



*Understanding Dementia:
Considerations for those
with Intellectual Disabilities*

*Stephani Shivers, MEd, OTR/L, CDP
Chief Operating Officer - Community Services*

LiveWell

DEMENTIA SPECIALISTS

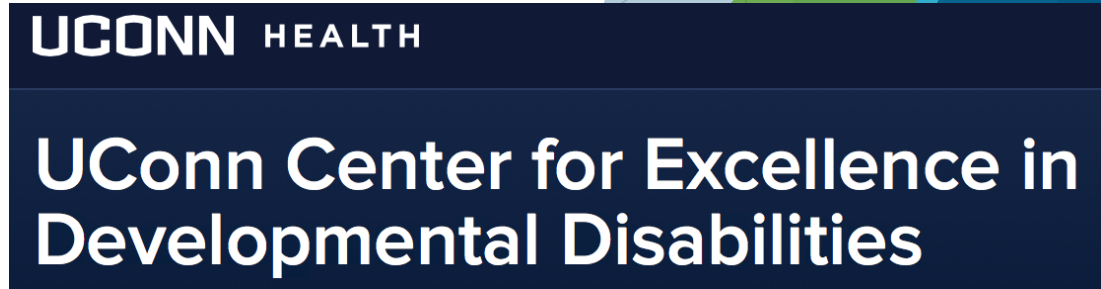
- ▶ Founded in 1990, as the Alzheimer's Resource Center
- ▶ Established history as thought leaders and pioneers in dementia services seeking to positively transform the way people living with dementia (PLWD) are viewed, engaged and supported
- ▶ Campus in Southington, CT home to 133 people living with dementia (skilled nursing and assisted living communities)



- ▶ Suite of community services including Adult Day Center, support groups for Persons Living with Dementia and Carepartners
- ▶ Community & Carepartner Education workshops
- ▶ Dementia Navigation Services
- ▶ Memory & Cognitive Disorders Specialty Practice - Counseling, Geriatrician, Palliative Care MD, OT, PT, SLP, Licensed Clinical Social Worker
- ▶ LiveWell Institute - Transforming communities through education, thought leadership and advocacy to advance the wellbeing and inclusion of people as they age.

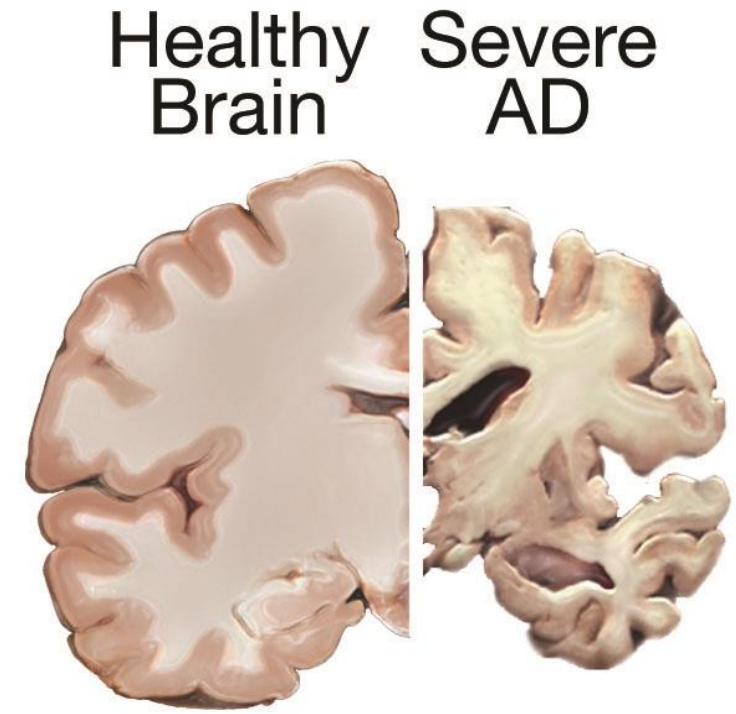
Navigating Dementia: LiveWell's Administration on Community Living - Alzheimer's Disease Program Initiative

- ▶ *Dementia Capable Care of Adults with ID & Dementia* 3-day training (Nov. 2019)
- ▶ ID & Dementia Summit (2021)
- ▶ Formation of CT ID & Dementia Stakeholder Workgroup
- ▶ OT intervention Skills2Care®-ID for families and group home staff



What is dementia?

- ▶ General term describing a category of conditions that deteriorate the brain
- ▶ Brain changes impact a person's abilities in daily activities and relationships
- ▶ Alzheimer's Disease is a specific type of dementia, and is the most common form



Alzheimer's Disease and Dementia

- More than 85 types
- AD is a specific type, most prevalent
- ~5.8 million Americans with AD
- 15 million caregivers
- Someone develops AD every 67 seconds
- 6th leading cause of death in USA
- 1 in 10 people age 65 and older, 1 in 3 people age 85 and older has AD
- AD is fatal - over 500,000 deaths annually

Types of Related Dementias

- Vascular Dementia/Cognitive Impairment (VCI)
- Frontotemporal Degeneration (Pick's Disease)
- Parkinson's Disease
- Lewy Body Disease
- Huntington's Disease
- Creutzfeldt-Jakob Disease
- Korsakoff Syndrome

Down Syndrome & Alzheimer's

- Extra gene
- Significant increase in risk for AD
- 30% age 40, 50% age 50

<https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome>

What can affect memory/cognition?

- Depression
- Medications
- Metabolic/Vitamin issues
 - ▶ *B12, E, hypothyroidism*
- Infections - UTI
- Inflammation
- Cancer, tumors
- Vascular conditions - stroke
- Toxic exposure

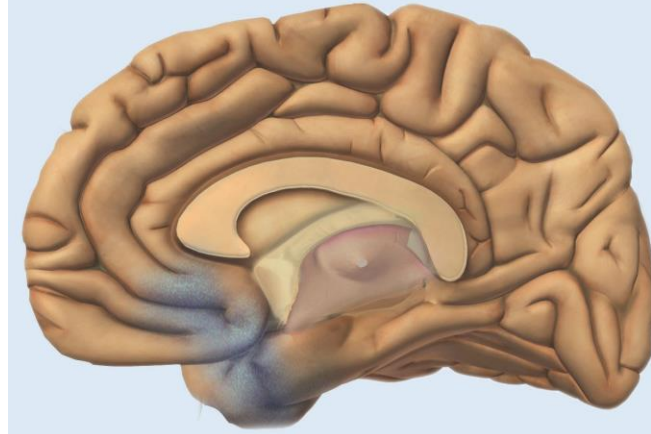
Can't assume all changes are due to dementia!

Changes from Dementia

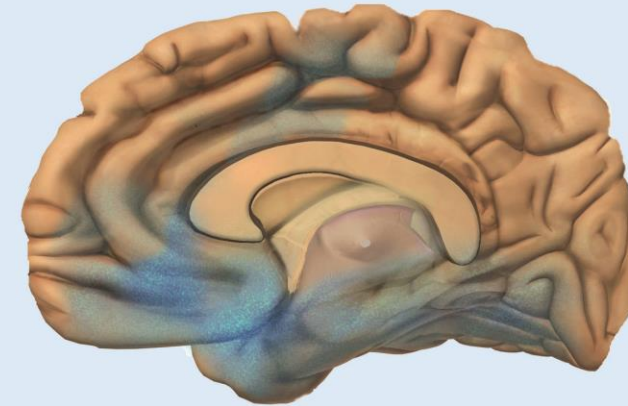
Brain changes cause a decline in one or more of the following areas:

memory
executive function
visual spatial function
language
processing
muscle movement
sensory functions

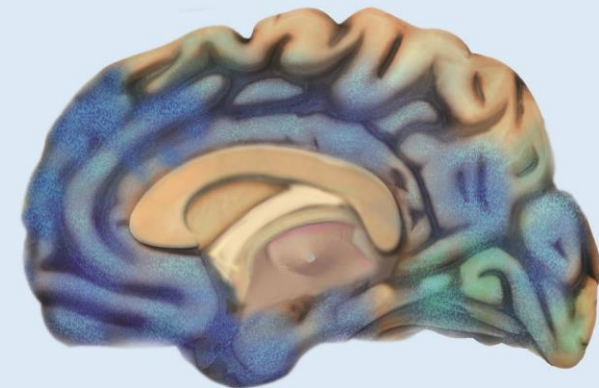
Preclinical AD



Mild to Moderate AD



Severe AD



Understanding Memory Changes

Episodic Memory: Recent or past events and experiences, such as where you parked your car this morning or the dinner you had with a friend last month.

Problems with Episodic memory are hallmarks of Alzheimer's Disease.

<https://memory.ucsf.edu/symptoms/memory>

Understanding Executive Function:

Information gathering and organization

- attention, planning, sequencing, problem-solving, working memory, cognitive flexibility, abstract thinking, rule acquisition, selecting relevant sensory information

Evaluating information and regulating responses

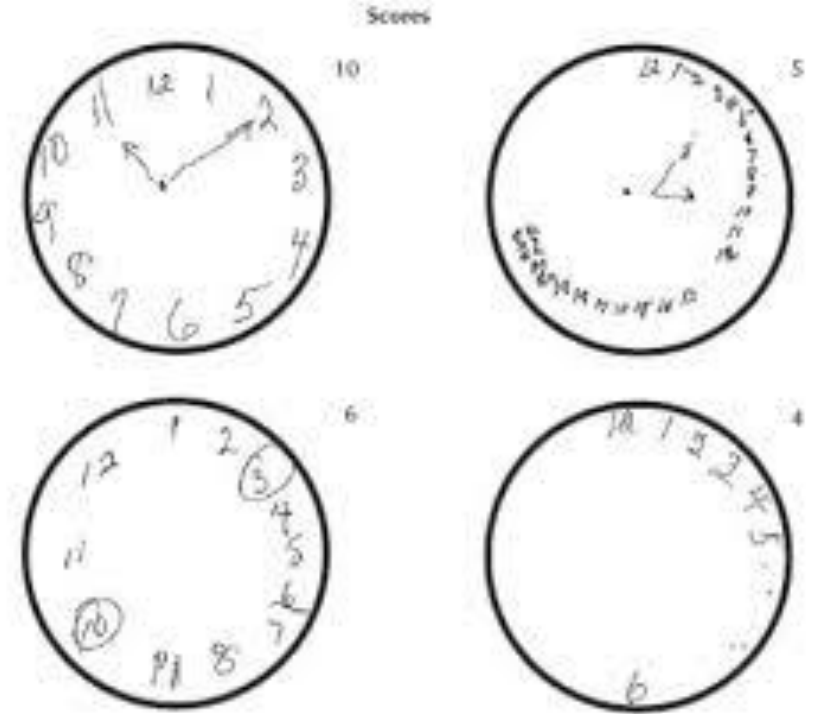
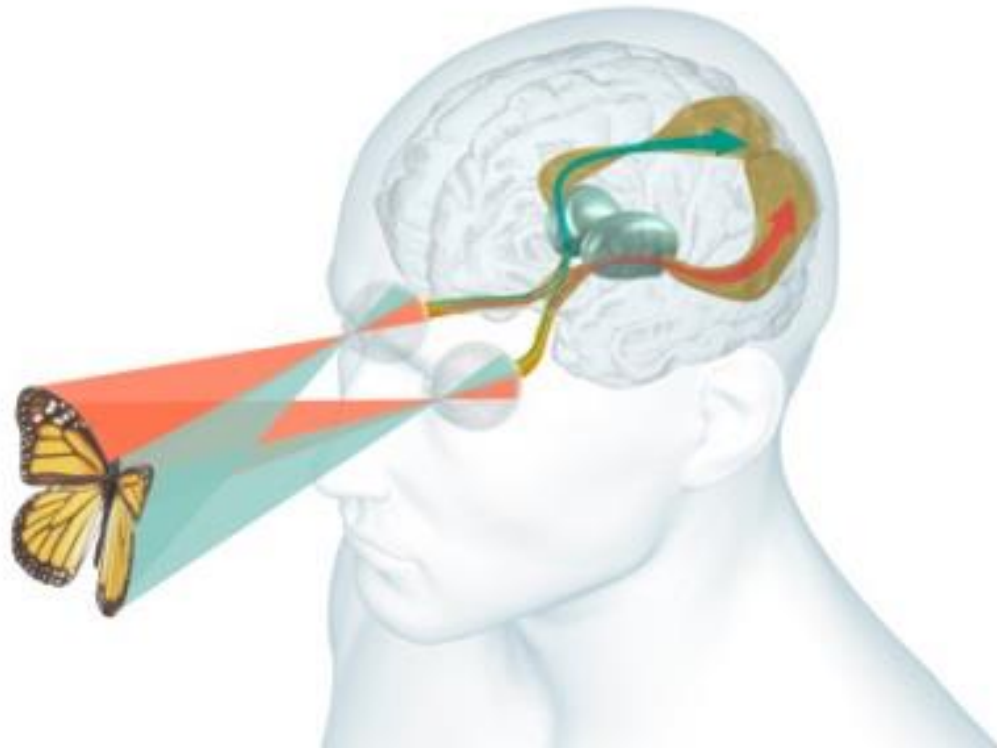
- initiation of action, self-control, emotional regulation, monitoring internal and external stimuli, behavior initiation/inhibition, moral reasoning, decision-making

Executive Function Changes

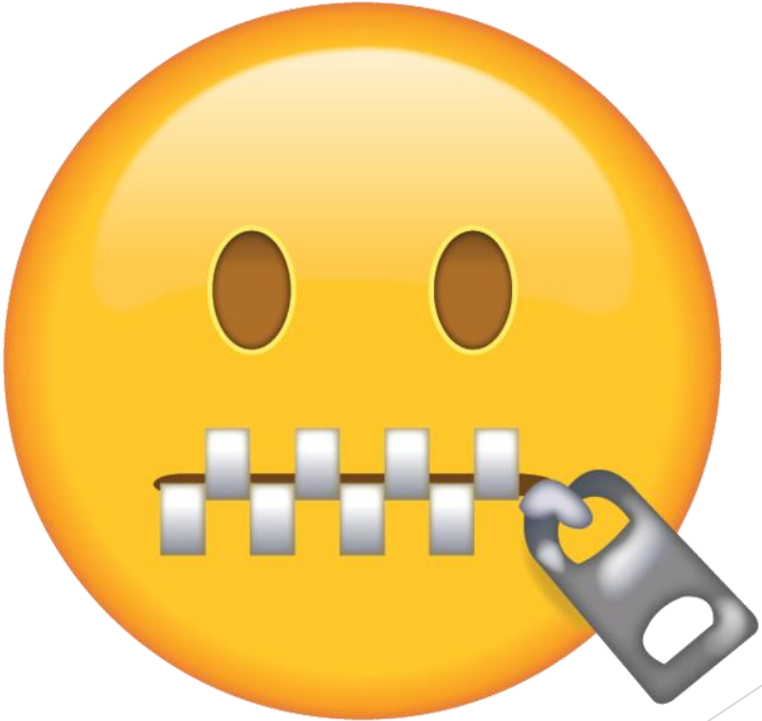
- ▶ Difficulty organizing
- ▶ Inability to multitask
- ▶ Difficulty in planning and initiation (getting started)
- ▶ Trouble planning for the future
- ▶ Difficulty processing, storing, and/or retrieving information
- ▶ Mood swings
- ▶ Lack of concern for others
- ▶ Loss of interest in activities
- ▶ Socially inappropriate behavior
- ▶ Inability to learn from consequences from past actions
- ▶ Difficulty with abstract concepts
- ▶ Unawareness or denial that their behavior is a problem



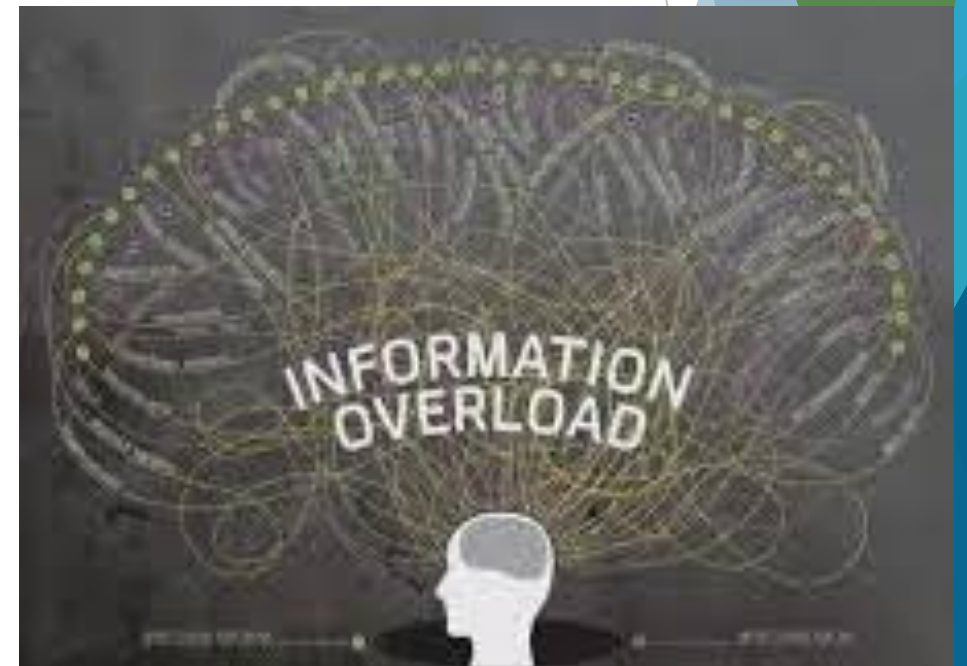
Visual Spatial Changes



Language Changes



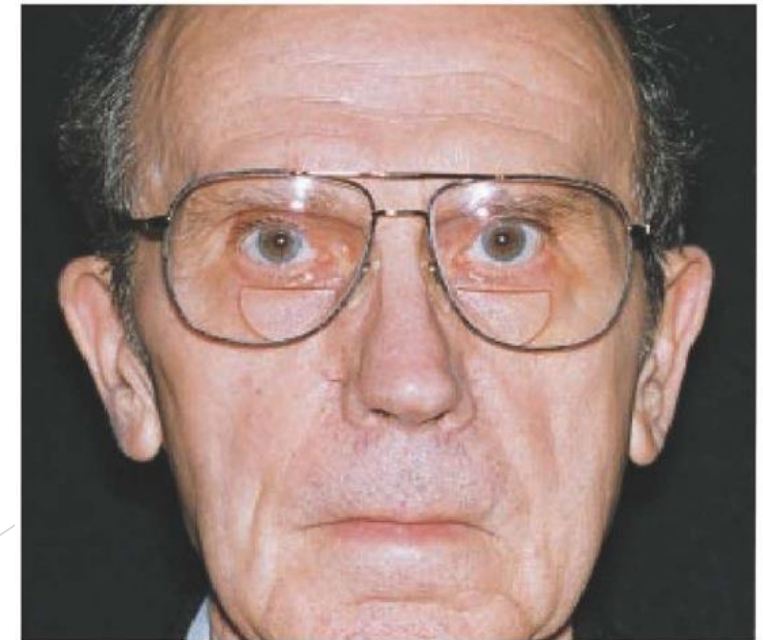
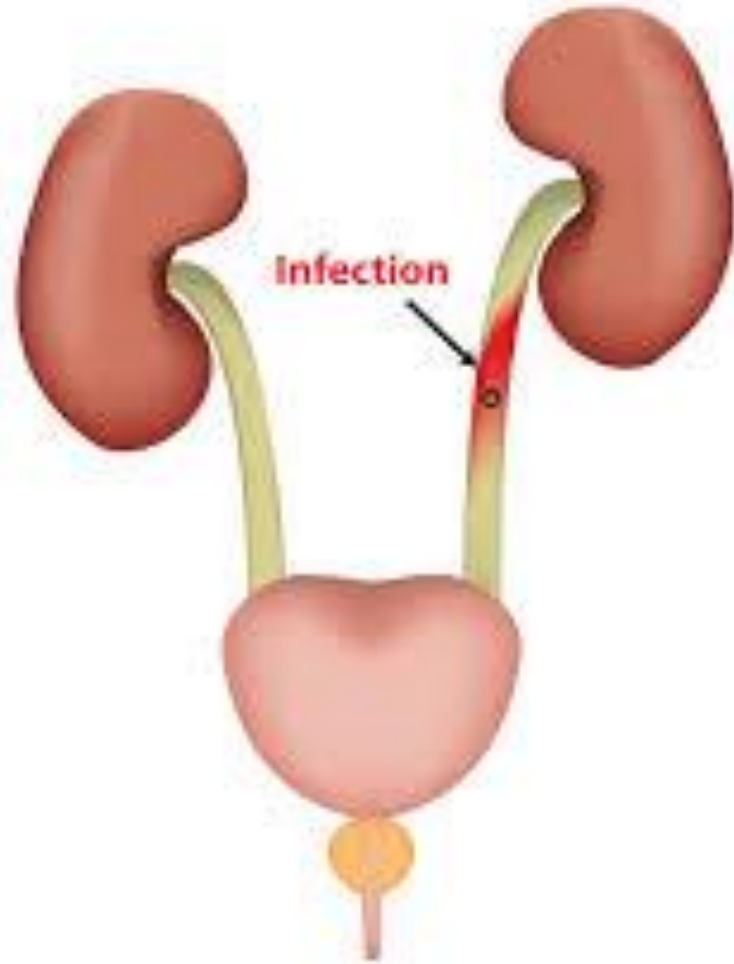
Processing Changes



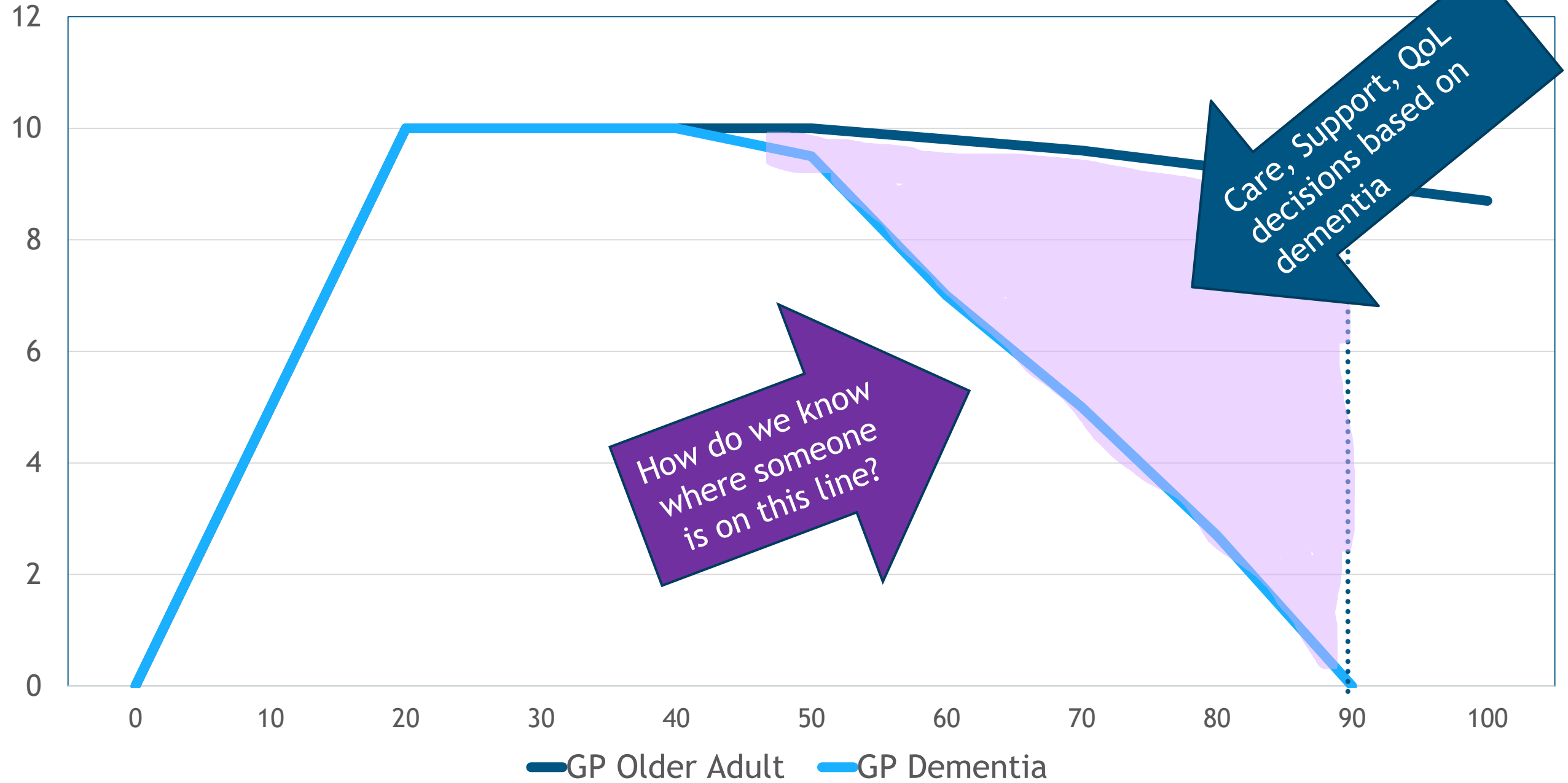
Physical Changes



Physical Changes



Cognition/Function in Aging vs. Dementia



Understanding Functional Stages

Functional Scales

- Functional Assessment Staging Test (caregiver report)
- Allen Cognitive Levels

Why stage?

- Provide an idea of what abilities are and what will be affected
- Guide for planning
- Baseline understanding of abilities for comparison

Staging Estimates - general population

- Early Alzheimer's - 2-7 years
- Moderate Alzheimer's - 2-7 years
- Late Alzheimer's - 1-3 years

Functional Landmarks - Early stages

- Person is able to complete many **routine and familiar tasks** with someone checking in for safety and to problem solve. (ACL 5, GDS 2,3)



Functional Landmarks - Middle stages

- Person can follow **step by step instructions** through an activity to accomplish a task (ALC 3, GDS 5)
- Person is able to **use their hands** and **move their body parts** in familiar patterns with **fine and gross motor movements** (ALC 3, GDS 5)



*Will need someone living with them
to provide intermittent support*

Functional Landmarks - Late stages

- Person is able to use their hands for tactile and sensory pleasures. May have some gross motor movement (ALC 2, GDS 6)
- Person is able to connect to sensory stimulation (ALC 1, GDS 7)



*Will need someone living with them
to provide moment by moment support*

Common changes with progression

Symptom	Mild	Moderate	Severe
Sequencing (praxis)	Small changes e.g. showering without soap or how to pay a bill	Unable to coordinate the steps to dress	May no longer be able to use a spoon
Agnosia (association/meaning - can be with any sense[visual, auditory, touch])	May not recognize memory problems, driving problems	Not understanding a toilet vs sink; hairbrush vs toothbrush	May not recognize self, others, meaning for care
Language Use and Understanding	Forget words, substitute words	Difficulty finding words to complete thought or meaning	Limited use of words
Motor Function	May need more focus for balance/tasks	Coughing/stumbling	Choking/falling
Sleep	May have some change in circadian rhythm	Daytime rests/sleep may be required	May begin to sleep upwards of 20 h/d

FAST Scale - Normal to Moderate

Stage 1: No difficulty, either subjectively or objectively

Stage 2: Complains of forgetting location of objects;
subjective work difficulties

Stage 3: Decrease job functioning evident to coworkers;
difficulty in traveling to new locations

Stage 4: Decreased ability to perform complex tasks
(e.g., planning dinner for guests, handling finances)

Stage 5: Requires assistance in choosing proper clothing

FAST Stage 6 - Moderate to Severe Dementia

- A. Improperly putting on clothes without assistance or cueing
- B. Unable to bathe properly (e.g., not able to choose proper water temp)
- C. Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue)
- D. Urinary incontinence
- E. Fecal incontinence
 - ▶ Occasionally or more frequently over the past weeks from knowledgeable informant

FAST Stage 7 - Severe Dementia

- A. Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview
- B. Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview

Hospice Eligibility

- C. *Ambulatory ability is lost (cannot walk without personal assistance)*
- D. *Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.)*
- E. *Loss of ability to smile*
- F. *Loss of ability to hold up head independently*

Hospice Eligibility for Dementia

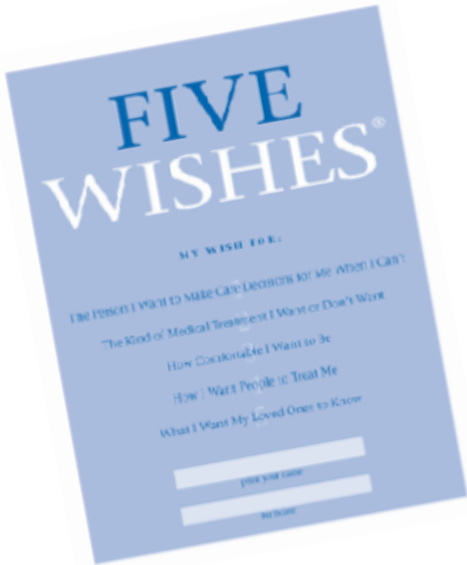


Hospice

- ▶ Stage 7C or beyond according to the FAST Scale
- ▶ AND one or more of the following conditions in the past 12 months:
 - ▶ Aspiration pneumonia
 - ▶ Pyelonephritis (kidney infection)
 - ▶ Septicemia
 - ▶ Multiple pressure ulcers (stage 3-4)
 - ▶ Recurrent fever
 - ▶ Other significant condition that suggests a limited prognosis
 - ▶ Inability to maintain sufficient fluid and calorie intake in the past 6 months (10% weight loss or albumin < 2.5 gm/dl)

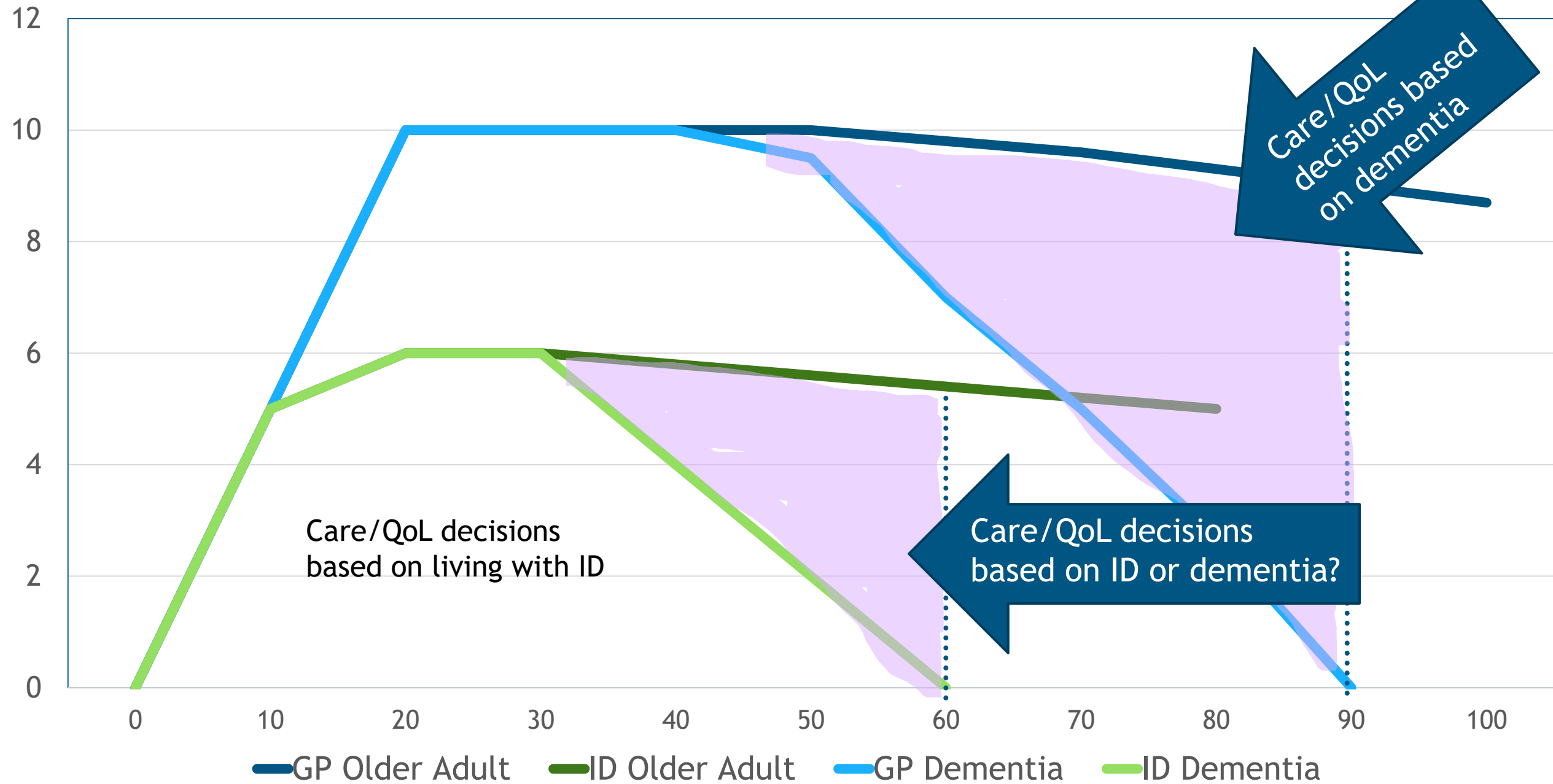
GOALS of CARE

ID or Dementia?



BEST PRACTICES

Cognition/Function in Aging vs. Dementia



Recommendations

- ▶ Identify best practice resources for the care and support of individuals living with an intellectual disability AND dementia including diagnosis, non-pharmacological interventions, medication management, palliative care and advance directives
- ▶ Specialized Task Group to explore the unique care, rights, and surrogate decision-making needs for this emerging population. Review existing policies and systems and evaluate alignment with needs of those with ID & Dementia.
- ▶ Mandate education for direct care workers and families on new ways to support those living with ID & Dementia
- ▶ Specialized occupational therapy interventions for family and group home caregivers
- ▶ Support for newly forming CT ID & Dementia Stakeholder Network (formation is part of LiveWell's ACL-ADPI grant)

References

Alzheimer's Association

- ▶ <http://www.alz.org/>

Association for Frontotemporal Degeneration

- ▶ <https://www.theaftd.org>

Lewy Body Dementia Association

- ▶ <https://www.lbda.org>

National Institute on Aging - Alzheimer's and Related Dementias

- ▶ <https://www.nia.nih.gov/health/alzheimers>

University of California San Francisco Memory Center

- ▶ <https://memory.ucsf.edu/symptoms/memory>

Contact Information

Stephani Shivers, MEd, OTR/L

COO- Community Services

sshivers@livewell.org

860-628-3020

Signs & Symptoms

1. Memory loss that disrupts daily life.
2. Challenges in planning or solving problems.
3. Difficulty completing familiar tasks at home, at work or at leisure.
4. Confusion with time or place.
5. Trouble understanding visual images and spatial relationships.

http://www.alz.org/alzheimers_disease_know_the_10_signs.asp

Signs & Symptoms

6. New problems with words in speaking or writing.
7. Misplacing things and losing the ability to retrace steps.
8. Decreased or poor judgment.
9. Withdrawal from work or social activities.
10. Changes in mood and personality.