Town Hall Forum
Alzheimer's Caregiver Journey:
Practical Advice for a Progressive Disease
May 17, 2018

Defining the Disease

Understanding the Relationship Between Progression and Changes in Behavior

and

Taking Care of Yourself

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Talk Outline

- Introduction including key points
- Defining dementia and Alzheimer's disease in various ways
- Preparing for progression: depression, sleep disturbance, wandering
- Obtaining appropriate treatment based on stage of illness
- Taking care of yourself
- Summary

Seven Key Points

1) Dementia is a general term for deterioration of previously acquired intellectual abilities significant enough to impair function

2) Alzheimer's disease is the most common cause of dementia

3) Most dementias are progressive and problem behaviors tend to be stage specific

4) Learning and preparing will help make the Alzheimer's journey as safe and as comfortable as possible

5) Early recognition of critical changes in the disease progression is important and facilitates optimal intervention and adaptation

6) New or suddenly worsened problem behaviors require careful assessment

7) Caregivers need to take care of themselves in order to provide optimal care to those living with dementia

Defining Dementia

- **Dementia**: brain injury or malfunction from any of a large number of diseases that causes a deterioration of previously acquired intellectual abilities of sufficient severity to interfere with social or occupational functioning. Memory disturbance is often, but not necessarily, the most prominent symptom. In addition, there may be impairment in abstract thinking, judgment, impulse control, and/or personality change. Dementia may be progressive, static, or reversible, depending on the underlying cause and the availability of effective treatment. Most dementias, however, are progressive.

Adapted from *A Psychiatric Glossary, Fifth Edition*,

American Psychiatric Association

Dementia: Epidemiology

- Dementia of the Alzheimer's type accounts for approximately 55% of all cases (approx. 5.7 million in U.S.)
- The frequency of the next 4 most common dementias are listed below and coupled with Alzheimer's disease account for approximately 90% of all dementias:
  - Vascular Dementia
  - Mixed (Alzheimer's and Vascular)
  - Lewy Body Dementia
  - Frontotemporal Dementia
- Other dementias which are relatively uncommon include: Parkinson's disease with dementia, Huntington's disease, corticobasilar degeneration, HIV-associated dementia, multiple sclerosis, chronic traumatic encephalopathy, other causes

DSM-5:
Major Neurocognitive Disorder

A. Evidence of **significant** cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on:
   1. Concern of the individual, a knowledgeable informant, or the clinician that there has been a **significant** decline in cognitive function; and
   2. A **substantial** impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another qualified clinical assessment

B. The cognitive deficits **interfere** with independence an in everyday activities (i.e., at a minimum, requiring assistance with complex instrumental activities of daily living such as payin gbills or managing medications).

C. The cognitive deficits do not occur exclusively in the context of a delirium.

A. The cognitive deficits are not better explained by another mental disorder (e.g., major depressive disorder, schizophrenia).

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition,* 2013

DSM-5:
Minor Neurocognitive Disorder

A. Evidence of **modest** cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on:
   1. Concern of the individual, a knowledgeable informant, or the clinician that there has been a **mild** decline in cognitive function; and
   2. A **modest** impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another qualified clinical assessment

B. The cognitive deficits **do not interfere** with capacity for independence an in everyday activities (i.e., at a minimum, requiring assistance with complex instrumental activities of daily living such as paying bills or managing medications).

C. The cognitive deficits do not occur exclusively in the context of a delirium.

D. The cognitive deficits are not better explained by another mental disorder (e.g., major depressive disorder, schizophrenia).

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition,* 2013

DSM-5: Alzheimer's Dementia

For major neurocognitive disorder:

Probable Alzheimer's disease is diagnosed if **either** of the following is present; otherwise, **possible Alzheimer's disease** should be diagnosed.

1. Evidence of a causative Alzheimer's disease genetic mutation from family history or genetic testing
2. All three of the following are present:
   a. Clear evidence of decline in memory and learning and at least one other cognitive domain (based on detailed history or serial neuropsychological testing).
   b. Steadily progressive, gradual decline in cognition, without extended plateaus
   c. No evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological, mental, or systemic disease or condition likely contribtuting to cognitive decline

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, 2013

DSM-5: Alzheimer's Dementia

For mild neurocognitive disorder:

Probable Alzheimer's disease is diagnosed if there is evidence of a causative Alzheimer's disease genetic mutation from either genetic testing or family history

Possible Alzheimer's disease is diagnosed if there is no evidence of a causative Alzheimer's disease genetic mutation from either genetic testing or family history, and all three of the following are present:

A. Clear evidence of decline in memory and learning
B. Steadily progressive gradual decline in cognition, without extended plateaus
C. No evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological or systemic disease or condition likely contributing to cognitive decline

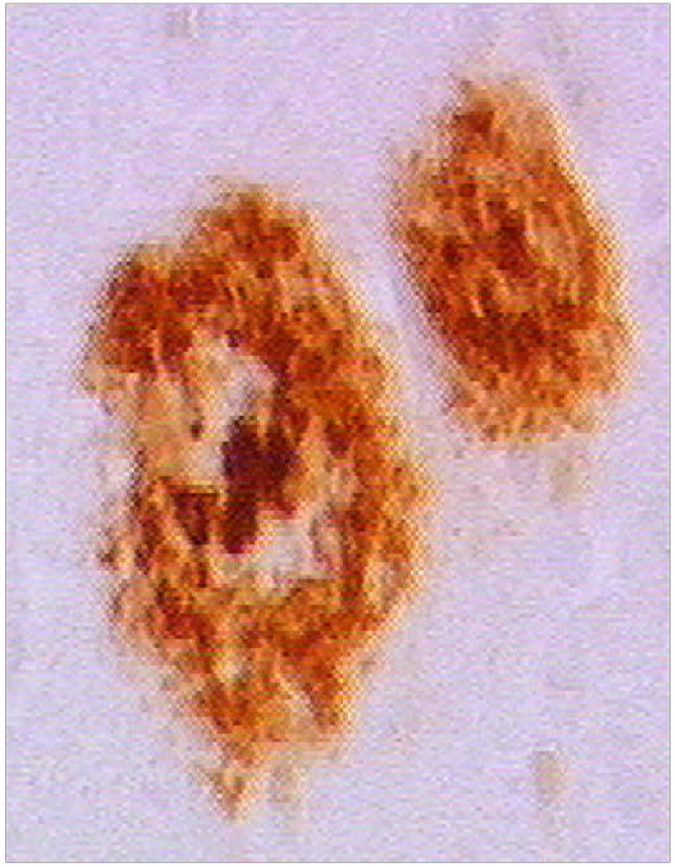
American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition,* 2013

Defining Alzheimer's Disease Based on Organ/Tissue Changes

- There are 3 consistent neuropathological hallmarks
  - Neuritic Plaques (Amyloid-rich senile plaques)
  - Neurofibrillary tangles
  - Neuronal degeneration – synapse and cell loss
- These changes eventually lead to clinical symptoms, but may begin years before the onset of symptoms

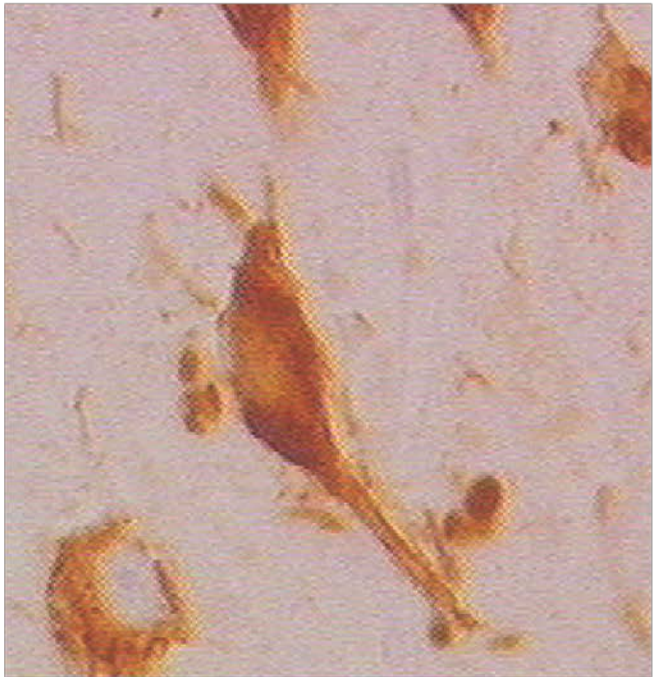
ß-Amyloid Plaques

- **Neuritic plaques** are extracellular
  - Primarily made of the abnormal protein called ß amyloid
- ß amyloid is found in the cortex and limbic nuclei with the highest concentration in the hippocampus
- It is toxic to nerve cells and causes their demise



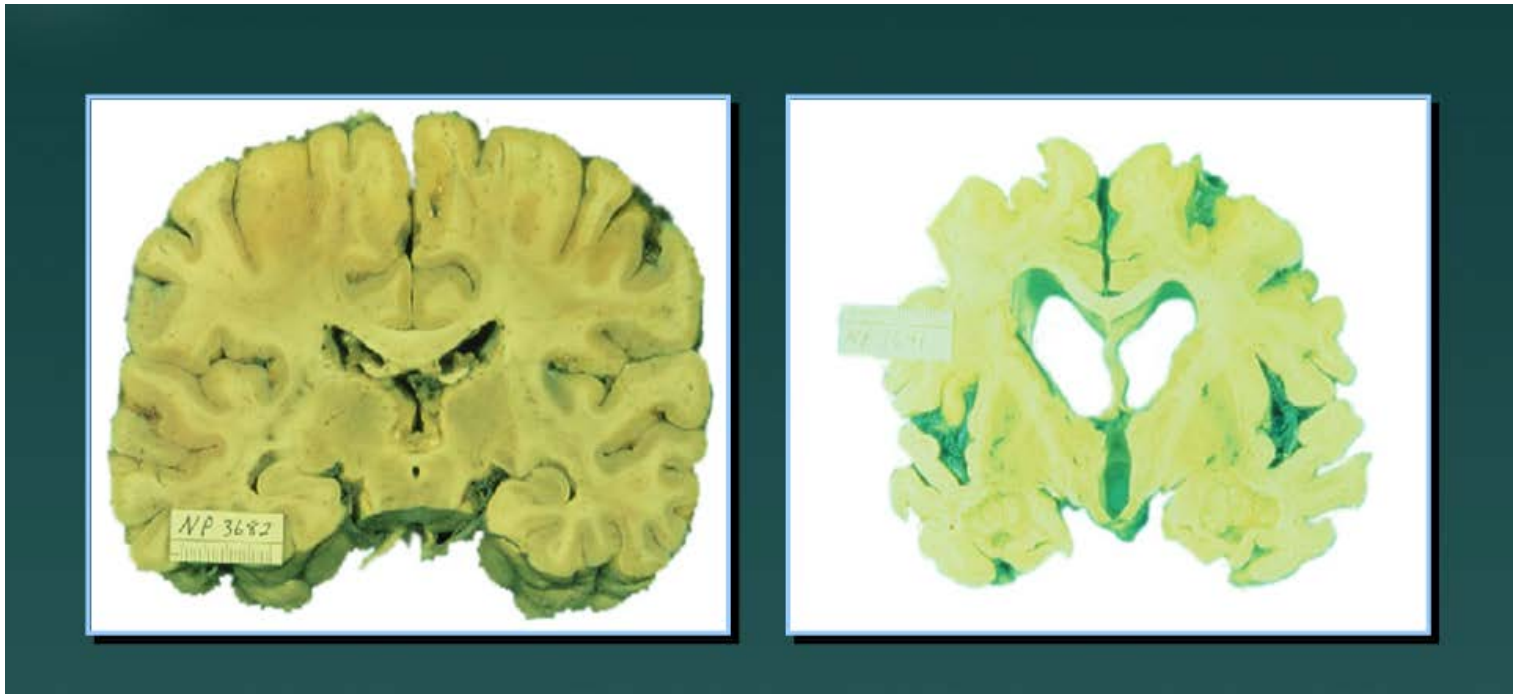
Neurofibrillary Tangles

- Neurofibrillary tangles are intracellular collections of abnormal filaments, which have a distinct paired helical structure.
  - It is unique to Alzheimer's disease
    - The neurofibrillary tangles of supranuclear palsy do not have the paired helical structure
- Found through out the neocortex and limbic nuclei



Loss of Nerve Cells in Alzheimer's Dementia

- The deep layers of the temporal cortex and the hippocampus sustain the greatest degree of nerve cell and synaptic loss



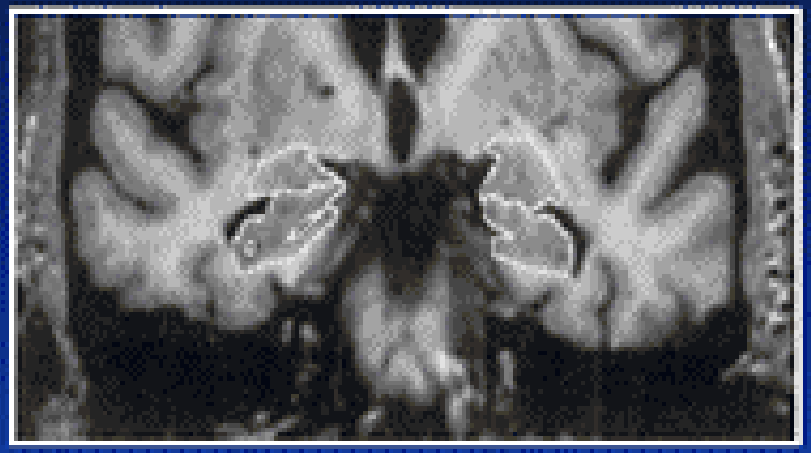
Lacor et al. J Neurosci 2004; 24:191-200

Methods of Staging Alzheimer's Disease

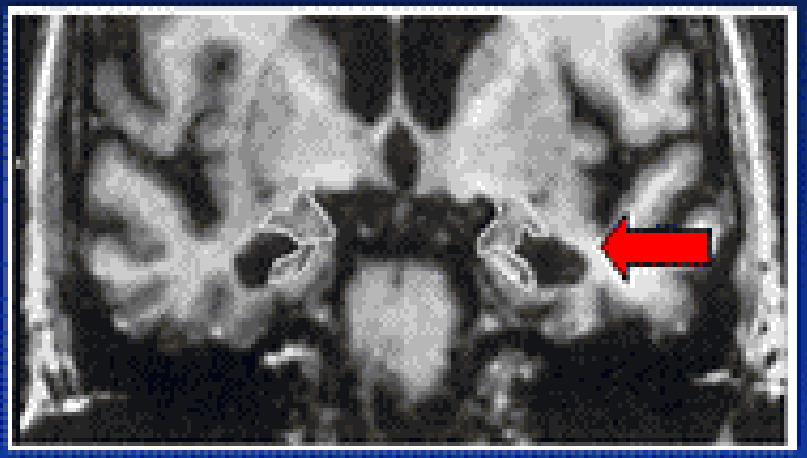
- There are a variety of approaches to staging Alzheimer's disease:
  - Assessments of brain anatomy or physiology
  - Clinical characteristics and functional losses
  - Care needs
  - Performance on cognitive tests
  - Behavioral issues

Coronal MRI: Hippocampal Atrophy in AD

Control

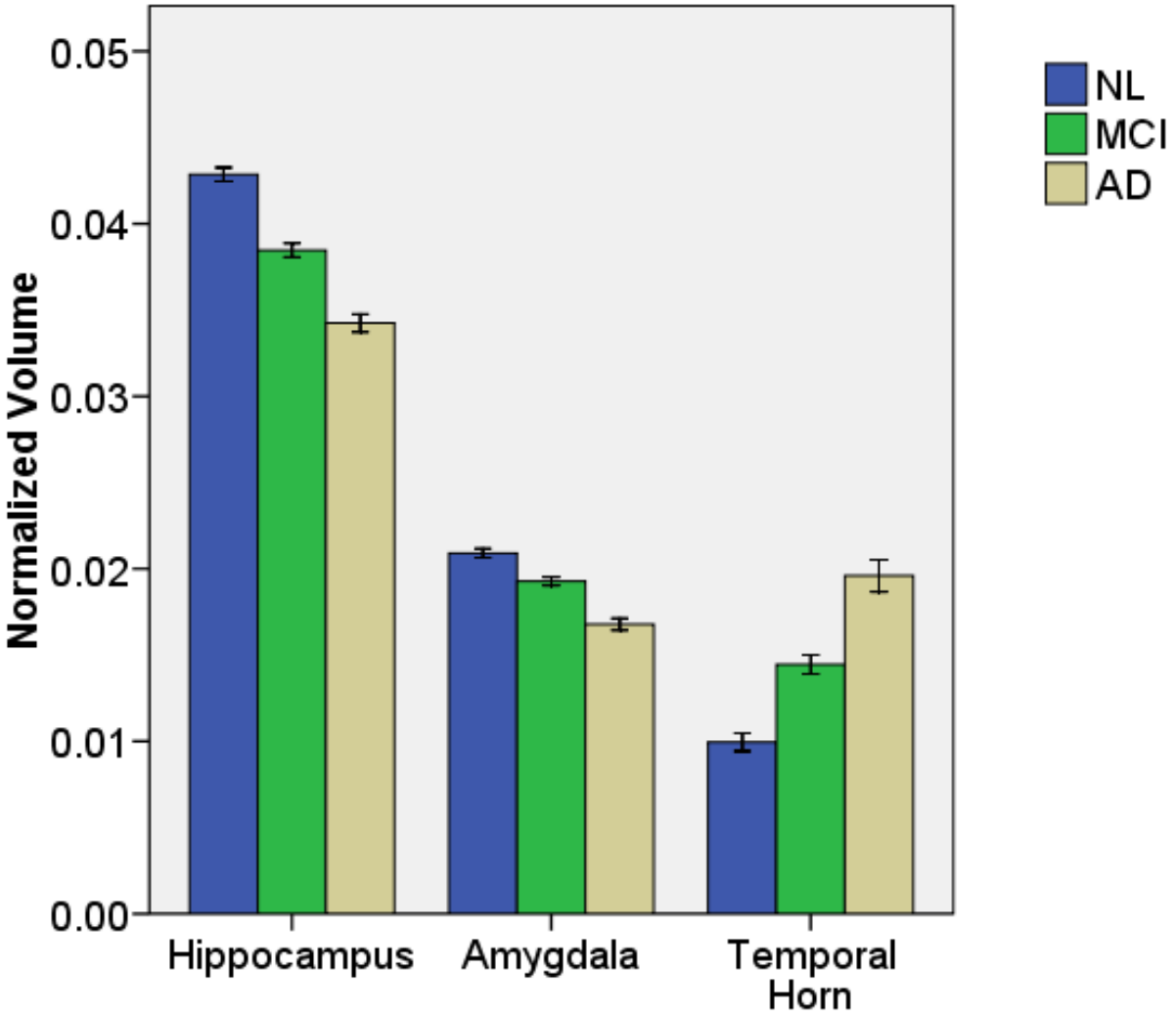


AD



Jack et al. *Neurology*, 1997.

ADNI Preliminary Analysis



Methods of Staging Alzheimer's Disease Based on Function

- Rating systems sometimes used by clinicians and researches include:
  - Clinical Dementia Rating (CDR)
    - Consists of 7 stages
  - The Global Deterioration Scale (GDS)
    - Consists of 5 Stages
  - Functional Assessment Staging (FAST)
    - Consists of 7 stages

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Incapacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
1	No difficulty either subjectively or objectively	No deficit	Normal adult	50 years

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Incapacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
2	Complains of forgetting location of objects. Subjective work difficulties.	Subjective forgetting	Age-associated memory impairment Or Mild Neurocognitive Disorder (MCI)	15 years

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Incapacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
3	Decreased job functioning evident to coworkers. Difficulty traveling to new locations. Decreased organizational capacity.	Complex occupational performance	Mild Alzheimer's dementia	7 years

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
4	Decreased ability to perform complex tasks (e.g. planning dinner for guests), handling personal finances (e.g. forgetting to pay bills), difficulty marketing	Instrumental activities of daily life (IADLs)	Mild to moderate AD	2 years

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
5	Requires assistance in choosing proper clothing to wear for the day, season, or occasion (e.g. wears the same clothing repeatedly, unless assisted)	Activities of daily living (ADLs)	Moderate AD	18 months

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
6	a) Improperly puts on clothes (e.g. may put on street clothes at bedtime or put shoes on wrong feet or difficulty with buttons) b) Unable to bathe properly	Deficient ADLs Deficient ADLs	Moderately severe AD Moderately severe AD	5 months 5 months

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
6	c) Inability to handle the mechanics of toileting (e.g. forgets to flush, does not wipe properly or properly dispose of toilet tissue)	Deficient ADLs	Moderately severe AD	5 months

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
6	d) Urinary incontinence e) Fecal incontinence	Incipient incontinence Incipient incontinence	Moderately severe AD	4 months 10 months

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
7	Over an average day: a) Speech limited to approx. 6 intelligible words or fewer	Semi-verbal	Severe AD	12 months
	b) Speech limited to a single intelligible word	Semi-verbal	Severe AD	18 months

Functional Assessment Staging (FAST)

Functional (FAST) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
7	c) Cannot walk without help	Nonambulatory	Severe AD	12 months
	d) Cannot sit up without help	Immobile	Severe AD	12 months
	e) Loss of ability to smile	Immobile	Severe AD	18 months
	f) Loss of ability to hold up head	Immobile	Severe AD	12 months

Methods of Staging Alzheimer's Disease: Performance on Cognitive Tests

- Commonly used bedside cognitive screening tests
  - MMSE
  - SLUMS
  - MOCA
  - RUDAS
- All based on 30 maximum points
  - Mild Dementia 21-30 points
  - Moderate dementia 11-20 points
  - Severe Dementia 0-10 points

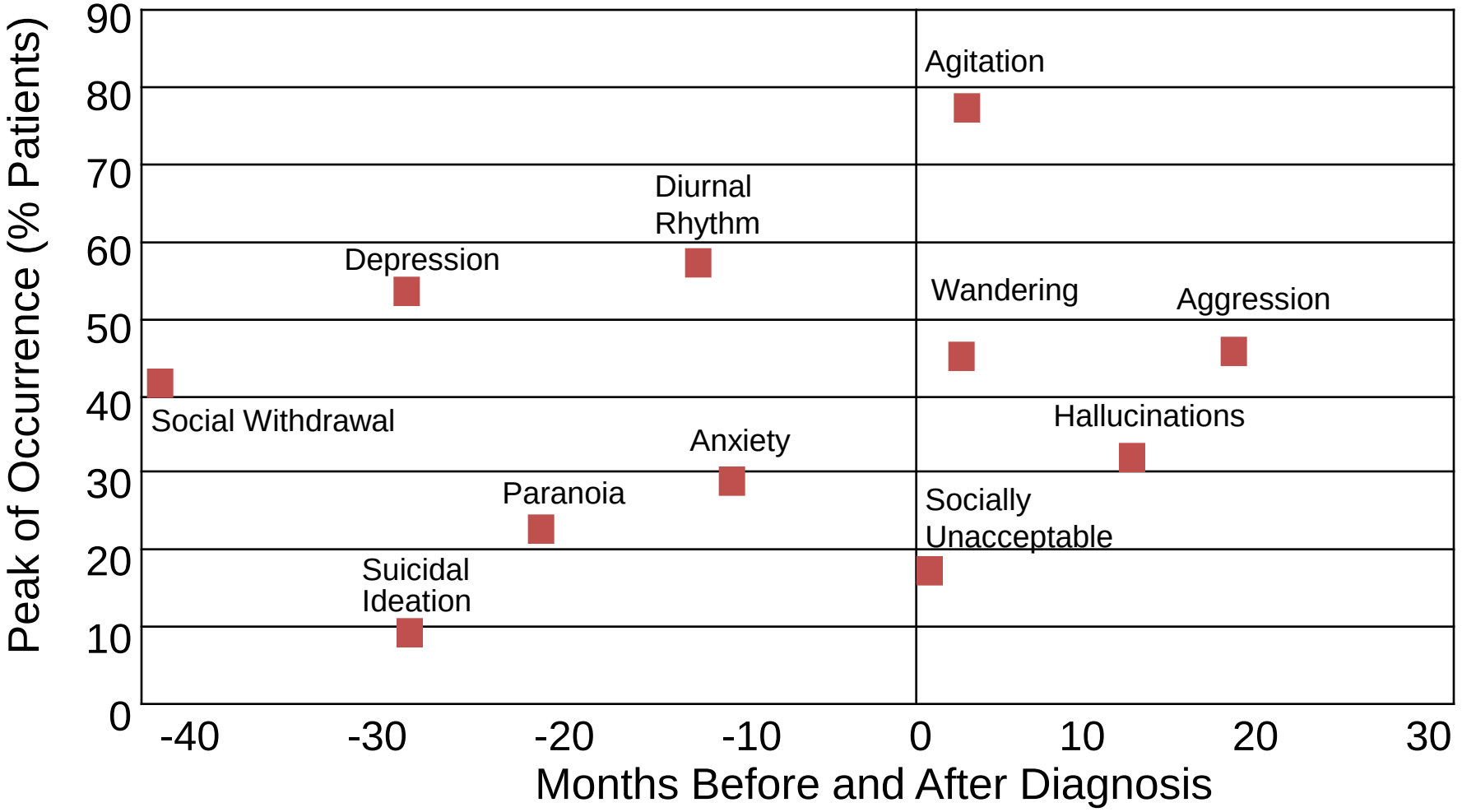
Functional Assessment Staging Test

Functional (FAST) STAGE	CHARACTERISTICS	APPROXIMATE DURATION	TYPICAL MMSE SCORE
1	No objective findings. Subjective and evolving preclinical changes only	50 years	30
2	Forgets location of objects, subjective work difficulties	15 years	30
3	Decreased functioning in demanding settings, difficulty traveling to unfamiliar locations	7 years	27
4	Cannot plan complex tasks (e.g. shopping)	2 years	24

Reisberg B. Functional assessment staging (FAST). Psychopharm Bulletin 24(4): 653-59, 1984


Pickles by Brian Crane
WHEN'S LUNCH?
YOU ALREADY HAD LUNCH. DON'T YOU REMEMBER THAT DELICIOUS TUNA SANDWICH?
OH...YEAH. THAT WAS GOOD.
BETWEEN EARL'S BAD MEMORY AND THE POWER OF SUGGESTION, I'M SPENDING LESS TIME IN THE KITCHEN AND HE'S LOSING A LITTLE WEIGHT.

Peak Frequencies of Behavioral Symptoms in Alzheimer's Disease



Jost BC, et al. *J Am Geriatr Soc*. 1996;44:1078-1081

Preparing for Changes

- Learn as much as possible about the disease including indications of disease progression
- Educate you family members and other members of your social support network about the disease

Preparing for Changes

- Take steps now to make the future better:
  - Learn and document the wishes and priorities of your loved one (e.g. Advance directives, DPOAs)
  - Learn about potentially helpful resources and programs (e.g. Medicare benefits, The Glenner Centers, the Alzheimer's Association, residential facilities)
  - Select and hire a team of professionals to help you (e.g. a geriatrician, an elder law expert, others)
  - Form a comfortable working partnership with your loved one's clinicians
  - Join a support group
  - Enroll your loved one is the Safe Return Program
  - Renovate your home (e.g. special locks)

BACKGROUND

- Currently 60,000 San Diegan's estimated to be living with dementia. By 2030, this number is expected to be 94,000.
- As is the case just about every where, most dementia will be diagnosed and treated by Primary Care Providers
- Under the leadership of 2 SD County Supervisors, Diane Jacob and Ron Roberts,The Alzheimer's Project countywide initiative began in 2014 and was organized into 3 roundtables:
  - Cure
  - Care
  - Clinical
- Participants include neurologists, psychiatrists, geriatricians, members of caregiver communities

ChampionsforHealth.org/alzheimers

Website to be updated regularly with most current information

Protecting Yourself and Your Loved One from Harm

- **Recognizing Disease Progression**
  - Psychological factors (e.g. denial) may blind a loved one to indications of disease progression.
  - Living in another city or state may also interfere with recognition of disease progression.
  - Nonetheless, there are many reasons why recognizing disease progression is important.

Recognizing Disease Progression

- Recognizing disease progression in important because:
  - It helps you to protect yourself and your loved one from harm.
  - It allows you to adapt activities and communication so that you and your loved one who is living with dementia be as healthy and happy as possible

Some Guidelines for Dealing with Problem Behaviors

- A careful investigation may reveal triggers such as:
  - Noise
  - Changes in environment
  - Unfamiliar caregivers or visitors
  - Hunger
  - Fatigue
  - Need to toilet
  - Pain
  - Time of day (sundowning)

Some Guidelines for Dealing With Problem Behaviors

- Second, and especially if the behaviors are disruptive or dangerous, consult with an expert:
  - Discuss the behavior with members of your Alzheimer's caregivers support group.
  - Problem behaviors, especially those which are new or have a sudden onset, may indicate and underlying medical problem. An evaluation by a physician may be needed

Partner with Your Loved Ones Clinicians

- Partner with the physician who prescribes medications for your loved one. This will require open, effective communication.
- Learn as much as you can about each medication from the physician or from some other reliable source:
  - What symptoms is the medication supposed to treat?
  - What are the common side effects?
  - How long will the medication take to work?
  - Are there drug-drug interactions?

Partnering with Your Clinicians

- Other important questions which you should have answers for?
  - What should I do if a dose is missed?
  - Should the medication be taken with food?
  - Is my loving one taking too many medications?
  - Does each doctor who may be prescribing medications for my loved one know what other medications my loved one is taking?
  - Do the benefits of this medication outweigh the risks?

Medication Management Tips

- Store medications in a secure location.
- Have a system for confirming that medications have been accurately administered.
- Make sure someone other than you understands your loved ones medication regimen.
- Work with your doctor to keep the medication regimen as simple as possible.
- Make sure that diuretics are not prescribed to be taken at night.
- Make sure that the physician knows what medications are best based upon age and the presence of dementia

Seven Key Points

1) Dementia is a general term for deterioration of previously acquired intellectual abilities significant enough to impair function

2) Alzheimer's disease is the most common cause of dementia

3) Most dementias are progressive and problem behaviors tend to be stage specific

4) Learning and preparing will help make the Alzheimer's journey as safe and as comfortable as possible

5) Early recognition of critical changes in the disease progression is important and facilitates optimal intervention and adaptation

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7) Caregivers need to take care of themselves in order to provide optimal care to those living with dementia