



TEXAS TECH UNIVERSITY SYSTEM™

Current Interventions for Individuals with Dementia and their Care Partners

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Disclosures



I have no disclosures

Objectives for Today



- Identifying symptoms of dementia and concurrent mental health concerns
- Examine ways to reduce stress, burden, and pre-death grief in family caregivers
- Assess the current gold standard in diagnosing forms of dementia

Outline



Overview of Dementia



Prevalence of Dementia and Effect on
Caregivers



Diagnosing Dementia and the GIA Memory
Clinic



Pharmacological and Non-Pharmacological
Interventions for the Dyad

What is dementia?



TYPES OF DEMENTIA

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- Other, including Huntington's
- * **Mixed dementia:** Dementia from more than one cause

Behaviors that (usually) accompany dementia – Alzheimer's



Cause

- Involves tangles, amyloid plaque and atrophy of the brain

Characteristics

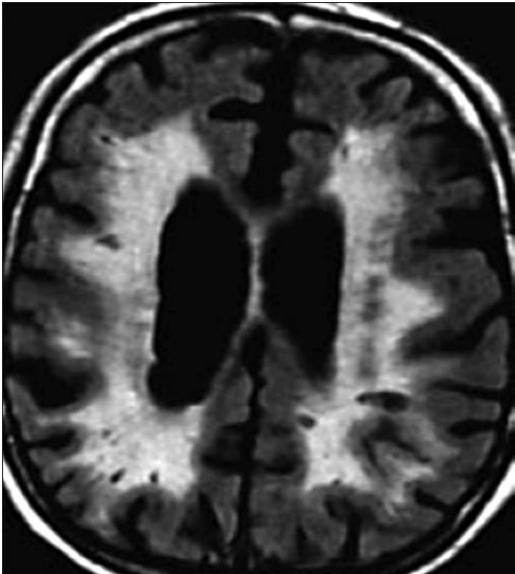
- Slow, insidious onset with a progressive but steady decline
- In the early stages
 - *Memory loss (short and long term)*
 - *Word-finding difficulties*
 - *Abstract vs. concrete*
- As disease progresses
 - *Greater memory loss*
 - *Impaired visuospatial skills (not knowing people/faces)*
 - *Language difficulties*
 - *Impaired functioning of ADLs*
 - *Impairment in executive functioning*

Behaviors that (usually) accompany dementia – Vascular dementia



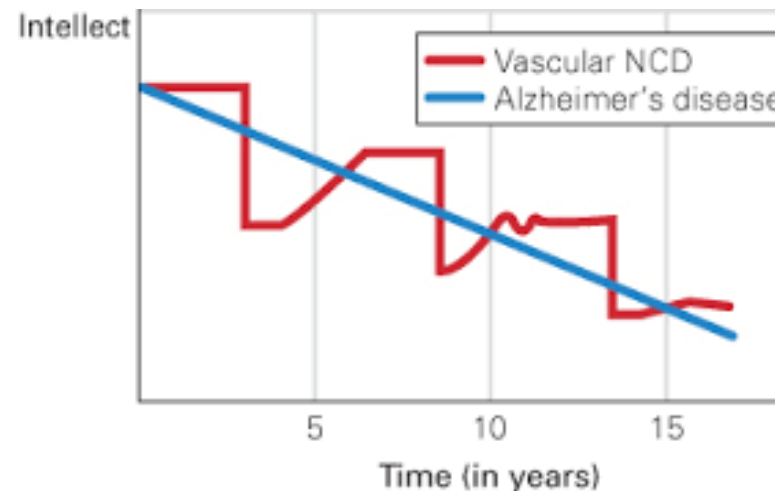
Cause

- Abrupt or gradual onset as a result of brain's blood supply being compromised by arterial disease



Characteristics

- Focal neurological signs of vascular disease such as, hypertension, diabetes mellitus, arterial disease, smoking
- Memory and language difficulties
- Slowing of thinking processes
- Mental health concerns (depression; anxiety; apathy)



Behaviors that (usually) accompany dementia – Lewy body dementia



Cause

- Small aggregations of a protein that occur in neurons in various areas of the brain, including the cerebral cortex in dementia with Lewy bodies

Characteristics

- Shares many characteristics with AD
- Visual hallucinations
- Recurrent falls
- Fluctuations in levels of conscious awareness
- Disturbed sleep and/or nightmares

Behaviors that (usually) accompany dementia – Frontotemporal dementia



Cause

- Affects frontal regions of the brain responsible for planning, emotion, motivation and language

Characteristics

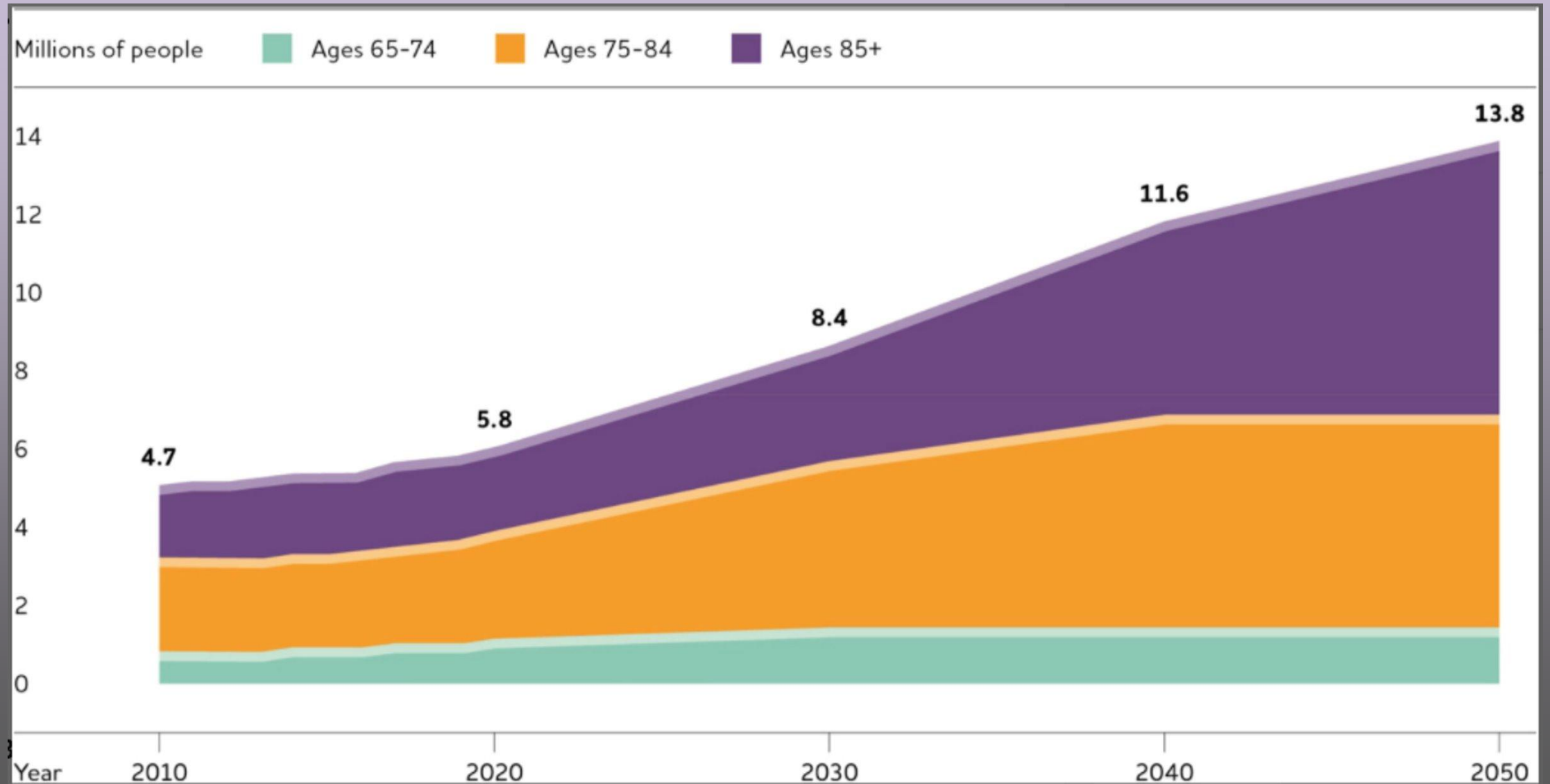
- See symptoms at a younger age
- Disinhibited and socially inappropriate behaviors, and impaired judgement
- Apathy
- Decreased motivation



Prevalence of Dementia and its Effect on Caregivers



Prevalence of AD/ADRD





Alzheimer's Disease in Texas

NUMBER OF PEOPLE
AGED 65 AND OLDER
WITH ALZHEIMER'S

YEAR	TOTAL
2020	400,000
2025	490,000

ESTIMATED % INCREASE

22.5%

PREVALENCE

333

OF
GERIATRICIANS
IN 2021

276.9%

INCREASE
NEEDED TO
MEET DEMAND
IN 2050

320,780

OF HOME
HEALTH AND
PERSONAL CARE
AIDES IN 2020

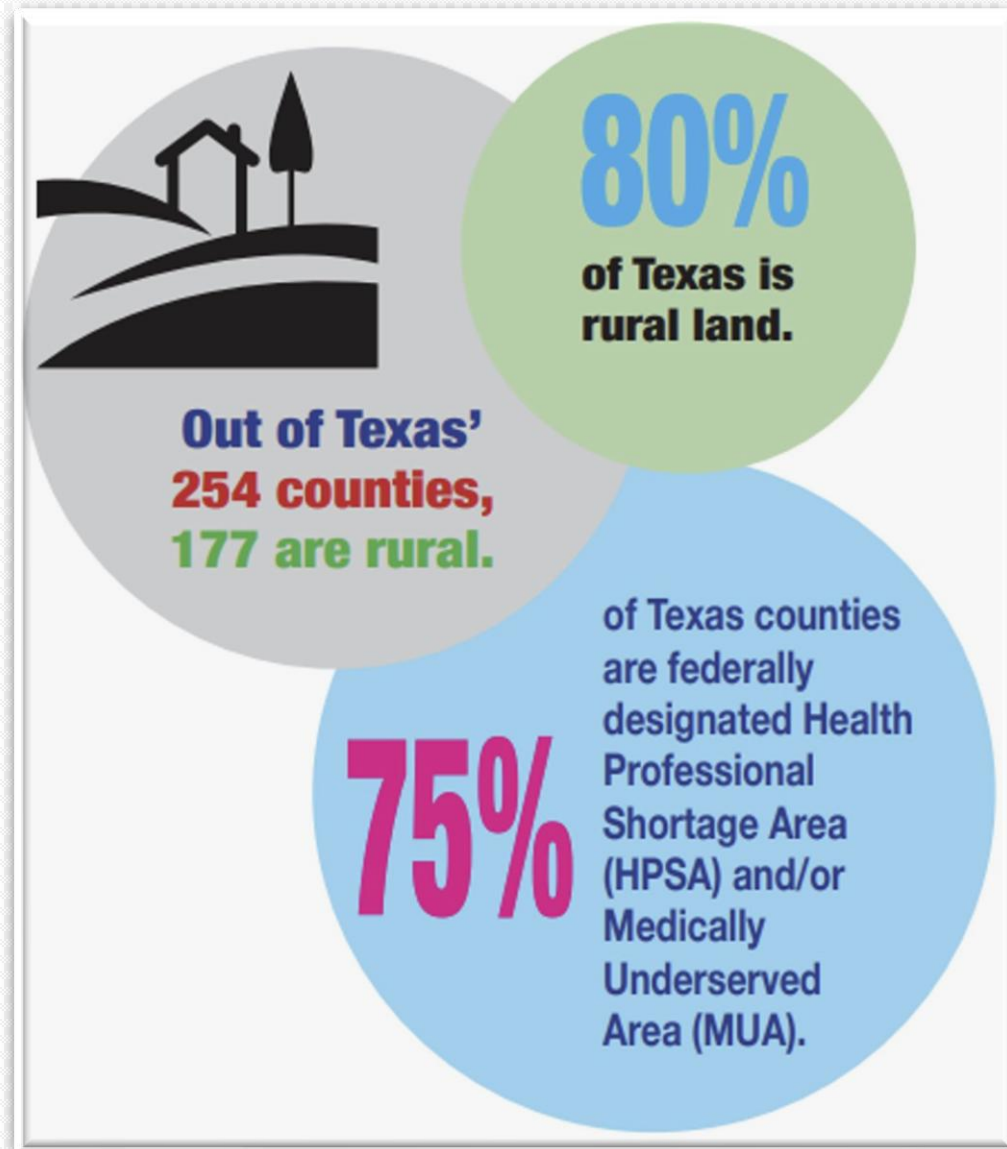
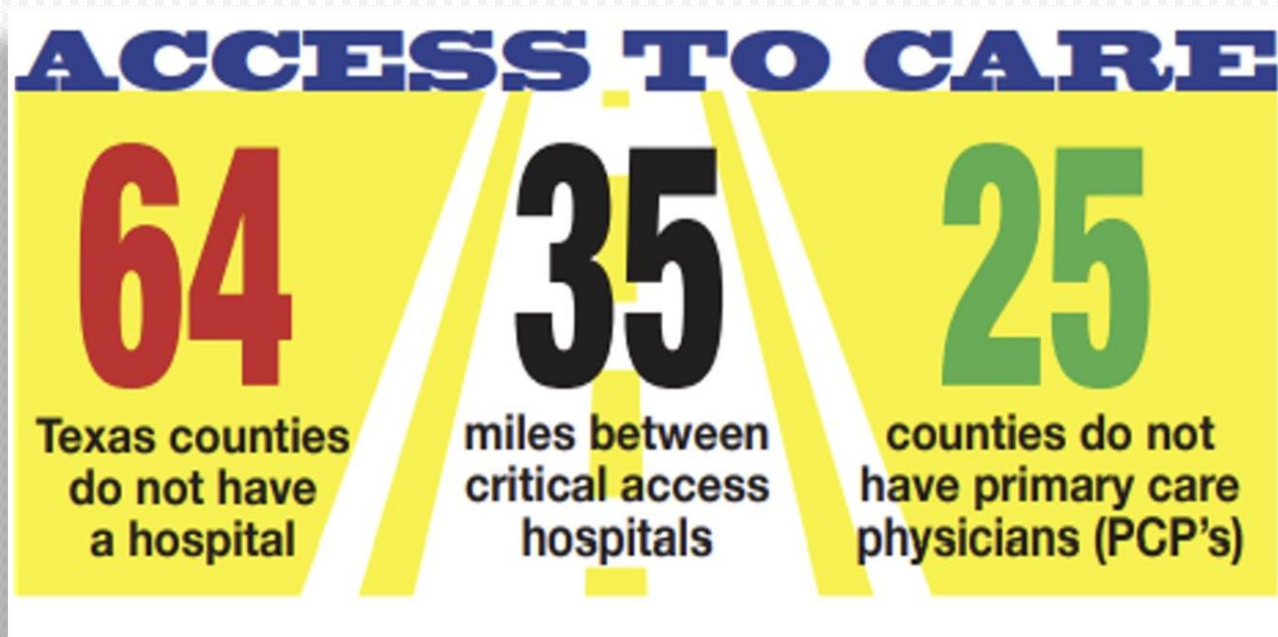
30.5%

INCREASE
NEEDED TO
MEET DEMAND
IN 2030

WORKFORCE



Access to Care for Texans

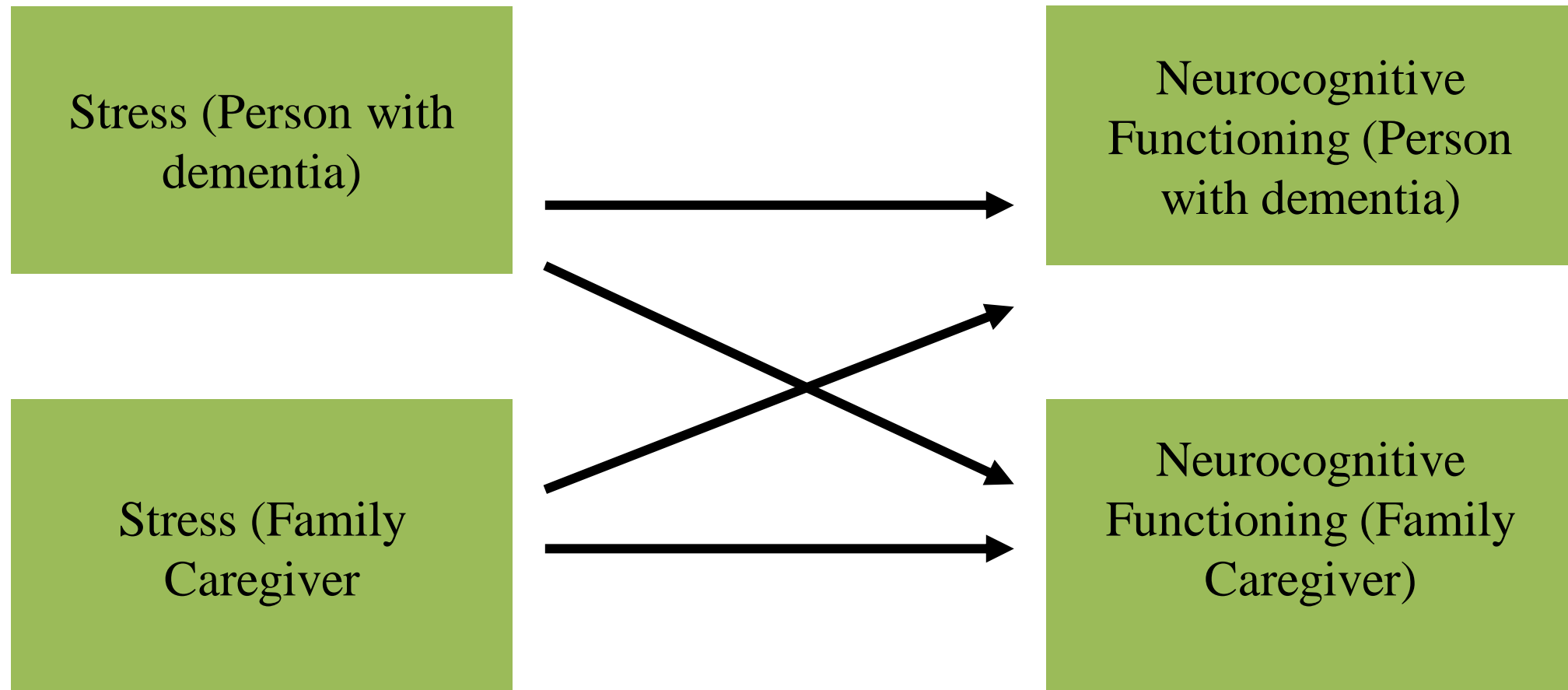


Care Partners in Texas



UNPAID CAREGIVERS (2022)	CAREGIVER HEALTH (2021)
1,000,000 # OF CAREGIVERS	59.0% OF CAREGIVERS WITH CHRONIC HEALTH CONDITIONS
1,507,000,000 TOTAL HOURS OF UNPAID CARE	26.7% OF CAREGIVERS WITH DEPRESSION
\$23,552,000,000 TOTAL VALUE OF UNPAID CARE	11.2% OF CAREGIVERS IN POOR PHYSICAL HEALTH
CAREGIVING	

Dyadic Model



Age-Related Cognitive Decline



Caregivers already at risk for age-related cognitive decline

- Predominantly affects individuals around age 65 (Tucker-Drob, 2019)
- As early as age 45 (Taylor et al., 2018)

Normal age-related declines subtly affect memory, processing speed, and attentional control but should not progress to serious functional impairment (D'Souza et al., 2021)

Exacerbated by:

- Stress
- Medical Conditions
- Psychosocial Factors

Cognitive Changes in Caregivers



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An Ironic Tragedy: Are Spouses of Persons with Dementia at Higher Risk for Dementia than Spouses of Persons without Dementia?

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Advance Access publication February 22, 2016



Research Article

Objective and Subjective Cognitive Problems among Caregivers and Matched Non-caregivers

Peter P. Vitaliano, MS, PhD,^{*.1.2} Ozge Ustundag, BS,² and Soo Borson, MD¹

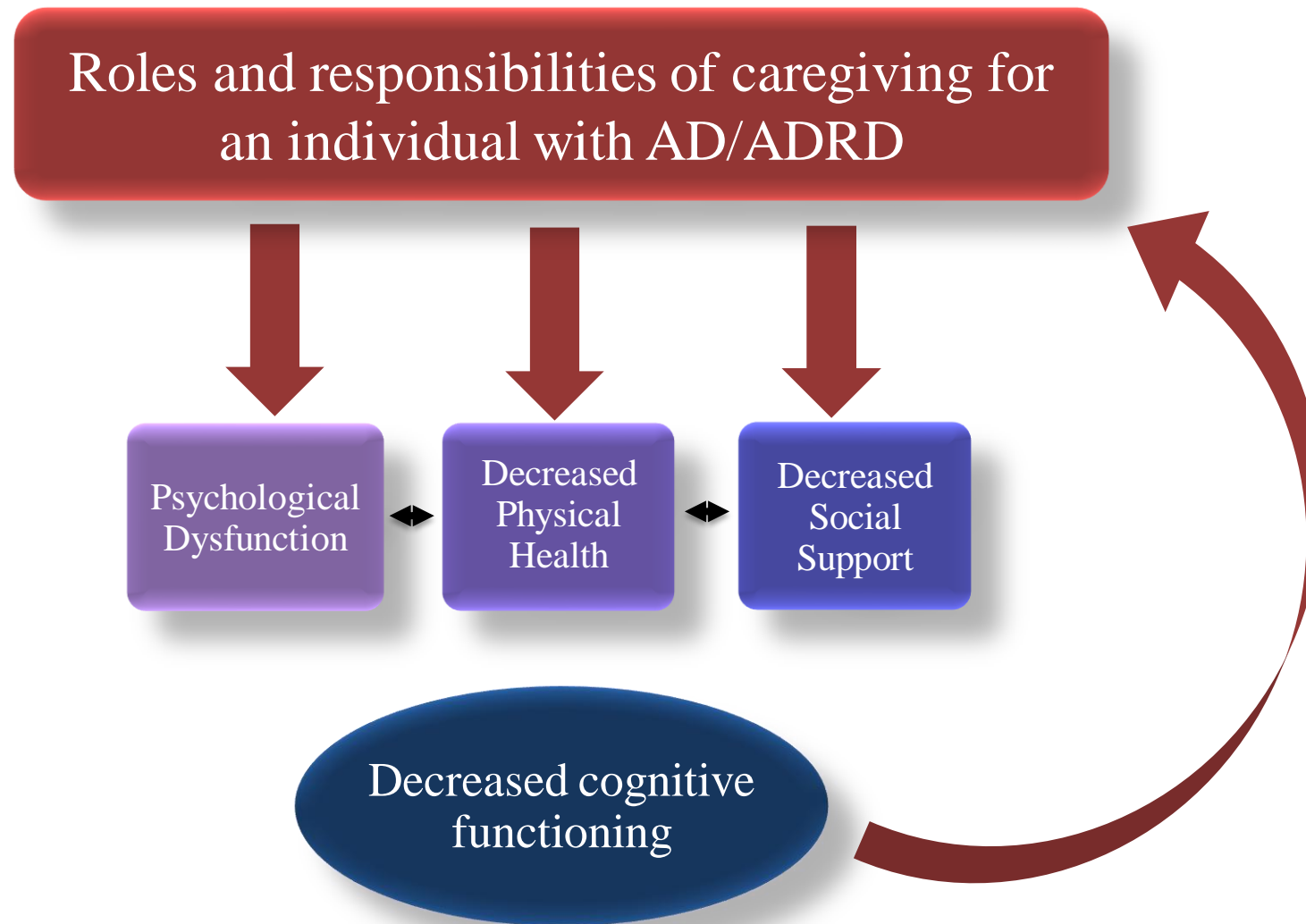
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Family Caregivers for Persons with AD/ADRD

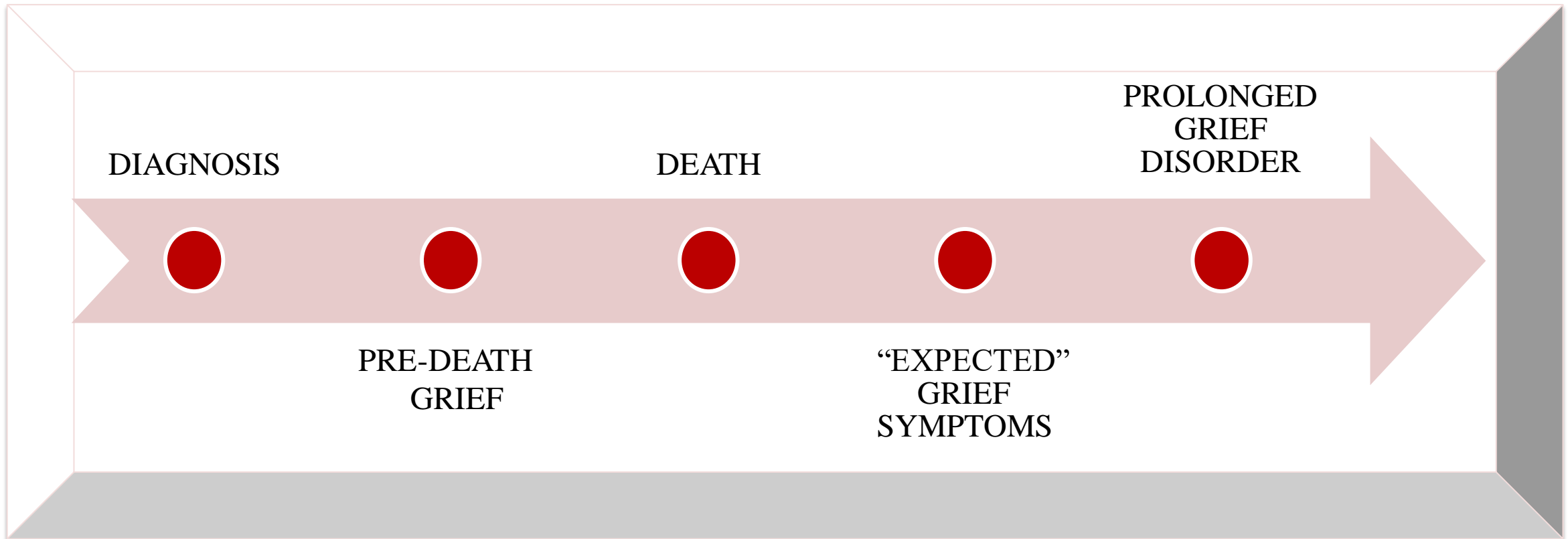




Some of the experiences
caregivers face you might
not have thought about...






Trajectory of Grief





Importance of Defining Pre-Death Grief

An examination and proposed definitions of family members' grief prior to the death of individuals with a life-limiting illness: A systematic review

Jonathan Singer¹ , Kailey E Roberts², Elisabeth McLean¹, Carol Fadalla⁴, Taylor Coats⁴, Madeline Rogers⁵, Madeline K Wilson³, Kendra Godwin⁶ , and Wendy G Lichtenthal⁴ 

Palliative Medicine

1–28

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Pre-Death Grief (PDG)

Pre-death grief is when a person experiences any symptoms related to losing someone with a terminal illness

More specifically, when synthesizing the results of this study, two overarching themes came to fruition:

- Illness-Related Grief
- Anticipatory Grief



Illness-related grief (IRG)



IRG is *present-oriented*

- Longing and yearning
- The experience of grief before the death of a family member that relates to the numerous, multiplicative losses that can be incurred when a family member has a life-limiting illness
- Feelings of emotional pain, sorrow, or pangs of grief related to the family member's functional impairment

Anticipatory Grief (AG)



AG is *future-oriented*

Family members' grief experience while the person with the life-limiting illness is alive but that is focused on feared or anticipated losses that will occur after the person's death



Importance of Comprehensive Assessment



The Alzheimer's disease (AD) continuum

IWG-2

Asymptomatic at risk
or presymptomatic

Prodromal

Mild AD dementia

Moderate AD dementia

Severe AD dementia

NIA-AA

Preclinical

AD with MCI
(prodromal AD)

AD with
mild dementia

AD with
moderate dementia

AD with
severe dementia

FDA

Stages 1 and 2

Stage 3

Stage 4

Stage 5

Stage 6

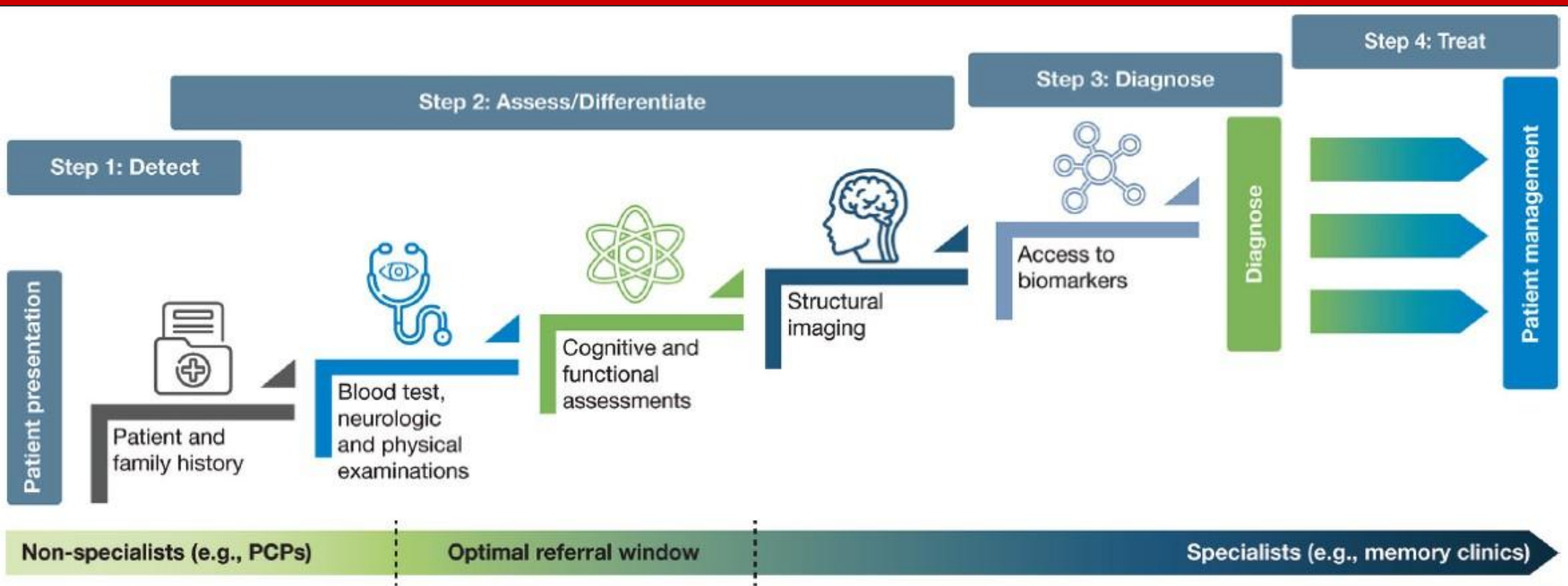
ASSOCIATED AD
PATHOLOGY / SYMPTOMS

Evidence of AD pathology ($A\beta$ and tau deposits / neuronal injury)

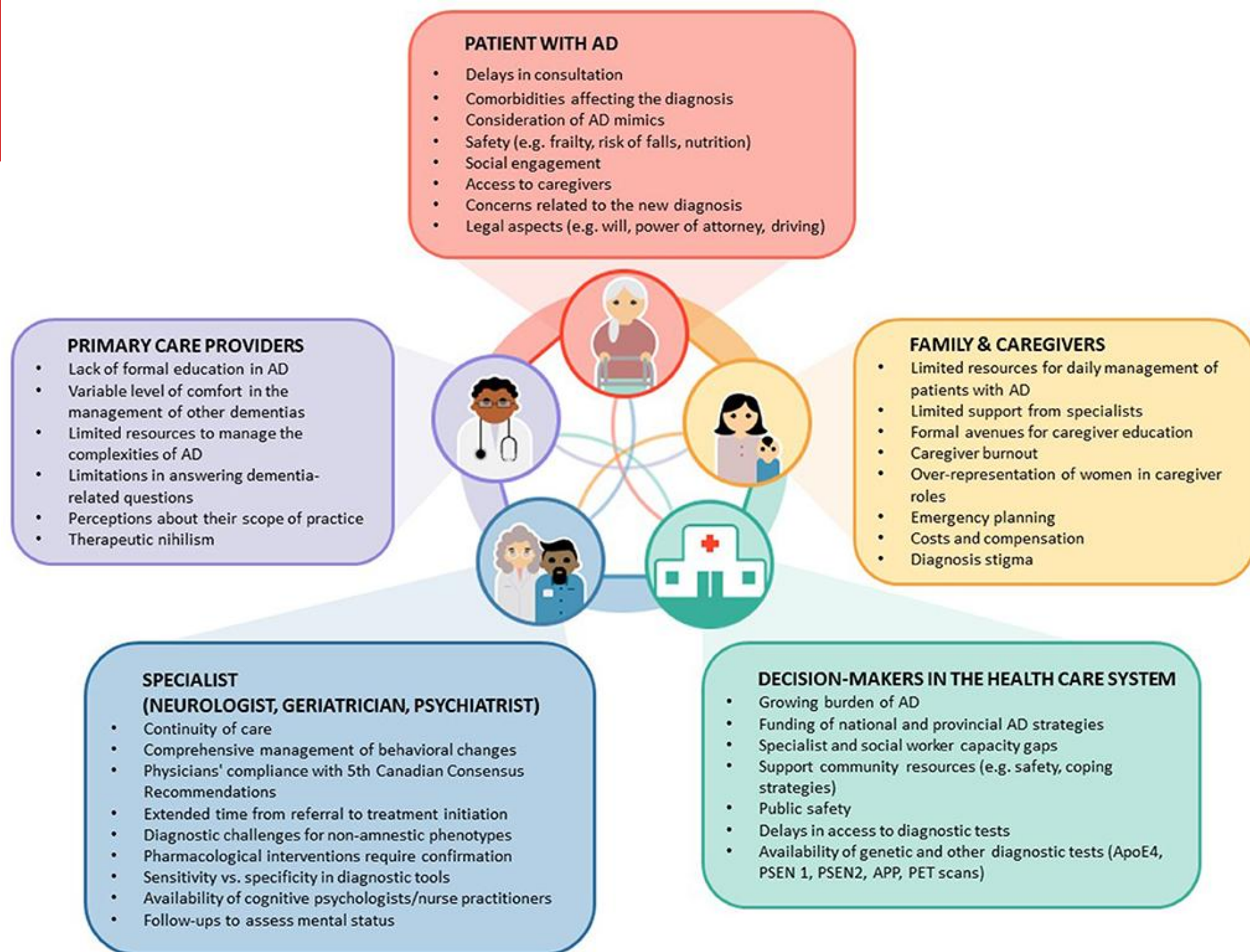
Behavioral and psychological features*

Cognitive impairment

Functional impairment



	Step 1: Detect	Step 2: Assess/Differentiate		Step 3: Diagnose	Step 4: Treat
Recommended tests	<ul style="list-style-type: none">• Patient history, including family history• Caregiver perspective• Medical and disease history• Medication count• Lifestyle data (smoking, alcohol, exercise)	<ul style="list-style-type: none">• Blood tests (full blood count, TSH, BG, serum B12, liver and renal function tests)• Genotyping• Neurologic examination• Physical examination	<ul style="list-style-type: none">• Cognitive: AD8, IQCODE, MMSE, MoCA, Mini-Cog, or QRDS• Functional: A-IADL-Q, FAST, or FAQ• Behavioral: GDS or NPI-Q	<ul style="list-style-type: none">• MRI• FDG-PET*	<ul style="list-style-type: none">• Amyloid PET• CSF Aβ42, p-tau and t-tau• CSF Aβ42/Aβ40
					<ul style="list-style-type: none">• Symptomatic treatments (e.g., Ach inhibitors, NMDA receptor antagonist)• Lifestyle changes• Social work support• Clinical trial registries





GIA Comprehensive Memory Clinic



Best way to help
the dyad...
Comprehensive
assessment to
start





Comprehensive Assessment

Blood-based biomarkers

- Amyloid tau
 - lower levels indication of Alzheimer's
- p-tau 217
 - Higher levels indication of Alzheimer's disease

Imaging

- Magnetic Resonance Imaging (MRI)
- Positron Emission Tomography (PET)

Clinical

- In person Assessment
- Medication management
- Assess ADL (e.g., bathing; feeding) /IADLS (e.g., managing finances; shopping)
- Assess GAIT (e.g., walking)

Neuropsychological Testing

- Immediate, short term, and long term Memory
- Executive Functioning
- Visuospatial Memory
- Attention
- Language

GIA Memory Clinic Team



Dr. Jonathan Singer, Ph.D.
Neuropsychologist
GIA Memory Clinic Director



Dr. Gayle Ayers, D.O.
Geriatric Psychiatrist
Co-Medical Director



Dr. John Bertelson, M.D., FAAN
Neurologist
Co-Medical Director



Carolyn Perry, M.S., CCC-SLP
Speech Language
Pathologist



Alayna Jump, B.S.
Senior Patient Service
Specialist



Veronica Molinar-Lopez, B.S.
Director of Outreach

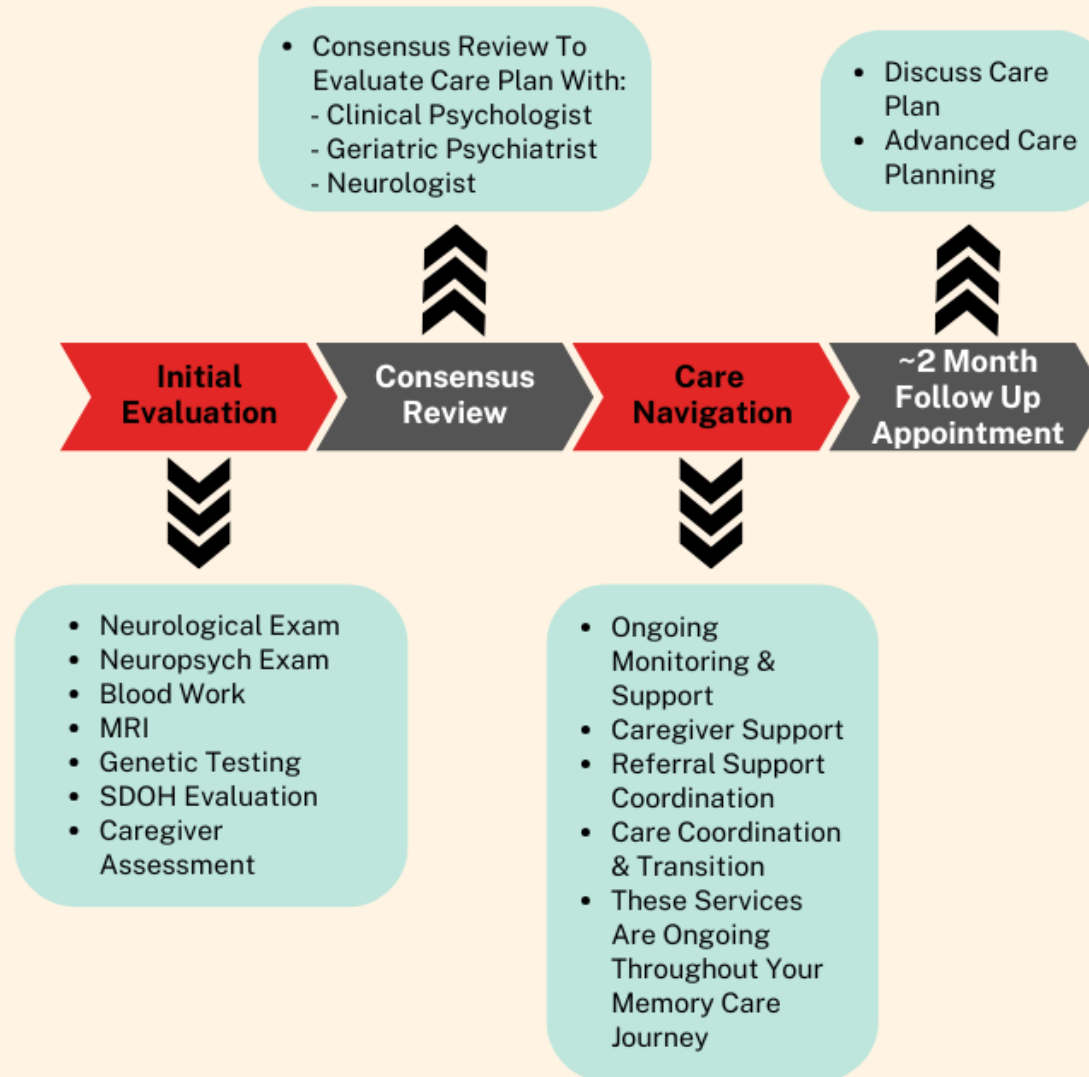


Dr. Volker Neugebauer, M.D., Ph.D.
GIA Executive Director



Ruben Gonzales, B.A.
Business Manager

GIA Memory Clinic Patient Projected Timeline



September 11, 2023

CMS Announces New GUIDE Model for People Living with Dementia and Their Caregivers

No Co-Pay or Co-Insurance cost for participants

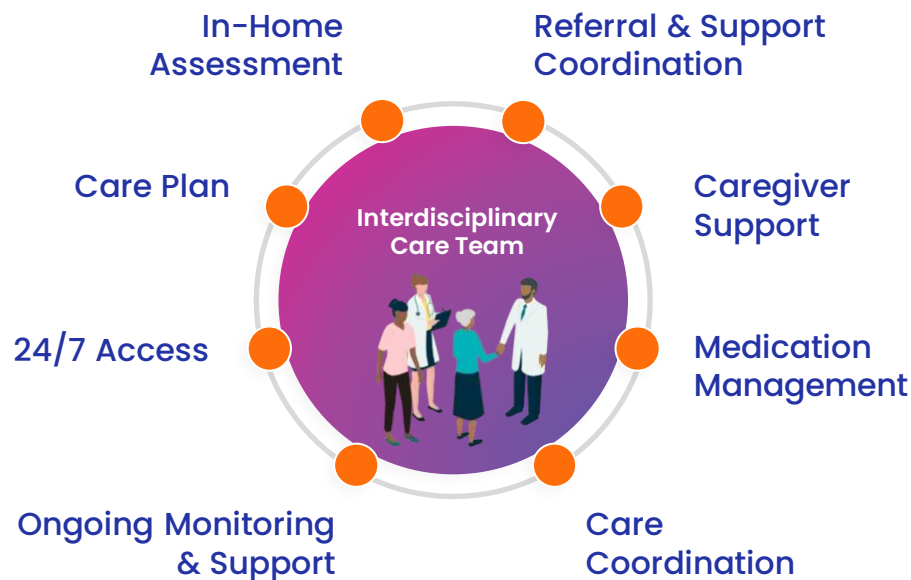
Interdisciplinary Care Team



Care Navigator



Dementia Proficient Clinician



24/7 Help Line



\$2,500 of Respite Care



Caregiver Education Program



Annual In-home Assessment



Medicare Patient Eligibility

Required To Enroll:

- Has Dementia – confirmed by Physician
- Enrolled in Medicare Part A & B
- Have Medicare as Primary Payer

Disqualified If:

- Enrolled in Medicare Advantage
- Enrolled in PACE
- Elected hospice benefit
- Living in Long-term nursing home



Pharmacological Interventions



Infusions (Leqembi)



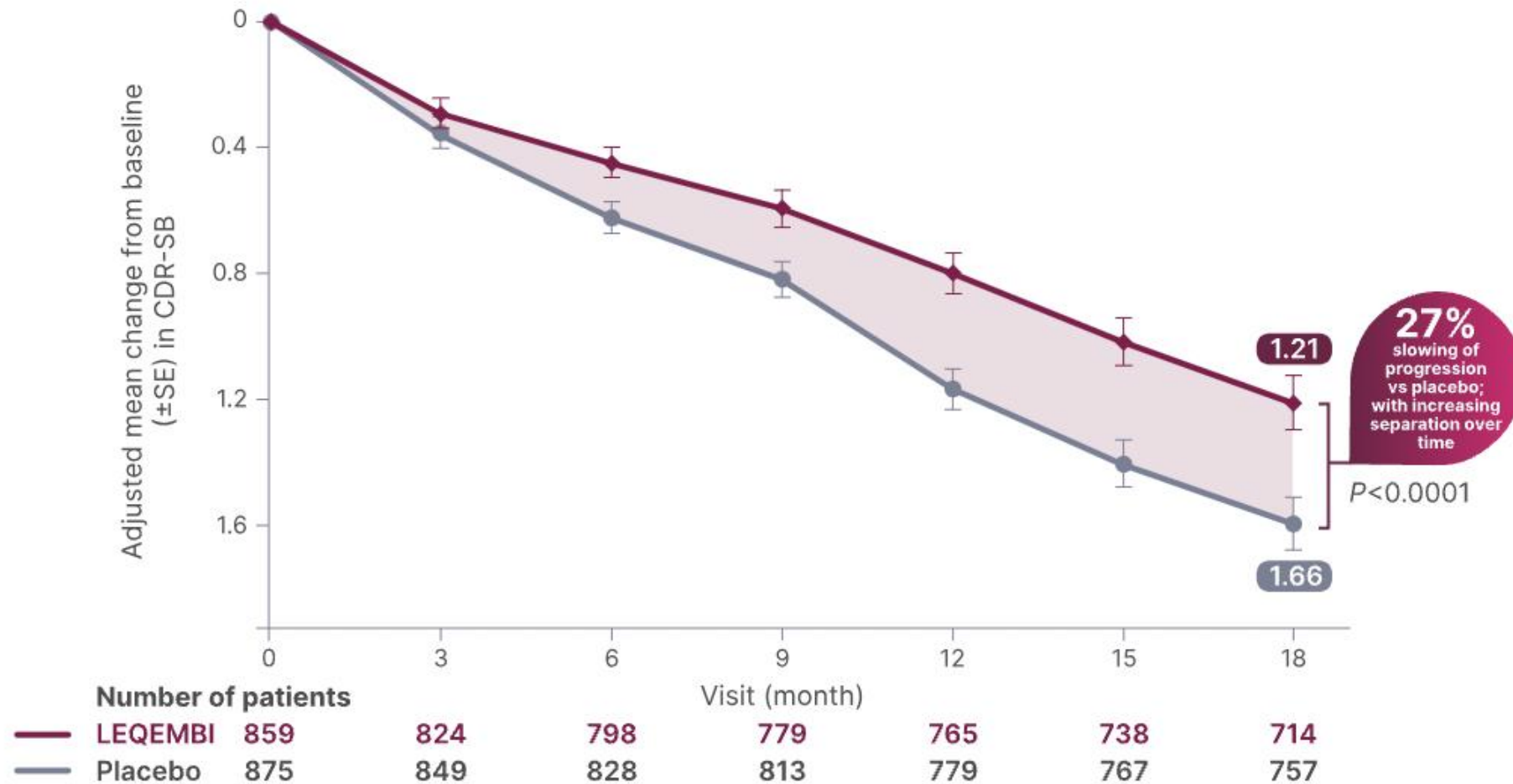
- MCI due to Alzheimer's disease and Mild Alzheimer's dementia
- Mechanisms
 - LEQEMBI clears plaque.
 - LEQEMBI supports neuronal function by clearing highly toxic protofibrils that can continue to cause neuronal injury and death even after plaques are cleared
- Hour infusion every other week
- MRIs before your treatment (also, after your 5th, 7th, and 14th infusions)

Infusions (Leqembi)



SLOW PROGRESSION!!!

CDR-SB: Change from baseline in cognition and function at 18 months²

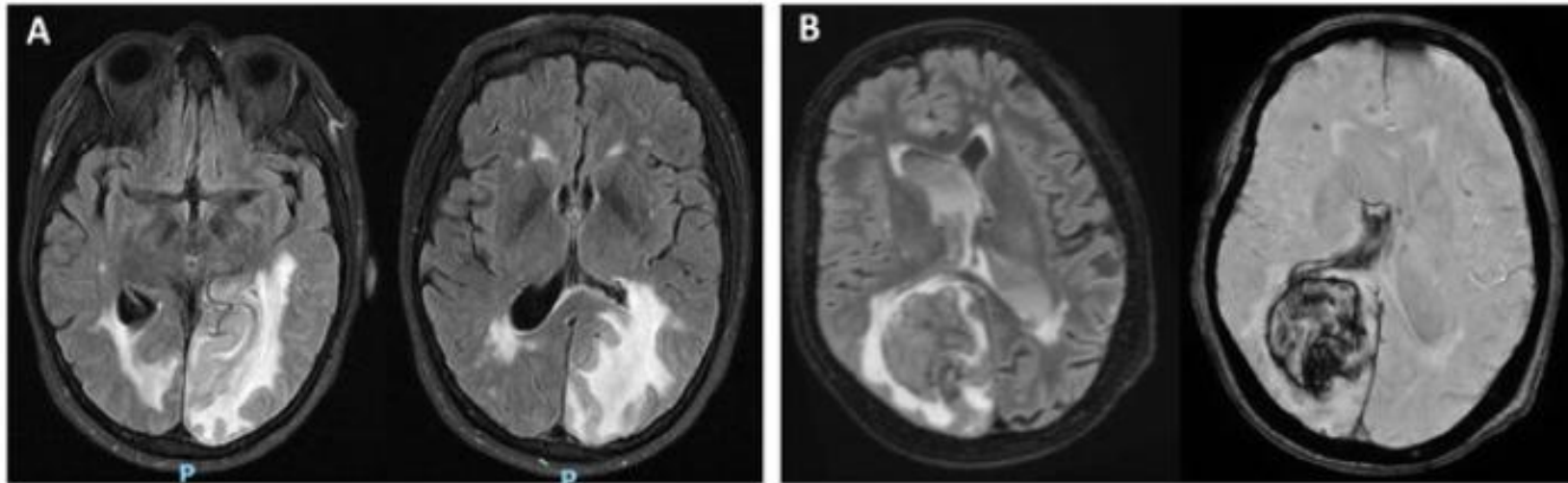


Infusions (Leqembi)



Major Side Effect

- Amyloid-Related Imaging Abnormalities (Brain bleeds)



serious symptomatic ARIA under lecanemab
(Villain et al., 2022)



Non-Pharmacological Interventions



Intervening on BPSD Symptoms



- Our primary non-pharmacological intervention is around managing behavioral and psychological symptoms of dementia (BPSD).
- Responding effectively:
 - Redirection
 - Simple instructions (abstract vs. concrete)
 - Ask specific questions
- Reduce Stress and Burden

Respite and Individual Skill Building



- **TX-CARES**
 - **Telehealth TX-CARES**
- **CREATIVE MINDS**



TX-CARES & Telehealth TX-CARES Methodology

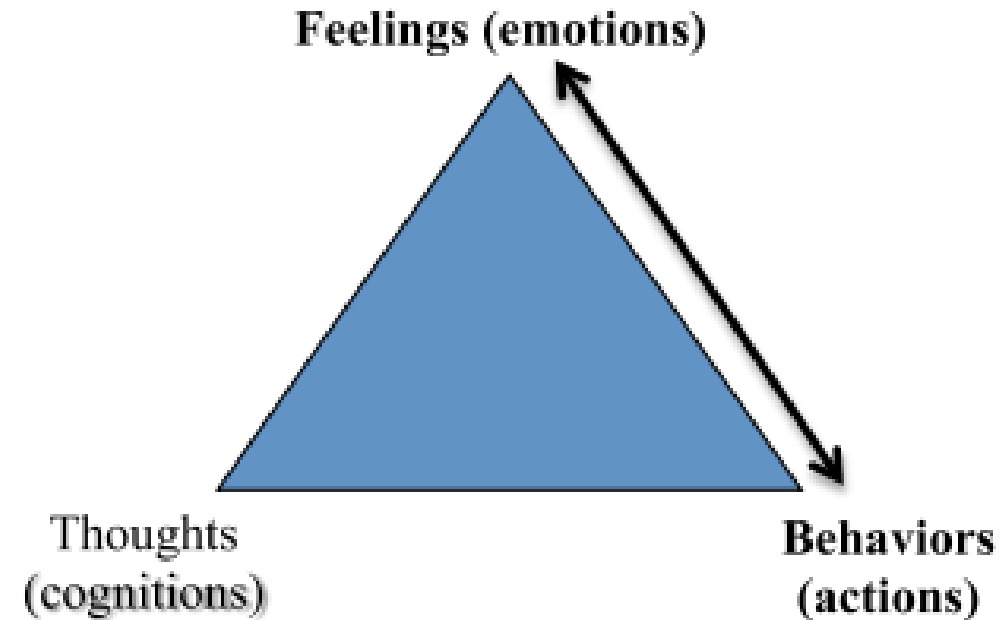


- Randomized control trials to test two evidence-based psychological interventions
 - *Primary aim: reducing pre-death grief in family caregivers of persons with AD/ADRD*
- Behavioral Activation vs. Mindfulness Based Cognitive Therapy
- Physiological markers (e.g., heart rate variability), biological markers (e.g., IL-6; IL-10), and fMRI

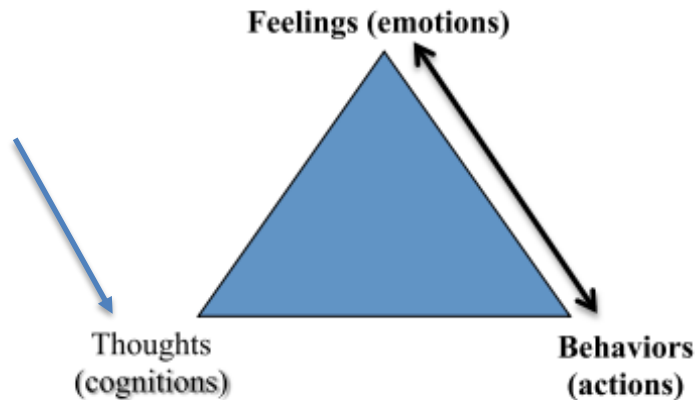
Behavioral Activation



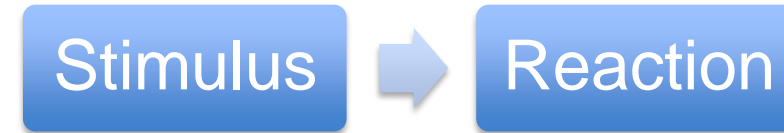
Behavioral activation helps us understand how behaviors influence emotions, just like cognitive work helps us understand the connection between thoughts and emotions.



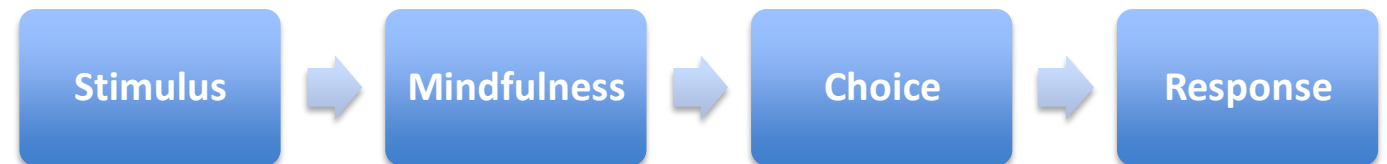
- Mindfulness
- Cognitive therapy techniques



Without Mindfulness:



With Mindfulness:



Creative Minds



12-week Respite Intervention



3 Hours a Week

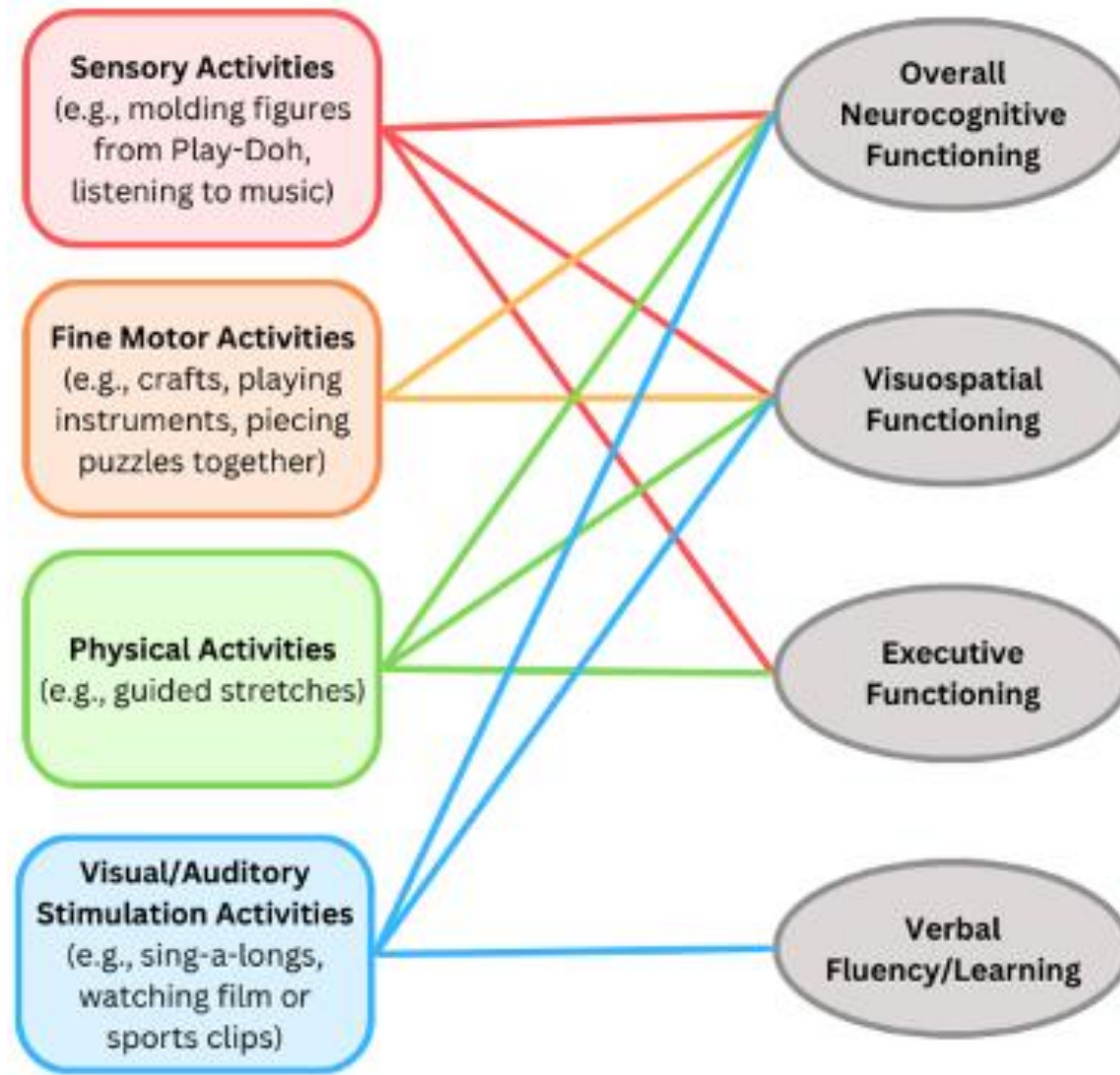


Persons with AD/ADRD



Neurocognitive Evaluation of the
Dyad

Creative Minds: Intervention Sessions



Creative Minds: Family Caregivers



Outcomes

- Stress
- Pre-death grief
- Caregiver burden
- Anxiety
- Depression
- Coping
- Neurocognitive functioning
- Inflammation markers





Abbreviated ACT for persons with Mild Neurocognitive Disorder



Abbreviated ACT



- 6 sessions of one on one (care partner can join)
- Focuses on accepting the diagnosis
- Identifying goals and engaging in valued behaviors
- Building SMART goals

S Specific	M Measurable	A Attainable	R Realistic	T Time-bound
<p>Do: Set real numbers with real deadlines.</p> <p>Don't: Say, "I want more visitors."</p>	<p>Do: Make sure your goal is trackable.</p> <p>Don't: Hide behind buzzwords like, "brand engagement," or, "social influence."</p>	<p>Do: Work towards a goal that is challenging, but possible.</p> <p>Don't: Try to take over the world in one night.</p>	<p>Do: Be honest with yourself- you know what you and your team are capable of.</p> <p>Don't: Forget any hurdles you may have to overcome.</p>	<p>Do: Give yourself a deadline.</p> <p>Don't: Keep pushing towards a goal you might hit, "some day."</p>

How do I identify my values???



- Goals and values are different things
- Values, are the things that matter to us, like what we want to be known for.
- Goals are how we get there.
- Going West Example
 - The driving to California is the goal, while the value is going West.

Examples



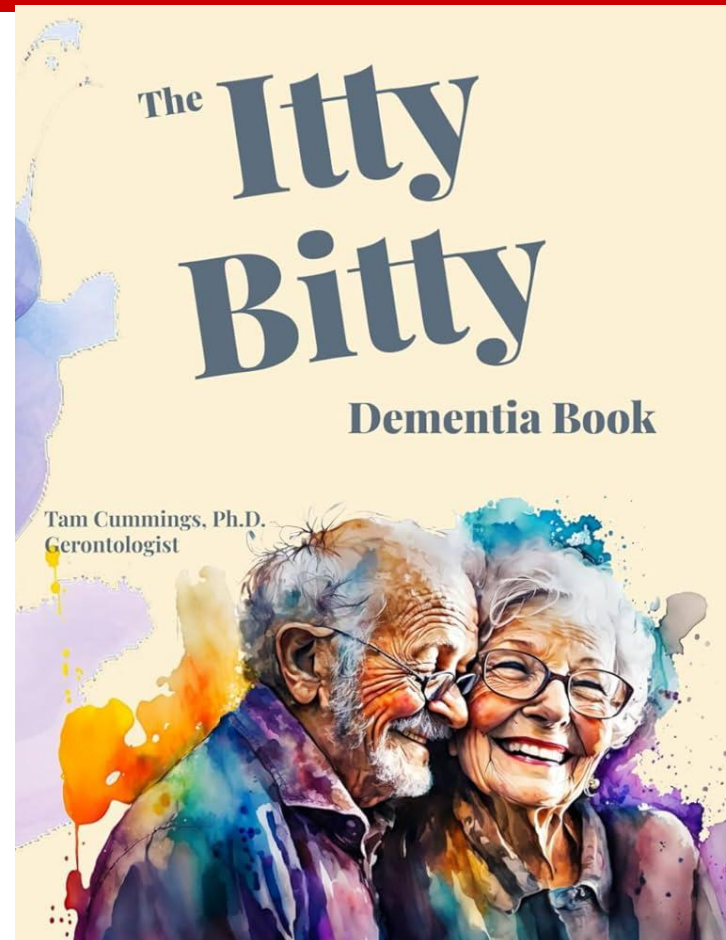
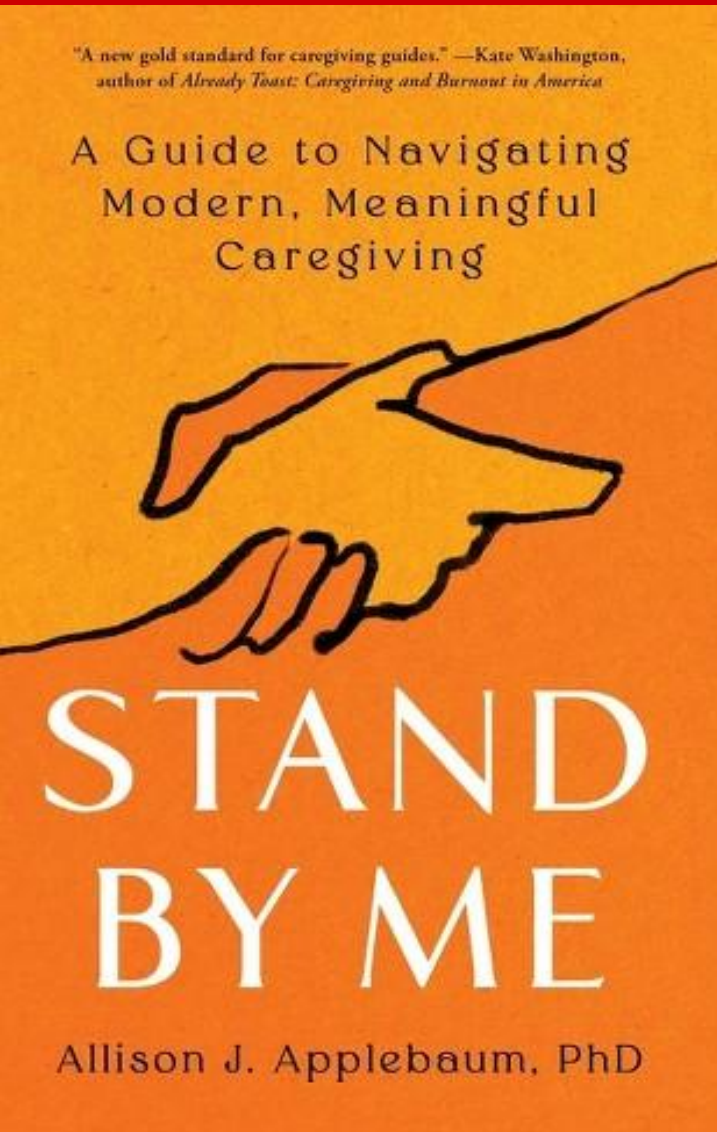
Example:

- Going fishing
 - Why do you enjoy it?
 - It allows them to be outside, or gives them solitude, or they like catching their dinner.
 - Use that to define the value, then help them think of alternative goals in service of that value.

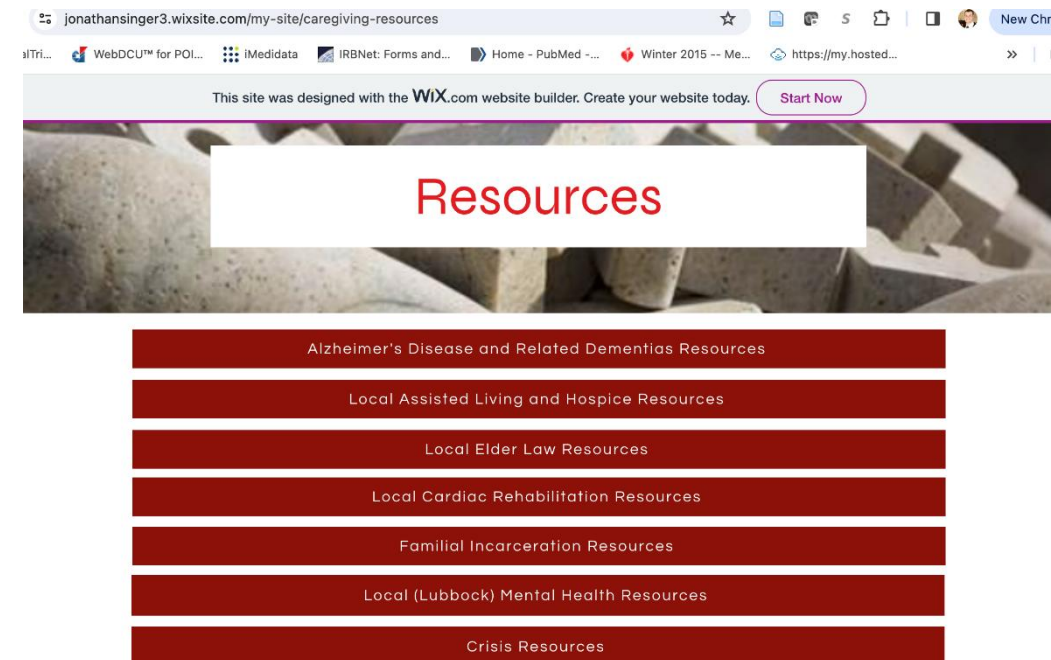
Example (help your care recipient):

- Their goal is to drive again
- Ask them why they value driving (probably independence)
- Let's think of goals that align with this value of independence that they can do

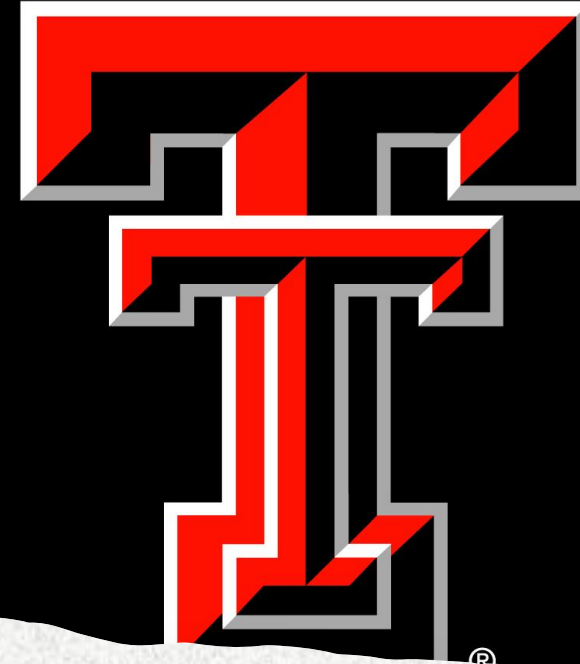
Psychoeducation Resources



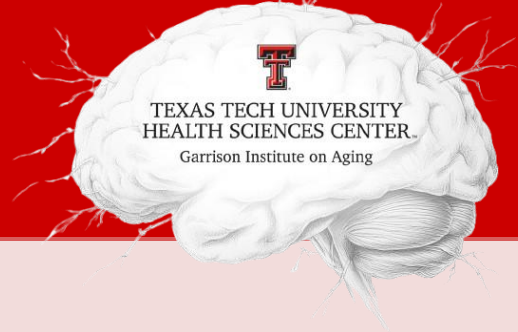
24/7 HOTLINE CONNECTS FAMILY
CAREGIVERS TO DEMENTIA
SPECIALISTS- Alzheimer's Association
(800)-272-3900)



<https://jonathansinger3.wixsite.com/my-site/ad-adrd-resources>



“I do what I do because I believe no one should face death or loss alone, but should be held in love. It is an honor to journey beside so many”



Acknowledgements



Participants



Lab Members



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