

Town Hall Forum
A Caregiver's Road Map for the Alzheimer's
Journey



**Alzheimer's:
Defining the Disease,
Preparing for Progression,
Protecting Yourself and Your
Loved One from Harm**



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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
- Protecting yourself and your loved ones from harm
- Summary



Key Points

- Dementia is a general term for deterioration of previously acquired intellectual abilities
- Alzheimer's disease is the most common cause of dementia
- Most dementias are progressive and problem behaviors tend to be stage specific
- Learning and preparing will help make the Alzheimer's journey as safe and as comfortable as possible
- Early recognition of critical changes in the disease progression is important and facilitates optimal intervention and adaptation.
- New or suddenly worsened problem behaviors require careful assessment



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 of 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.

Adapted from *A Psychiatric Glossary, Fifth Edition*,
American Psychiatric Association



Dementia: Epidemiology

- Dementia of the Alzheimer's type accounts for approximately 65% of all cases (approx. 4 million in U.S.)
- The following three have roughly the same prevalence and coupled with Alzheimer's account for over 90% of all dementias:
 - Lewy Body Dementia
 - Vascular Dementia
 - Frontotemporal Dementia
- Other uncommon dementias include: Parkinson's disease with dementia, Huntington's disease, corticobasilar degeneration, and multiple sclerosis

DSM-IV-TR:

Alzheimer's Dementia

- A. The development of multiple cognitive deficits manifested by both:
 - 1) Memory impairment
 - 2) One or more additional deficits
 - a) Aphasia (language disturbance)
 - b) Apraxia (impaired ability to carry out motor activities despite intact motor function)
 - c) Agnosia (failure to recognize or identify objects despite intact sensory function)
 - d) Disturbance in executive functioning (planning, organizing, sequencing, abstracting)
- B. The cognitive deficits cause significant impairment in social and occupational functioning and represent a significant decline from a previous level of functioning

DSM-IV-TR:

Alzheimer's Dementia

- C. The course is characterized by gradual onset and continuing cognitive decline
- D. The cognitive deficits are not due to any of the following:
 - 1) Other central nervous system conditions that cause progressive deficits in memory and cognition (e.g. cerebrovascular disease, Parkinson's disease, Huntington's disease, subdural hematoma, NPH, brain tumor)
 - 2) Systemic conditions that are known to cause dementia (e.g. hypothyroidism, vitamin B12 or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection)
- E. The deficits do not occur exclusively during the course of a delirium
- F. The disturbance is not better accounted for by another psychiatric disorder (e.g. schizophrenia)

The Pathology of Alzheimer's Disease: Defining AD 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

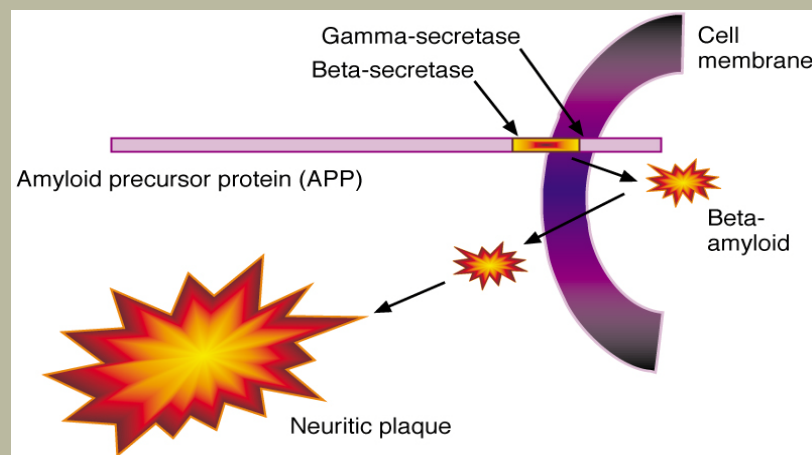
β -Amyloid Plaques

- **Neuritic plaques** are extracellular
 - Primarily made of the abnormal protein called β amyloid
- β 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



Amyloid Protein Processing

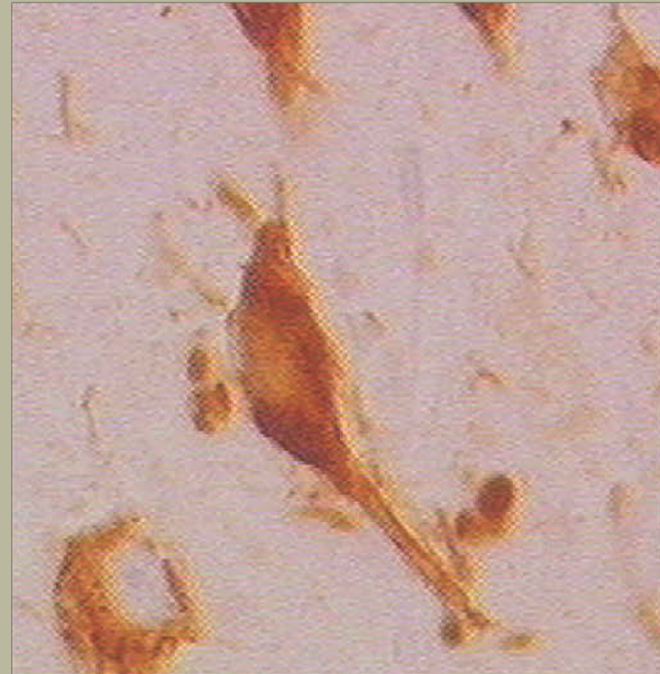
- Amyloid Precursor Protein (APP) is metabolized by intracellular proteases
 - β -secretase cleaves APP at an extracellular site beyond the cell membrane
 - γ -secretase cleaves APP in the transmembrane portion of the protein
 - These cleavages produce β -amyloid peptides and then protofibrils that are neurotoxic
 - After transport to extracellular space the β -amyloid peptides aggregate to form plaques which mature to neuritic plaques
 - APO- ϵ 4 may facilitate accumulation of β -amyloid



Cummings JL: The Neuropsychiatry of Alzheimer's Disease and Related Dementias. Martin Dunitz; 2003

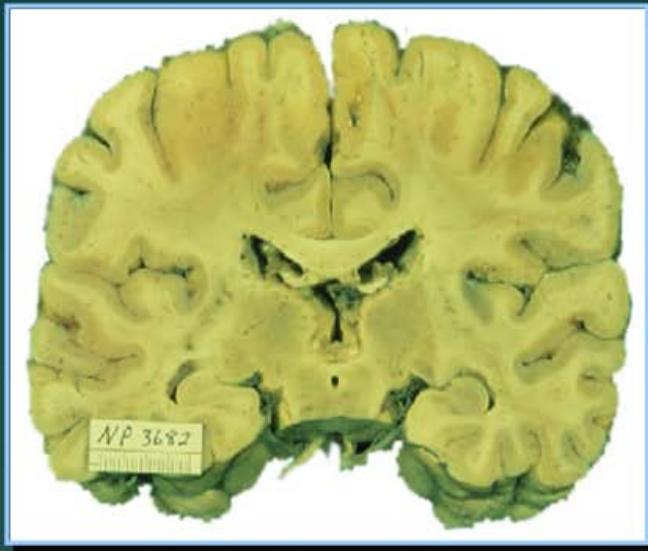
Neurofibrillary Tangles

- 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
- Neurophil threads are related.
 - Paired helical filamentous structures clustered among the dystrophic neurites of senile plaques



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



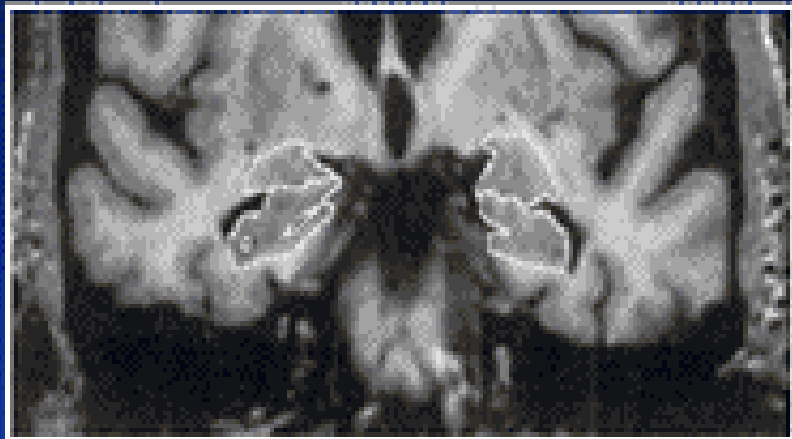


Methods of Staging Alzheimer's Disease

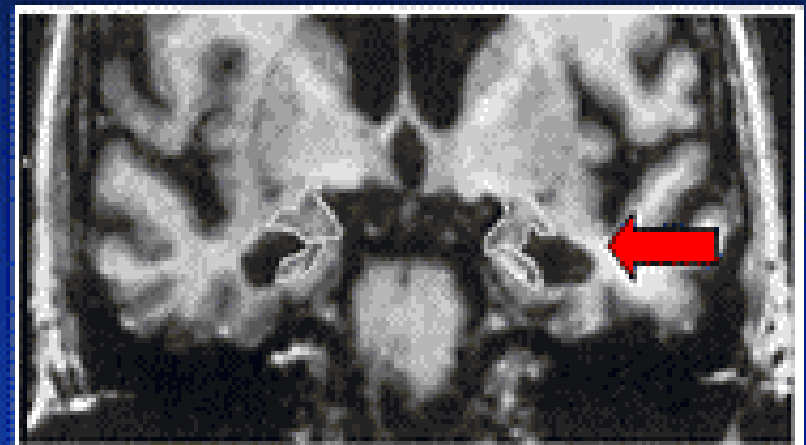
- There are a variety of approaches to staging Alzheimer's disease:
 - Assessments of brain anatomy or physiology
 - Clinical characteristics and functional losses
 - Care needs
 - Performance on cognitive tests
 - Behavioral issues

Coronal MRI: Hippocampal Atrophy in AD

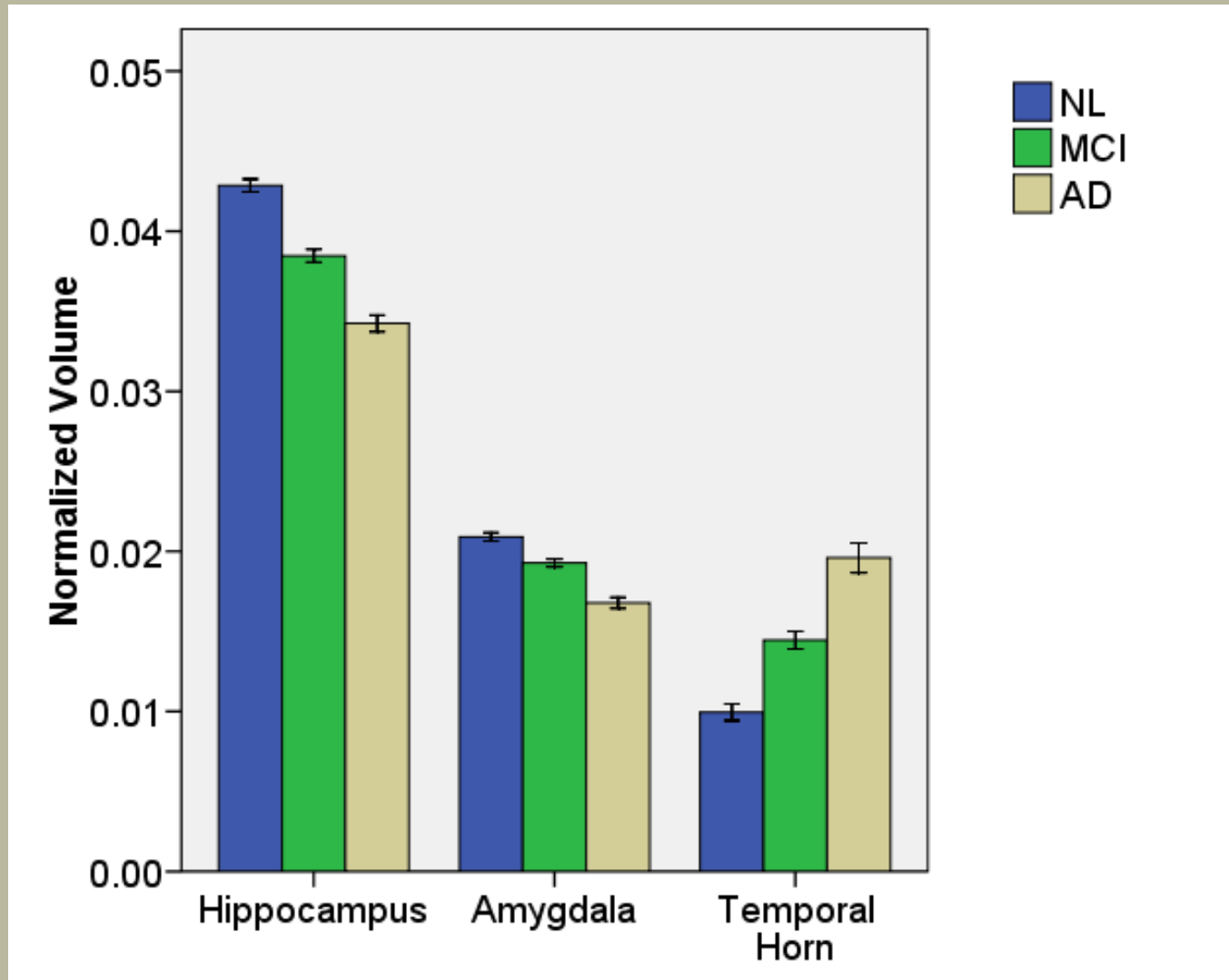
Control



AD



ADNI Preliminary Analysis





Methods of Staging Alzheimer's Disease

- 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	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 cognitive impairment	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 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)	Deficient ADLs	Moderately severe AD	5 months
	b) Unable to bathe properly	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	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	Incipient incontinence	Moderately severe AD	4 months
	e) Fecal incontinence	Incipient incontinence		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

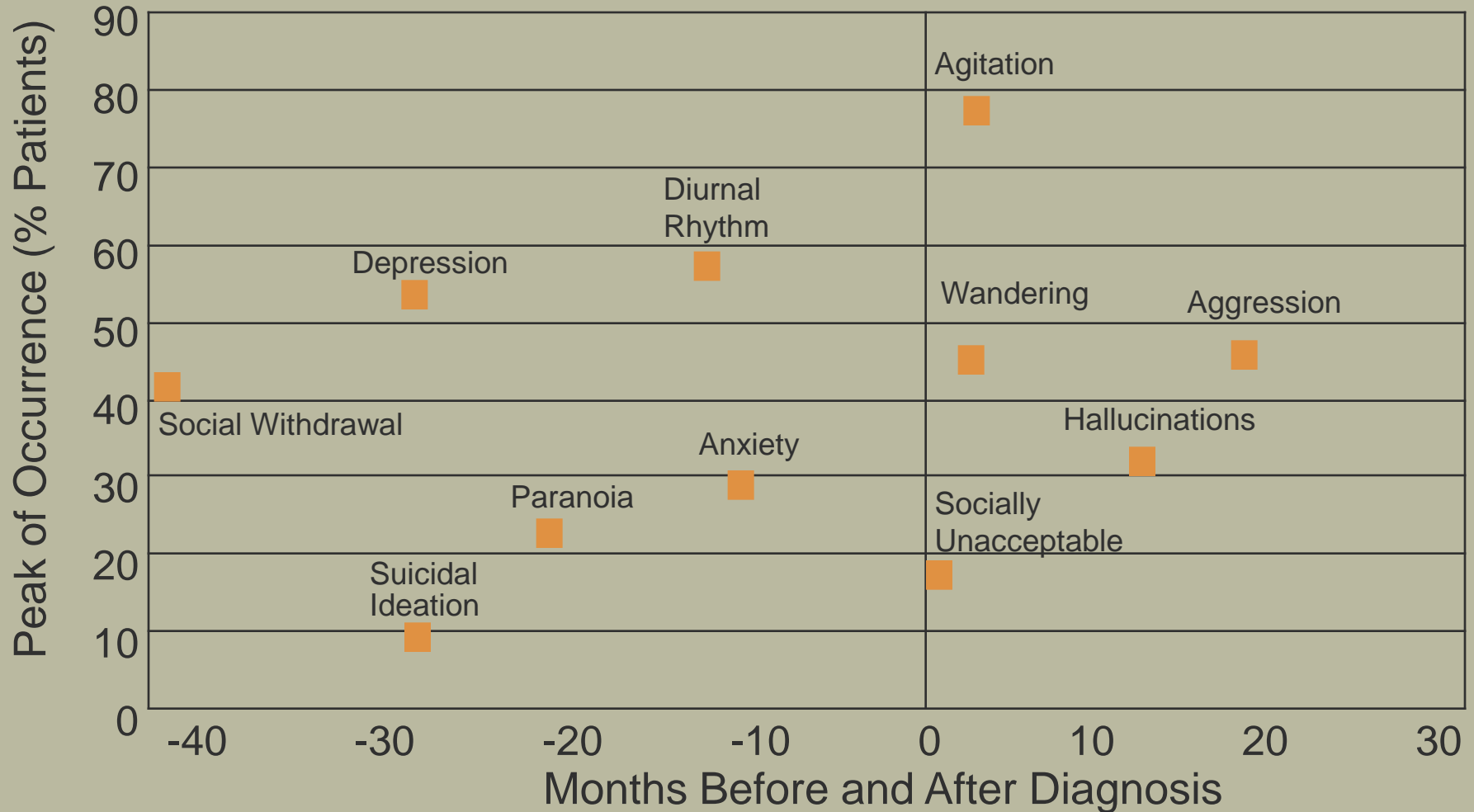
Functional Assessment Staging (FAST)

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

Functional Assessment Staging Test

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

Peak Frequencies of Behavioral Symptoms in Alzheimer



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 in the Safe Return Program
 - Renovate your home (e.g. special locks)

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 is 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.

Meaningful and Stimulating Activities for Stage 1 Dementia

- Take advantage of the person's ability to express and/or exhibit likes and dislikes and to maintain talents and hobbies, family relationships, and interests
- Assistance should be provided to allow the person to experience the greatest amount of success in as many cases as possible.
- Planned activities should blend into a familiar daily schedule
- An activity hour may not be appropriate and may cause the person to feel insulted because this seems "childish"

Meaningful and Stimulating Activities for Stage 2 Dementia

- **Sensory activities:** e.g. tactile activities using textures, lotions/massage and animals; manipulating locks, zippers, buttons, or Velcro
- **Activities of daily living:** e.g. setting the table, sorting laundry, folding laundry, giving a manicure
- **Physical activities** e.g. target games, par courses (a walking exercise course with stations along the way at which different exercises and stretches are done)

Meaningful and Stimulating Activities for Stage 3 Dementia

- **Sensory activities:** e.g. looking at pictures or family albums, listening to music
- **Activities of daily living:** brushing the person's hair, gentle massage of hands or back while speaking in a soft tone,
- **Physical activities:** e.g. stretching, passive range of motion, hugs, holding hands



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 an 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.



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