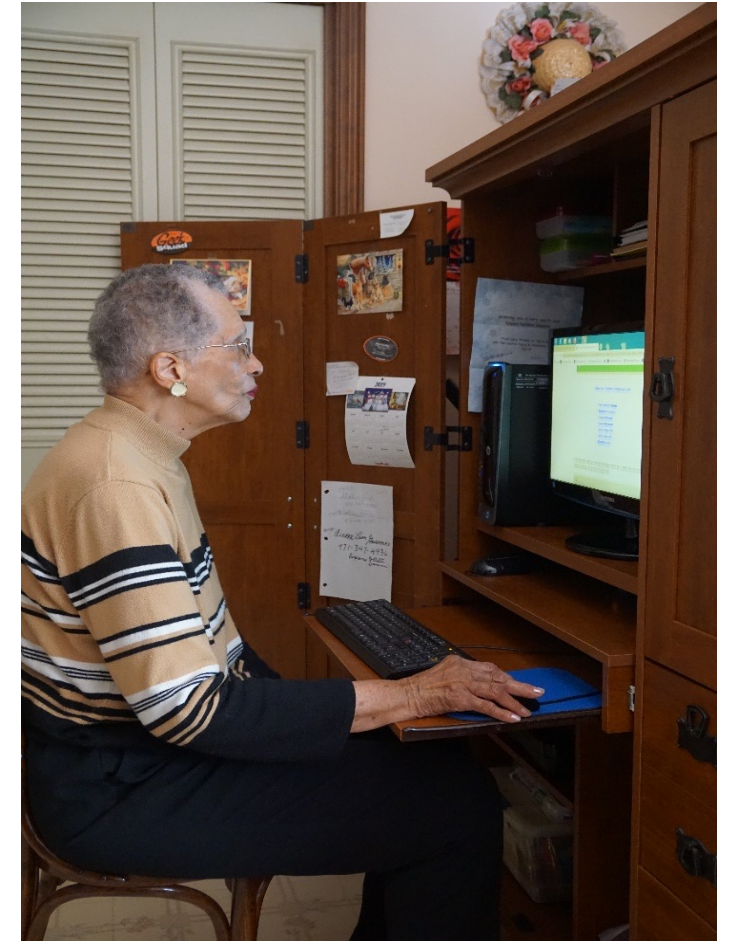
## How to join a study?

- Contact our research coordinator, Natasha Spoden
- **Phone:** 503-494-7647
- **Email:** [adresearch@ohsu.edu](mailto:adresearch@ohsu.edu)



# Examples of available studies

- **Clinical trials:** Testing ways to treat, detect and prevent memory loss and dementia
- **Online surveys:** Sharing your opinions about healthcare and technology to help inform our research
- **Longitudinal:** Allow researchers to collect data about you (using surveys and observations) over an extended period of time to gain insight into the aging process
- **Educational programs for caregivers:** Learning skills and techniques for caring for someone with dementia and provide feedback about the online program
- **At home monitoring:** Using a system of sensors and technology devices to collect objective data about aging at home and assessing future aging-related needs



# How to contact us

For more information, contact the research team at the Layton Center

503-494-7647

[adresearch@ohsu.edu](mailto:adresearch@ohsu.edu)



# References

Alzheimer's Association (2023). 2023 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia;19(4). DOI 10.1002/alz.13016.

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Zhu JM, Howington D, Hallett E, et al. Behavioral Health Workforce Report to the Oregon Health Authority and State Legislature. Oregon Health & Science University; 2022. [https://www.ohsu.edu/sites/default/files/2022-02/PRP\\_113\\_Behavioral\\_Reimbursement\\_Report\\_02.01.22\\_V2.pdf](https://www.ohsu.edu/sites/default/files/2022-02/PRP_113_Behavioral_Reimbursement_Report_02.01.22_V2.pdf)







# Thank You!

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@healthpolicywd



# Dementia in Rural Oregon

## Caring at the End of the Journey

Rod Harwood, M.Div., MA, QMHP-C  
Older Adult Behavioral Health Coordinator  
Certified Positive Approach to Care Trainer & Consultant  
Greater Oregon Behavioral Health Inc.



Oregon  
Older Adult Behavioral Health Initiative



# Dementia in Rural Oregon

## Caring at the End of the Journey

Caring for a person with dementia at the end of life has some unique challenges. Navigating frequent hospital stays, advanced directives, living wills, do not resuscitate orders, palliative care and giving the person living with dementia permission to pass will be discussed.

1. Advocating at more frequent hospital stays
2. Advanced Directives, living wills and Do not resuscitate orders (DNR) – planning in ADVANCE
3. Letting Go vs Giving Up - Giving the person permission to pass



# Table of contents

0



1

Hospital management  
of older adults

0



3

Planning in ADVANCE

0



2

Advocating at more  
frequent hospital stays

0



4

Letting Go vs Giving Up





01

## Hospital management of older adults

# Hospital management of older adults



## People age 65 and older

Make up just 16.9 percent of the U.S. population but nearly 40 percent of hospitalized adults.



## Rate of Hospital Stays

Americans over age 74 had the highest rate of hospital stays, followed by those in their late 60s and early 70s.



## Percentage of Population

By 2030, the percentage of the population over 65 years of age will exceed 20 percent, or over 70 million people.



UpToDate®

**Melissa Mattison, MD** Literature review current through; **Mar 2023.** | Topic last updated: **Nov 16, 2021**



# Hospitalization rates and predictors in people with d



## Hospitalization Expected to Rise

For older people throughout the century, with people with dementia rising parallel



## Harmful and Distressing

Hospital admissions can be harmful and distressing for people with dementia who are less likely to receive adequate pain relief and more likely to receive potentially harmful medications



## Higher Risk

Higher risk of delirium than those without dementia

# Hospitalization rates and predictors in people with d



## Decline in Functionality

Commonly decline functionally during admission



## Avoidable Admissions are More Frequent

Avoidable admissions are more frequent for people with dementia.  
Readmission are common and costlier.



## Premature discharges

Pressures on hospitals to reduce admission length could also mean that people with dementia are prematurely discharged from hospital into long-term care



# Pain Management – Hip Fracture

- ✓ Forty-four percent of cognitively intact individuals reported severe to very severe pain preoperatively and 42% reported similar pain postoperatively.
- ✓ Half the cognitively intact patients who experienced moderate to very severe pain were prescribed inadequate analgesia for their level of pain.
- ✓ Eighty-three percent of cognitively intact patients and 76% of dementia patients did not receive a standing order for an analgesic agent.
- ✓ Advanced dementia patients received one-third the amount of opioid analgesia as compared to cognitively intact



**A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture**

[Pain Symptom Manage](#) 2000 Apr;19(4):240-8.

# 02

## Advocating at more frequent hospital stays

You can enter a subtitle here if you need it





# **Be Ready...reducing the stress and confusion**

## **What to Pack**

- ✓ **Health Insurance Card**
- ✓ **List of Medications**
- ✓ **Advance Directive**
- ✓ **Personal Information Sheet**
- ✓ **Snacks & Water Bottle**
- ✓ **Pain Medication (over the counter)**
- ✓ **Pad and Paper**
- ✓ **Small amount of cash**
- ✓ **Note outside of bag to bring cell phone & charger**



# Before a Planned Hospital Stay

- ✓ Hospitalization is not a matter of “if” but “when”
- ✓ Have a discussion as disease progresses as to when hospice may be a better choice
- ✓ Build a Care Partner Team of support
- ✓ Ask Medical Provider if some tests can be done before a planned admission
- ✓ Ask if regular medications can continue with admission
- ✓ Ask for private room if possible and ability care partner to stay 24 hrs a day
- ✓ Tell person living with dementia that the two of you will be spending time at hospital for short time





# Information for the Hospital Team About a Patient with Memory Problems

**Personal Info:** What does patient like to be called?

**I like to:** Does the patient usually watch TV or listen to the radio? If so, what shows or type of music or TV shows?

**Nutrition:** Patient usually eats these foods best:

**Medications:** Does that patient take his/her medications easily? If no, what cues or strategies work?

**Hygiene:**  
What is the patient's usual bathing schedule?

**Toileting:** Does the patient usually go to the bathroom: Alone?

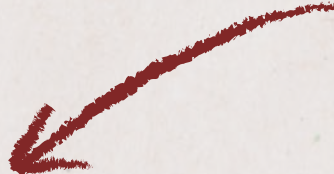
**Communication:** What is their best form of communication?

**Activity:** Mobility. Does he/she usually use a cane. Walker or wheel chair

**Sleep:** Patient usually goes to sleep easily? If no, what helps?

**Behavior/Mood:** What is the patient's typical personality type: quiet, friendly, scared

# Possible Atypical Pain Behaviors

- ✓ Agitation
  - ✓ Vocalizations
  - ✓ Grabbing or hitting
  - ✓ Excessive sleepiness
  - ✓ Repetitive movements
  - ✓ Pacing
  - ✓ Pushing furniture
  - ✓ Gritting teeth, grinding teeth, guarding
- 

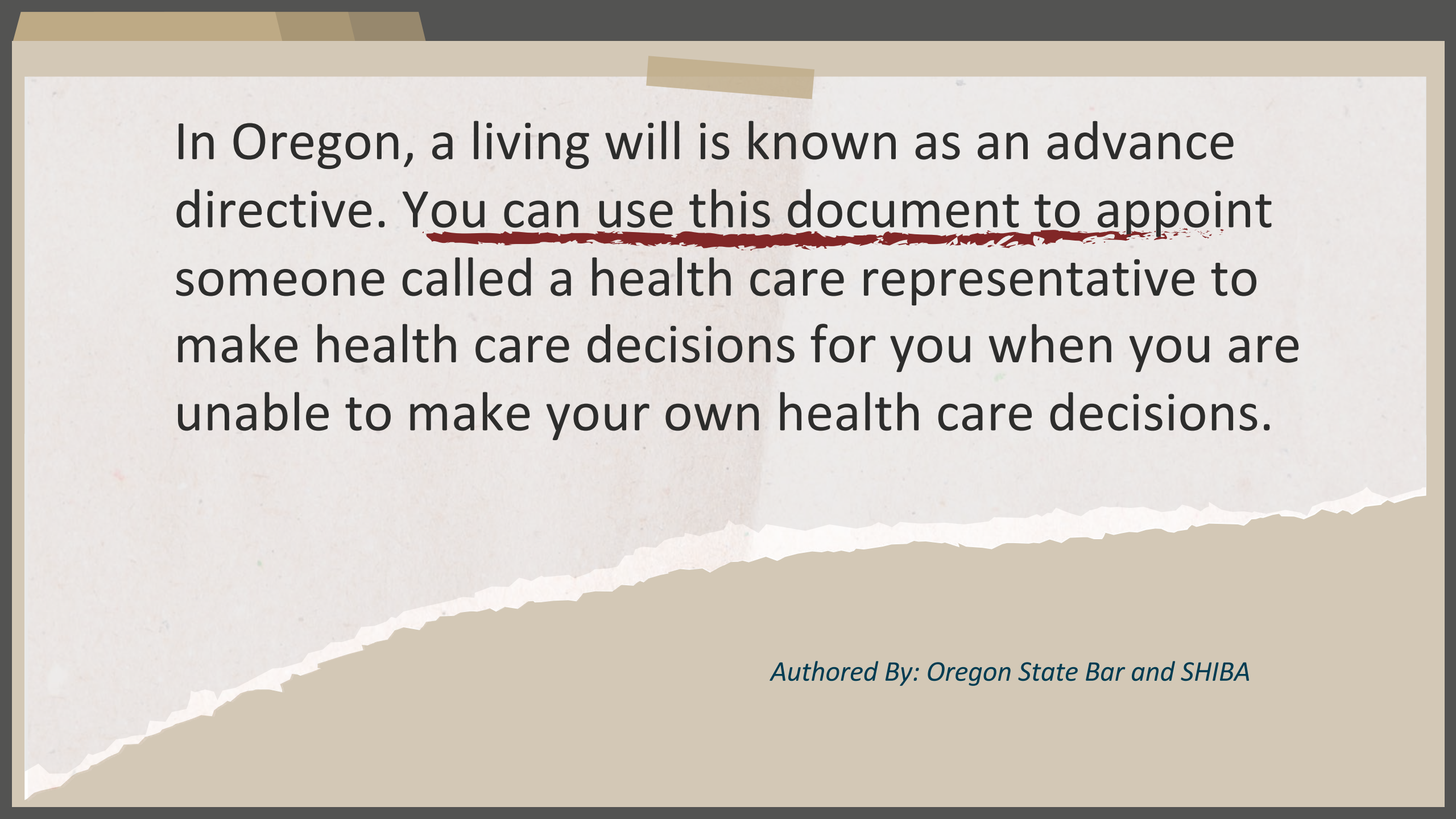


# 03

## Planning in ADVANCE

Advanced Directives, living wills and  
Do not resuscitate orders (DNR)





In Oregon, a living will is known as an advance directive. You can use this document to appoint someone called a health care representative to make health care decisions for you when you are unable to make your own health care decisions.

*Authored By: Oregon State Bar and SHIBA*



	<b>Advance Directive</b>	<b>POLST</b> (stands for Portable Order for Life Sustaining Treatment)
<b>Who is it for?</b>	All people 18 years and older.	People with a serious illness or who are older and frail and might not want all treatments.
<b>What kind of document is it?</b>	It is a legal document.	It is a medical order.
<b>Who signs it?</b>	You fill it out and sign it. A Notary Public or two witnesses sign it. Also, your health care representative signs it.	Your health care provider fills it out with your input. Then signs it.
<b>Do I need a lawyer?</b>	No.	No.
<b>Who keeps the form?</b>	You keep the original where loved ones can find it. You give a copy to your health care representative and provider.	Your health care provider's office keeps it and enters it into the electronic Oregon POLST Registry. They give you a copy. You can post it at home in a place where it is easy to find, like on the fridge.
<b>Can I change the form if I change my mind?</b>	Yes. You can tear up the old one. Then write a new one where loved ones can find it. You give a copy to your health care representative and provider.	Yes. You can ask for an appointment with your health care provider to change it.
<b>What if there is a medical emergency and I cannot speak for myself?</b>	Your health care representative speaks for you and honors your wishes.	The ambulance staff, hospital staff and health care providers look for the medical orders in the electronic data base and follow them.

Adapted from © The Next Door, Inc. 2019



# Oregon Advance Directive and Dementia

- ✓ Terminal Condition
- ✓ Advanced Progressive Illness
- ✓ Permanently Unconscious
- ✓ The Brain is Dying
- ✓ Gets Progressively Worse and is chronic - unable to communicate, swallow, care for self or recognize others
- ✓ May become Permanently Unconscious

# Oregon do not resuscitate (DNR) order

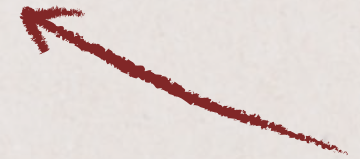
- ✓ Used to notify medical staff that a patient does not wish to receive cardiopulmonary resuscitation (CPR) when experiencing a medical emergency in which no pulse or breathing is reported.
- ✓ Without a DNR order in place, health care providers will have the responsibility of performing CPR in an attempt to save the patient's life.
- ✓ The DNR order can be requested from the patient's doctor or from another authorized individual.
- ✓ The order shall be signed by the patient and the authorized medical professional.



# DNR or AND? Is Language Important?

- ✓ DNR – Do not resuscitate
- ✓ Language that is familiar to all
- ✓ Can give misimpression that the attempt to resuscitate is likely to succeed
- ✓ The patient or family may think they are deciding whether they are deciding whether to live or die, even though in an end-of-life situation, all roads lead to death
- ✓ AND – Allow natural death
- ✓ Clearer language affirms that patients want nature to take its course, without CPR/ACLS
- ✓ Clarification needed in orders about what is not wanted (CPR/ACLS) and what is wanted (pain control, hydration, etc.)

The Ochsner Journal



# 04

## Letting Go vs Giving Up

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Giving the person permission to pass





# What are the Different Care Approaches to Consider?

- ✓ Health Promotion
- ✓ Curative
- ✓ Restorative
- ✓ Rehabilitative
- ✓ Maintenance
- ✓ Compensatory
- ✓ Palliative
- ✓ Hospice



# Acute Illness Versus Dementia

- ✓ You can FIX IT!
- ✓ IT gets better & goes away
- ✓ It lasts only a SHORT time
- ✓ Doctors KNOW what to do to make it better
- ✓ The person goes back to how they were pre-illness

- ✓ You can't change it
- ✓ It keeps getting WORSE No matter what you do!
- ✓ It lasts a LONG time –YEARS
- ✓ Doctors can offer only help –they can't fix it
- ✓ You can't go home again –The person is NEVER the same

# Letting Go Versus Giving Up

- ✓ When is it time? Holding on vs Supporting
- ✓ How will you know?
- ✓ What is enough?
- ✓ Who should help decide?
- ✓ How to balance OLD wishes/promises and the current realities
- ✓ How can we make it happen?
- ✓ What do we do instead?





**Normal Brain**



**Alzheimers Brain**



# Positron Emission Tomography (PET)

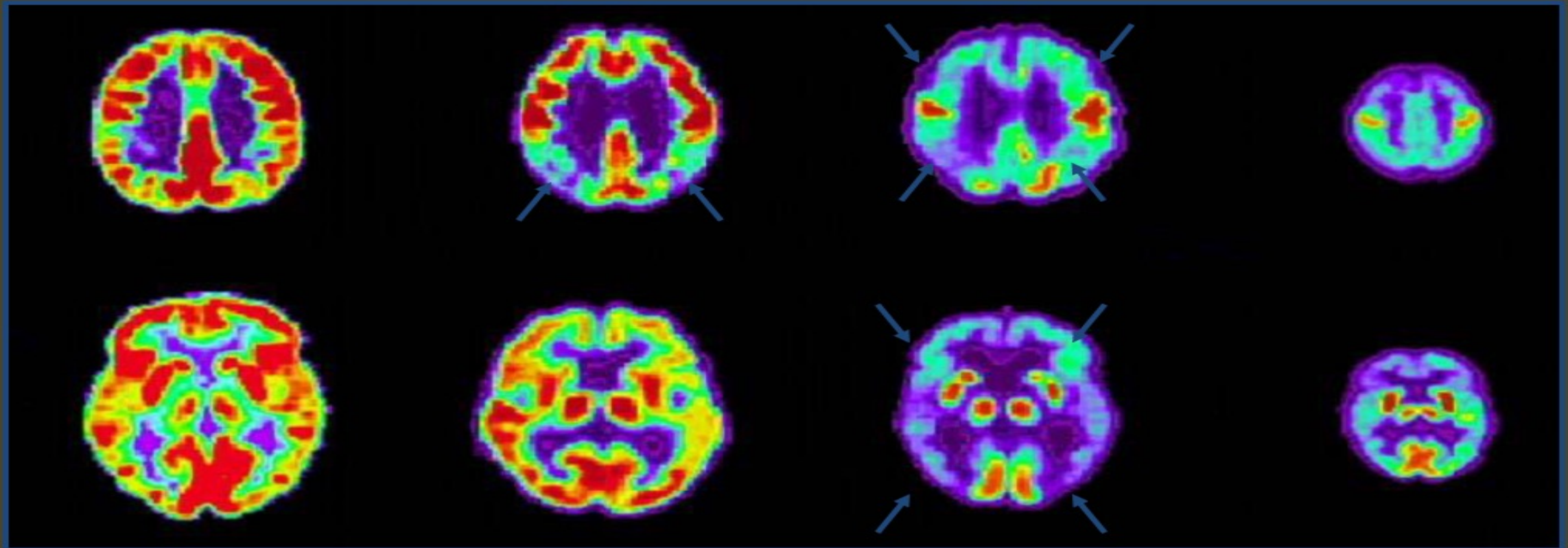
## Alzheimer's Disease Progression vs. Normal Brains

**Normal**

**Early  
Alzheimer's**

**Late  
Alzheimer's**

**Child**





# So When Should You Say WHEN!

- ✓ Cost versus benefit to the person
- ✓ What is *possible* VERSUS what is PROBABLE
- ✓ Best Case Outcome –Is it worth it?
- ✓ Big Picture for the person
- ✓ What did they tell you before? What matters to them?

# Coming to terms with the Loss

- ✓ Who are they... are they still able to be that person?
- ✓ Is this about them or about you or about someone else???





# Support at the End

**What would give them comfort?**

- ✓ **Hearing – Speak directly to person with slow calm voice and have favorite music playing**
- ✓ **Sight – Visual range limited- be within one arm's length and have pleasant and familiar**





# Support at the End

**What would give them comfort?**

- ✓ **Taste – hunger on decline but some people still enjoy a small taste of their favorite foods or beverages as a source of comfort.**



# Support at the End

**What would give them comfort?**

- ✓ **Smell – likely declined but some ideas are favorite perfumes or colognes, outdoor scents such as grass or particular flowers, and food scents. Essential oils**





# Support at the End

**What would give them comfort?**

- ✓ **Touch - comfort in this contact.**  
Keep in mind that light, fleeting touch can evoke an unpleasant ticklish sensation and can be a bit alarming, instead offer a gentle massage as pain relief, or they may prefer the sensation of a still hand placed firmly on the back of their hand, their shoulder, or just above their



Positive  
Approach  
to Care®



# Resources

Hospitalization rates and predictors in people with dementia: a systematic review and meta-analysis BMC Medicine 17, Article number: 130(2019)

A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. R.S. Morrison, A.L. Siu, Journal of Pain Symptom Management, 2000 Apr;19(4):240-8.

Alzheimer's Caregiving: Going to the Hospital: Tips for Dementia Caregivers. National Institute on Aging, <https://www.nia.nih.gov/health/going-hospital-tips-dementia-caregivers>

Oregon Advance Directive Form (PDF Fillable) including User guide (Multiple Languages) <https://www.oregon.gov/oha/ph/about/pages/adac-forms.aspx>

DNR, DNAR, or AND? Is Language Important? The Ochsner Journal, [Joseph L Breault](#), MD, ScD, MPH, CIP

5-things-you-need-to-know-about-the-senses-at-end-of-life-with-dementia  
Polly Logan, [teepasnow.com/blog](https://teepasnow.com/blog), Sept 15<sup>th</sup>, 2021



# Development of a Dementia Friendly Community

Beth Mastel-Smith, PhD, MS, RN

The University of Texas at Tyler





# Objectives

Define Dementia Friendly (DF)  
Community

Development of Dementia Friendly  
Baker County

How to become Dementia Friendly

Resources



# DF: Definition

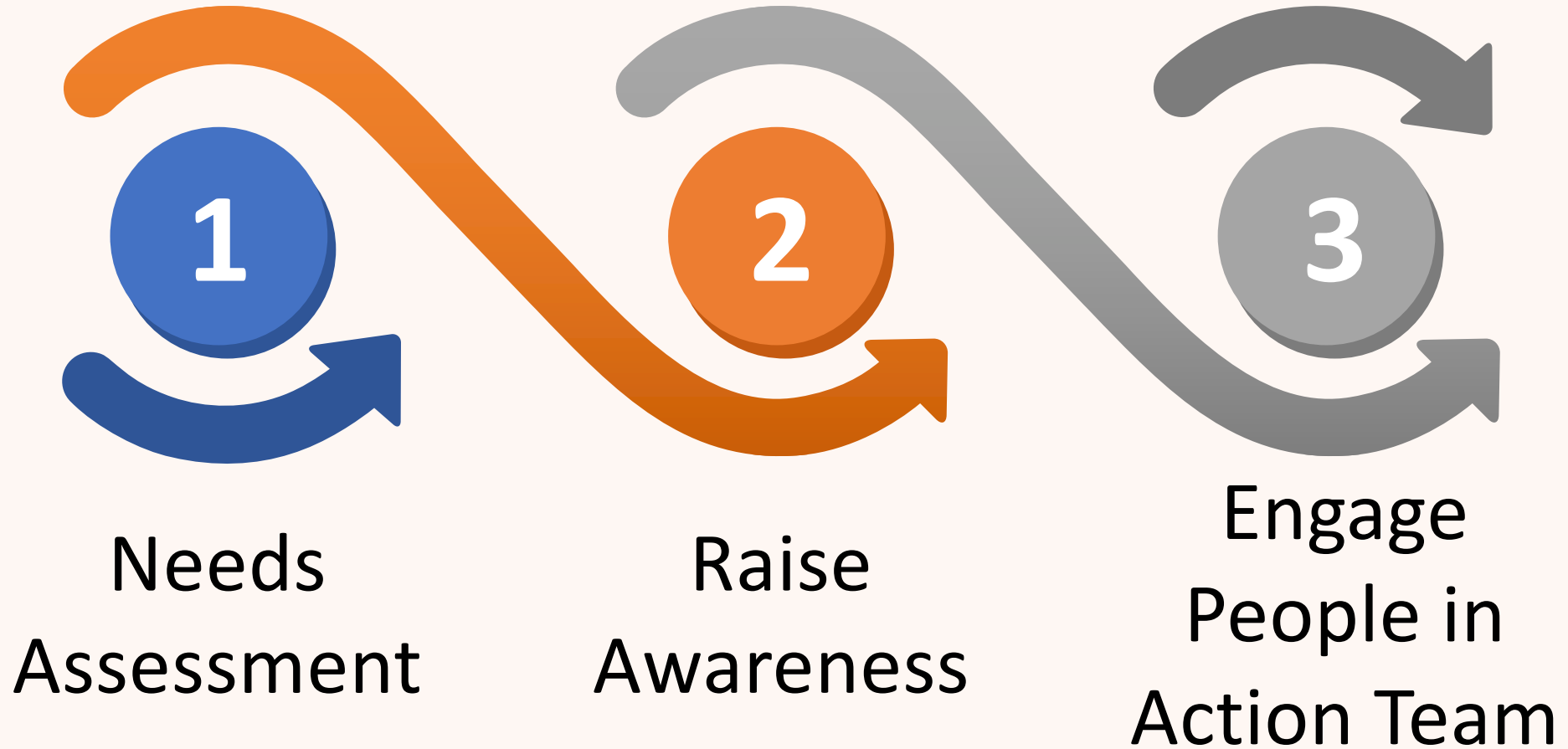
- Support people living with a dementia & care partners
- Objectives
  - **Reduce stigma**
  - **Empower people living with dementia**
    - Live independently
    - Engage in community activities
  - Raise awareness / understanding
  - Safe & inclusive environment
  - Support options
  - Quality of life
  - Reduce risk factors
- Dementia Friendly America (DFA)
  - Began in 2015
  - White House Conference on Aging
- 35 countries



Backstory

  
ORGANICALLY  
GROWN

# Community Outreach



## Needs Assessment

- Lack of:
  - Knowledge
  - Awareness
  - Resources
    - Respite
    - Day program
    - Caregiver support
    - In home care
    - Long-term care (LTC) staff
- Financial abuse
- Community strengths
  - Community & provider interest / support
  - Occupational therapy driving skills assessment
  - "Take me home"
  - Close knit
  - Networking
    - Faith
    - Neighborhoods
  - Care facilities
    - DNP serves LTC communities

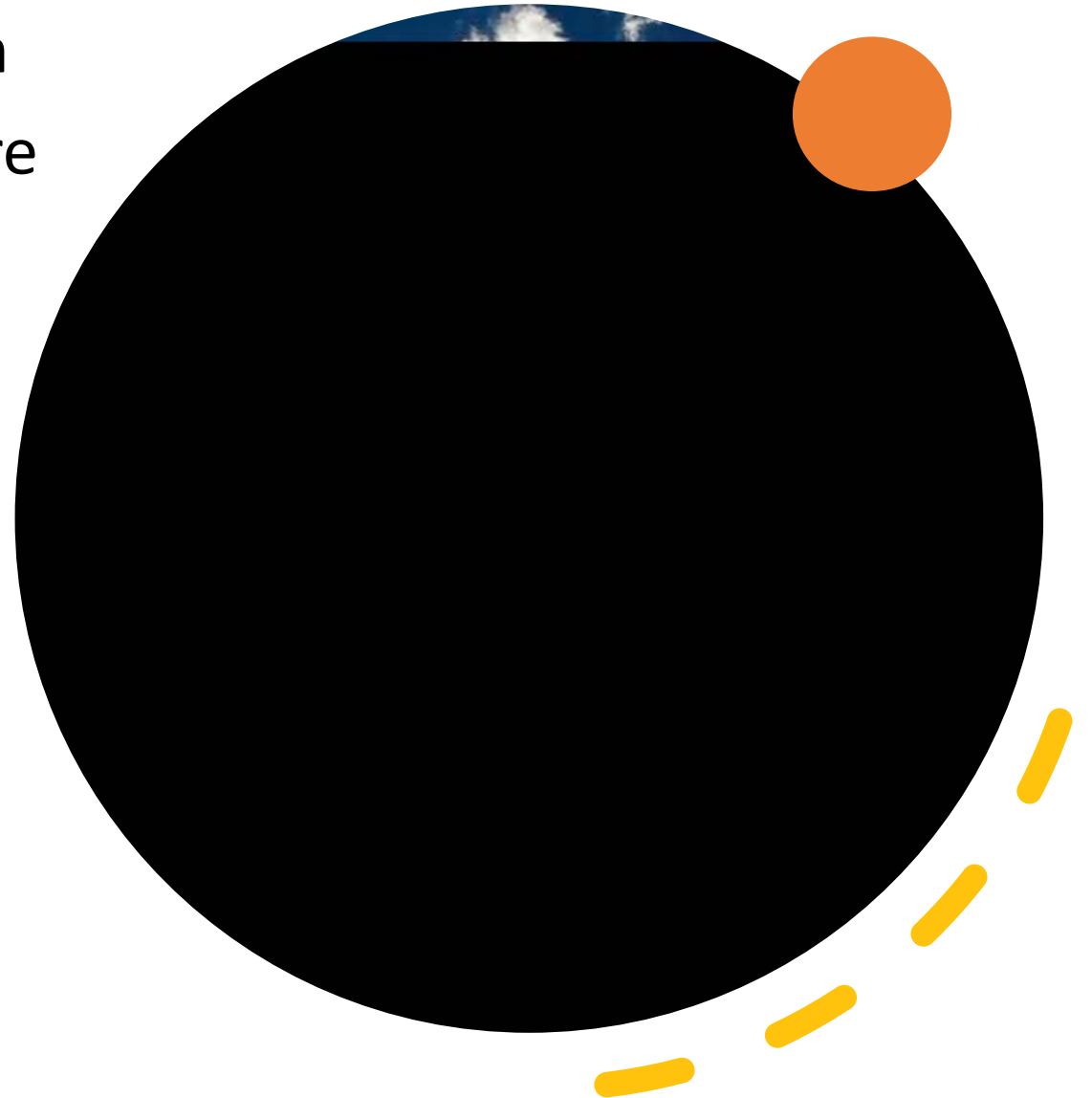


# WiNS



- 4 Positive Approach to Care Workshops (GOBHI)
  - Attendance: 50 people / session
  - Evaluations: 6+ out of 7
  - Participants taking part in Powerful Tools, a caregiver workshop
- Action Team
  - Grown from 3-4 people to 12
    - Includes 2 people living with a dementia
  - Offering monthly “Dementia Workshop & Connection”
  - Created a Dementia Friendly Baker County Facebook page
  - Prepared our Dementia Friendly America application

- Diverse representation on Action Team
- Determining an organizational structure



# DFA

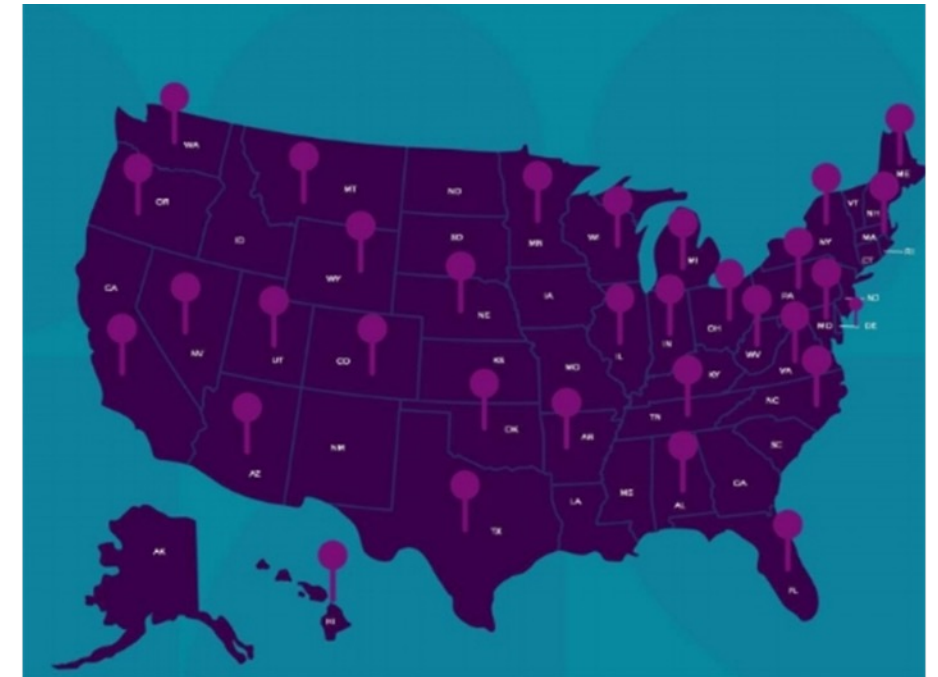


- Offers
  - Technical assistance
  - Toolkit
  - Examples of best practices
- <https://www.dfamerica.org/toolkit-getting-started>



# Joining DFA

- Expectations
  - Cross-sector team, 3 or more
    - Government
    - Clinical
    - Community based organizations
    - **People living with a dementia & care partners**
  - How community will be engaged
  - Champion organization
  - Evaluation
- Submit
  - Application form
  - 3 support letters



Acknowledgment



# Dementia-Friendly Communities

Why We Need Them and  
How We Can Create Them



Susan H. McFadden, PhD



# 2023 Forum on Aging in Rural Oregon

# Thank you!

