

Alyssa Aguirre, LCSW-S
Assistant Professor of Practice | Steve Hicks School of Social Work
Assistant Director of Dementia Care Transformation | Department of Neurology



WHAT STARTS HERE CHANGES THE WORLD

Learning Objectives



Part 1: Comprehensive Memory Center
Recognize the elements of an innovative
care delivery model that is co-designed by
patients

Part 2: Assessment Tools

Learn about common evaluation tools
and assessments to determine a diagnosis

Part 3: Frequently Asked Questions
A review of the most common questions
I get asked by patient's and families



Part 1: A New Model of Neurology Care



WHAT STARTS HERE CHANGES THE WORLD





Care Partner

Diagnosis

Delayed Fragmented

Communication
Among providers
Diagnosis feedback

<u>Support</u>

Coping: anxiety

Education

Exercise

Personalized Clinical Trial Legacy Projects

Depression/loss of purpose after diagnosis

Caregiver Burden

Patient

Faith/Spirituality and support groups



WHAT STARTS HERE CHANGES THE WORLD

Mission Statement

We provide evaluation and treatment to patients and families who are living with conditions that impact memory, behavior, and other cognitive functions. Our goal is to determine what is causing the changes and provide support throughout the process.

What's different about us?

- More efficient path to diagnosis and treatment
- Interprofessional team housed in one location (diagnosis and treatment)
- Improved coordination of care
- Care for patient and care partner(s)
- Longer appointments to gain understanding of individual concerns
- Ongoing support services to help meet goals



WHAT STARTS HERE CHANGES THE WORLD

Conditions We Treat

- Mild Cognitive Impairment (MCI)
- Alzheimer's Disease
- Posterior Cortical Atrophy
- Vascular Dementia
- Frontal Temporal Dementia
- Primary Progressive Aphasia
- Semantic Dementia
- Corticobasal Syndrome
- Dementia with Lewy Bodies
- Other Neurodegenerative Conditions

Our Services

- Neurological evaluation and treatment
- Psychiatric evaluation and treatment
- Neuropsychological evaluation
- Cognitive-linguistic and swallowing treatment
- Psychotherapy and supportive counseling
- Imaging, pharmacy and lab on-site
- · Advanced care planning



How did we help you?

Open about progression

Offering suggestions
Coordinating care

Planning for Hopefully-framed the future diagnosis Integrated Team

Maximize my quality of life



WHAT STARTS HERE CHANGES THE WORLD

What did you like?

Team-approach Openness
Encouragement Did not feel

Relief that it is rushed

finally here I'm part of the story

I felt valued

Treating me as a person, not a sick person



Part 2: Getting a Diagnosis & Assessment Tools



WHAT STARTS HERE CHANGES THE WORL

Benefits to getting a diagnosis

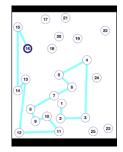
- Clinical trials
- Accurate medications
- Family conversations (travel, housing, finances)
- Apply for programs
- Legal planning
- Managing other medical conditions
- An explanation for worrisome symptoms









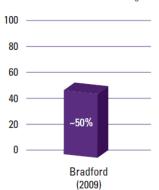




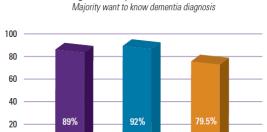
Disclosure of Diagnosis

Figure 1. 50% of patients with dementia have no medical record of diagnosis









Turnbull

(2003)

Holroyd

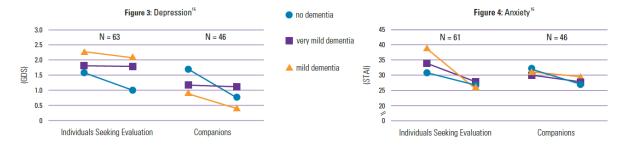
(1996)

Alz-Eu Harvard

(2011)

Figure 2. Surveys of US adults

Changes in depression and anxiety, pre-evaluation vs post-disclosure, in individuals and companions seeking a dementia evaluation.



Symptoms of anxiety and depression remain stable or even decline immediately after diagnosis (Carpenter, et.al (2008) JAGS 56:405–412)



WHAT STARTS HERE CHANGES THE WORLD

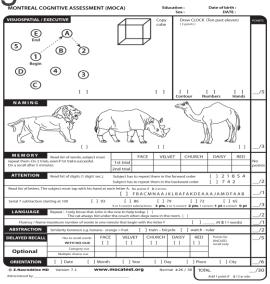
MoCA (Montreal Cognitive Assessment)

Pros

- Much more sensitive than MMSE in detecting MCI and early dementia
- More content tapping higher level executive functioning
- 30-point scale similar to MMSE
- Translations available in 35+ languages
- Free online

Cons

- Takes 10-14 min. to administer
- More complex administration and directions than MMSE





Part 3: Frequently Asked Questions





WHAT STARTS HERE CHANGES THE WORLD

FAQ's

- "What will the doctor do when I see him/her?"
 - You may answer questions about health history, family history, medication review, mood assessment, brain scan, blood tests or other lab work

FAQ's cont'd

- "My family thinks I have a problem with my memory, but I do not have a problem."
- "Everyone is a little forgetful sometimes."
 - Sometimes, memory loss can be reversed with treatment. In other cases, early diagnosis of a problem offers the best chance to treat symptoms and stay well.



WHAT STARTS HERE CHANGES THE WORLD

What is dementia?

de•men•tia: a group of symptoms affecting memory, thinking and social abilities severe enough to interfere with daily functioning- Mayo clinic

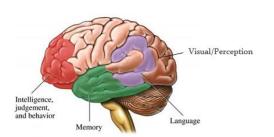


Figure 1. Common Forms of Dementia

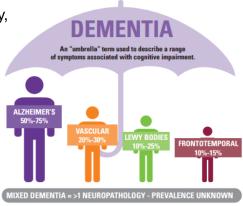


Image: Alzheimer's Association Facts & Figures



Location, location!





WHAT STARTS HERE CHANGES THE WORLD

Risk Genes

- Increase the likelihood of getting a disease, but don't guarantee it
- Several AD risk genes
- Strongest is APOE- e4
- APOE-e4 may be a factor for 40-65% of AD cases

Deterministic Genes

- Directly cause the disease
- Called autosomal dominant Alzheimer's disease (ADAD) or familial
- •Family members in multiple generations affected
- Extremely rare- only a few hundred families worldwide





Women and AD risk

Alzheimer's disease is the only neurodegenerative condition that affects women more than men.



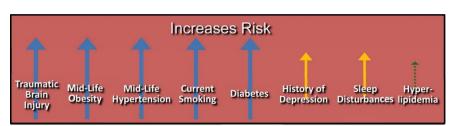


Women are at the epicenter of the Alzheimer's crisis. Almost two-thirds of American seniors living with Alzheimer's disease are women.

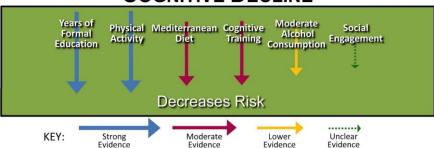
- An estimated 3.8 million women aged 65 and older are living with Alzheimer's.
- Among those aged 65 and older, 12% of women have Alzheimer's, compared with 9% of men.
- At age 65, women without Alzheimer's have more than a 1 in 5 chance of developing Alzheimer's during the remainder of their lives, compared with a 1 in 9 chance for men.
- Women in their 60s are more than twice as likely to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer.



WHAT STARTS HERE CHANGES THE WORLD



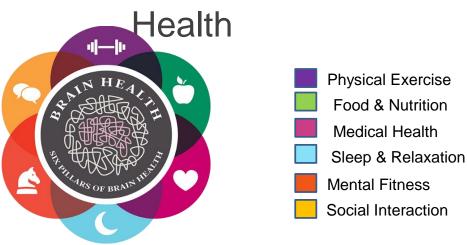
COGNITIVE DECLINE



Baumgart, M., Snyder, H., Carrillo, M., Fazio, S., Kim, H., Johns, H. (2015) Summary of the Evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. Alzheimer's & Dementia (11)6:718-726.



6 Pillars of Brain



Adapted From: Cleveland Clinic – 6 Pillars of Brain Health https://healthybrains.org/pillars/



WHAT STARTS HERE CHANGES THE WORLD

Care Partner Statistics

- 60% of dementia care partners experience moderate to severe stress and rated emotional stress as high to very high.
- About half of care partners suffer from anxiety and reported feeling a high level of burden.
- 35% of care partners report that their health has gotten worse due to care responsibilities.
- 30-40% of family care partners of people with dementia suffer from depression.
- Spouses are at 2.5 times higher odds to have depression than non-spouse care partners.
- In the year prior to care recipient's death, 59% of care partners felt they were on duty 24 hours a day, many felt it was extremely stressful.
- 84% of caregivers say they could use more information or support on caregiving topics
 - •Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals
 - •2017 Alzheimer's Association Facts & Figures
 - •Caregiving in the US, 2015, National Alliance for Caregiving and AARP



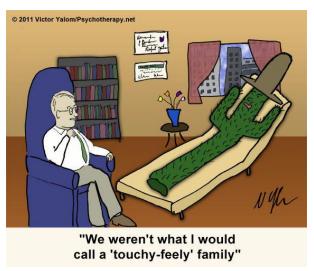
Is my family member in denial?

- Patients may have a range of reactions
- Acceptance, rejection, Anosognosia



WHAT STARTS HERE CHANGES THE WORL

So....What exactly happens in psychotherapy?





What do you talk about in counseling?

- Getting a diagnosis
- Telling family and friends
- Accepting the diagnosis
- Legal and Financial
- Communication
- Driving
- Emotional, spirituality, hope
- Routine and Structure
- Long term housing planning
- Long distance caregiving
- Grief and loss

- Intimacy
- Managing behaviors
- **Caregiver Identity**
- Feelings towards accepting help
- Community resources
- Understanding what to expect as the disease progresses
- Depression, Anxiety, Burden



Is counseling covered by insurance?



→ Psychiatric Diagnostic Interview



Psychotherapy, 30 minutes with patient and/or family member

--- Psychotherapy, 45 minutes with patient and/or family member

Psychotherapy, 60 minutes with patient and/or family member

--- Family psychotherapy without patient present

--- Family psychotherapy with patient present

90849

Multiple-family group psychotherapy

Group psychotherapy

90839

→ Patient in crisis





The Cues and Clues Model

- Is this behavior a problem?
- What is the behavior that concerns us and what is it related to?
- When does it happen?
- Where does it happen?
- Who is with the person when it happens?
- Why does it happen?
- Who is the person ie. Life experiences?
- Does the action need to change or can we live with it?
- If it needs to change, what can we do? How many potential solutions can we come up with?



WHAT STARTS HERE CHANGES THE WORLD

What are some communication strategies?

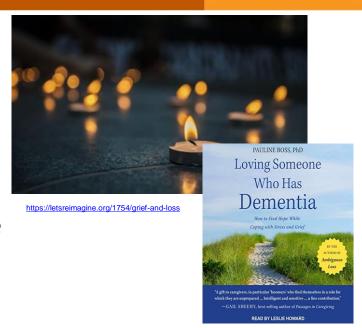
- It's hard when it's your own family member
- It's like learning a new language
- Role Play
- Self-compassion: You are going to make mistakes, we are all human
- Education: Reality-oriented vs. validation oriented
- Affirm the persons' feelings, show empathy
- Join with them in their reality
- Distract and/or relocate

TEXAS
The University of Texas at Austin

WHAT STARTS HERE CHANGES THE WORLD

Grief & Loss

- Ambiguous Loss
- Anticipatory Grief
- Photo activity
- Discussing the future
- Narrative life review





WHAT STARTS HERE CHANGES THE WORL



Alyssa Aguirre, LCSW-S

Assistant Professor of Practice | Steve Hicks School of Social Work Manager, Comprehensive Memory Center | Department of Neurology

alyssa.aguirre@austin.utexas.edu