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DISCLOSURE OF FINANCIAL RELATIONSHIP
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Academic Appointment
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Grant/Research Support
Douglas L. Johnson Endowed Chair for Neurosciences, Northwestern Memorial Foundation.

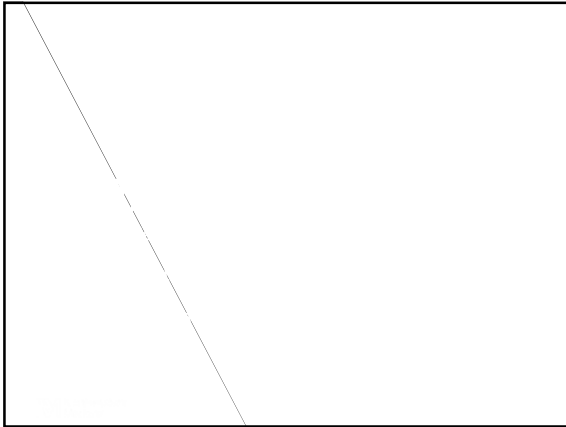
Speaker's Bureau, Consultant, Advisory Board, Major Shareholder
I have no actual or potential conflict of interest in relation to this program/presentation

"Off-label" uses of medications
I will not be discussing any "off-label" uses of any medications

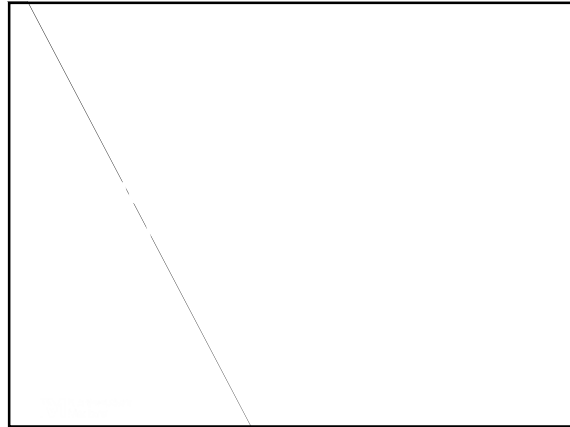
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CASE



Elsie Larson is an 82-year-old, right-handed married Caucasian female with 16 years of education, retired from teaching 17 years ago. For the last 10 years, her husband Bob has noticed a gradual decline in memory.

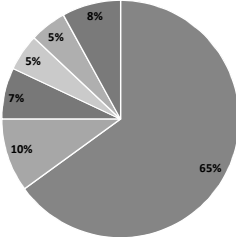
Now Elsie stays home during the day and declines invitations to go out. Elsie does not think she has a problem and is angry that Bob is insisting that she see a doctor.

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PREVALENCE: DEMENTIA TYPES

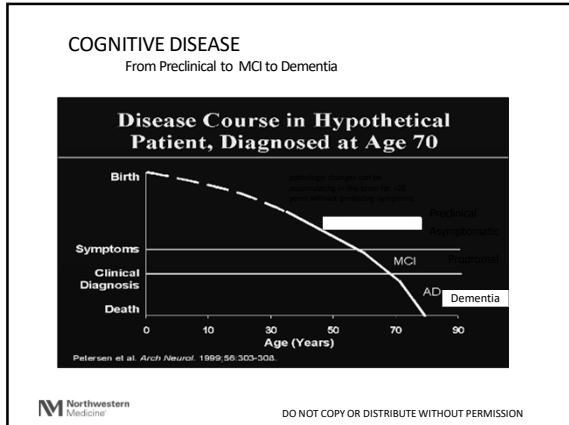
Types of Dementia



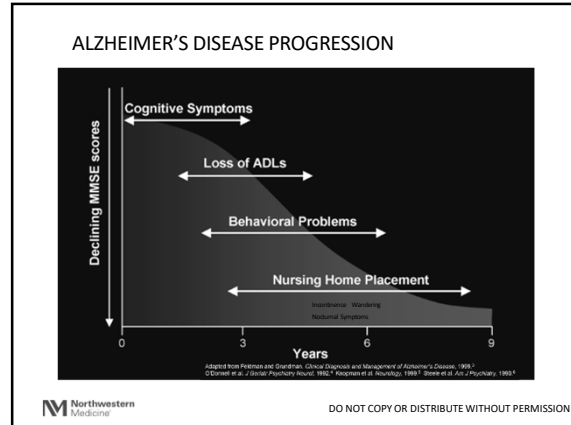
Dementia Type	Prevalence (%)
Alzheimer's Disease (AD)	65%
AD & Vascular	10%
AD & Lewy body	7%
Vascular	5%
Lewy body	5%
Other	8%

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WHY IS EARLY IDENTIFICATION KEY?

No disease modifying medications available yet.

- **Behavior Management:** Many neuropsychiatric symptoms are **treatable** (e.g. depression, sleep)
- **Advance Care Planning:** Helps families plan for the future, making living arrangements, take care of financial and legal matters, educate about behavior strategies and develop support networks – hopefully reducing caregiver burden. **Powers of Attorney: Health, Finances**
- **Safety Issues:**
 - forgetting to turn off stove or other appliances,
 - forgetting to pay bills,
 - getting lost when driving,
 - forgetting they are taking care of minor children/impaired adults,
 - forgetting emergency phone number 911.

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COMMON BEHAVIORAL SYMPTOMS OF DEMENTIA

- Anxiety/Depression
- Getting Lost / Wandering
- Apathy
- Psychosis
- Sleep
- Appetite
- Agitation/Aggression
- Disinhibition

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ANXIETY IN DEMENTIA

Need more research!

- Starkstein (2007) suggested GAD in dementia as
 - a) Excessive anxiety/worry that is difficult to control
 - b) Three of the following
 - Restlessness
 - Irritability
 - Muscle tension
 - Respiratory symptoms
- Believed to be distinct from agitation
- Comorbid with depression
- Difficult to appreciate in those with language deficits—somatic symptoms?

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DEPRESSION IN DEMENTIA


- 15-27% of individuals >65 living in the community have depressive symptoms. Prevalence twice as high in women
- Look for crying, tearfulness, hopelessness, self-deprecating comments.
- Look for change in appetite, sleep and energy level.
- White males over 65 yrs old account for 81% of all suicides annually.
- Can amplify cognitive deficits
 - Executive dysfunction
 - Slowed processing of information
 - Retrieval memory problems

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GETTING LOST/WANDERING

- Wandering:
 - Stress or fear – trying to escape an overstimulating environment
 - Searching – for someone or some place (psychosis)
 - Boredom
 - Basic needs—looking for bathroom, food, go for a walk
 - Past Routines— try to go to work, do chores, buy groceries
- We do not know what part of the brain controls wandering
- No good medications for this


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NONPHARMACOLOGICAL MANAGEMENT

Getting lost or wandering

- Getting Lost
 - GPS: Tile, Smart Phone
 - MedicAlert® + Alzheimer’s Association Safe Return®
- Wandering
 - Is there a pattern?
 - Same time of day? Provide activities
 - Searching for a loved one? Reassure will be visiting soon
 - Technology
 - Alarms, locks, video devices
 - Bookcase cover for a door, from www.alzstore.com
 - Provide safe and controlled environment for wandering




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APATHY IN DEMENTIA

“Doctor, he just sits in front of the TV all day!”


- Definition: It can be thought of involving simultaneous changes in 3 areas (Marin, 1991)
 - Behavior: initiating, sustaining, completing actions
 - Cognition: decrease in goal-related thought content
 - Emotion: diminished emotional responsivity
- Consequences
 - Daily functioning – lack of stimulation can hasten cognitive decline
 - Treatment adherence – medication, exercise
 - Quality of life -- goal-directed behaviors that contribute much to the day-to-day quality of life
 - Caregivers distress – undermines emotional connection to the patient

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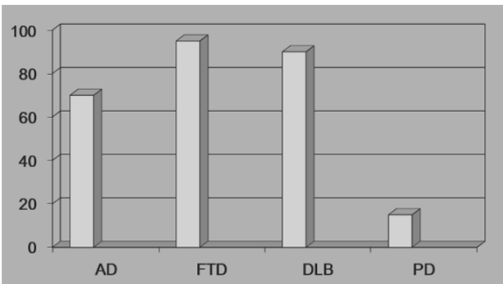
APATHY IN DEMENTIA

- Workup—Rule out
 - Medications
 - Depression
 - Sleep disorder
- Intervention
 - Provide predictable, routine, structured supported activities (“buddy system”)
 - Ensure tasks are simple so that the patient can complete them
 - break up complex tasks into smaller steps


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APATHY IN DEMENTIA




Dementia Type	Prevalence (%)
AD	~70
FTD	~95
DLB	~90
PD	~15

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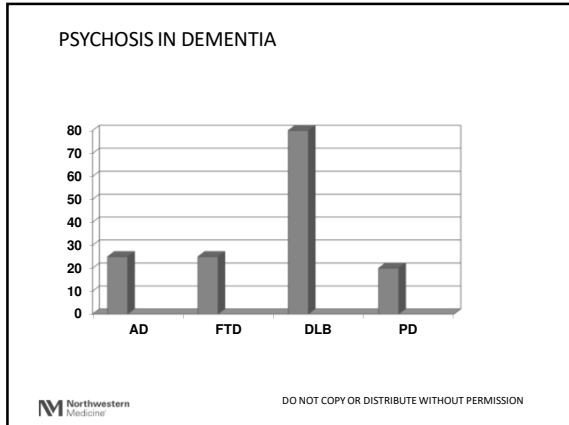
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PSYCHOSIS IN DEMENTIA

- Delusions
 - Someone is stealing, spouse is having an affair
 - misidentification syndrome
 - “you’re not my husband”
- Hallucinations
 - Typically visual, most common in Dementia of the Lewy Body Type
 - Do not be overly concerned if they are not distressing to the patient
- Management
 - Optimize hearing and vision
 - These symptoms may need antipsychotic medications if bothersome

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- ### SLEEP
- A sleep disorder may awaken patient at night (e.g. sleep apnea)
 - Circadian rhythm:
 - Get at least one half hour of sunlight within 30 minutes of your out-of-bed time.
 - Alcohol can have a rebound effect
 - Lack of activities and stimulation during the day may result in drowsiness and apathy during the day.
 - Regular exercise each day, preferable 40 minutes each day or an activity that causes sweating. It is best to finish exercise at least six hours before bedtime.
 - Bed for sleep only
 - Keep regular bedtime hours
 - Have a bedtime ritual

 - Review medications
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- ### MANAGEMENT OF APPETITE
- Loss of smell is common, making food less palatable
 - Minimize medications that cause nausea or constipation
 - Consider GERD symptoms
 - Evaluate for depression
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- ### WHAT IS AGITATION?
- Any inappropriate verbal, vocal, or motor activity
 - Not an expression of obvious need or confusion
 - May be aggressive
 - Verbal (temper outburst, screaming, threats, name calling)
 - Physical (hitting kicking, pushing, grabbing)
 - More common in men
 - May be linked to aggressive premonitory behavior
 - May be non aggressive
 - Verbal (complaining, repeating, constant talking)
 - Physical (checking, wandering, pacing, disrobing)
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- ### MANAGEMENT OF AGITATION
- Define the target behavior and track the frequency
 - A-B-C program (Antecedent, Behavior, Consequence)
 - Example: Every time the family take Mrs. Larson out to dinner she has a lovely time, but when she comes back she is up all night yelling
- A:** Antecedent: dinner out
- B:** Behavior: yelling
- C:** Consequence: instruct the family that going out is "too much for her"; they should bring dinner in
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- ### MANAGEMENT OF AGITATION
- Is it somatic?
 - Pain: arthritis, stiffness, undiagnosed fractures, inability to change posture.
 - Urinary or fecal impaction?
 - Hungry or thirsty?
 - Medication?
 - Review premonitory psychiatric and psychosocial
 - History of depression, substance abuse, PTSD?
 - Was person an introvert or an extrovert?
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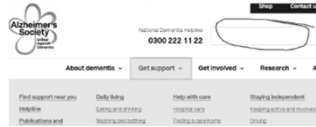
NONPHARMACOLOGICAL MANAGEMENT

Support Organizations – First Visit

- Dementia Australia (<https://www.dementia.org.au/>)



- Alzheimer's Society (<https://www.alzheimers.org.uk/>)




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UCSF'S TIPS FOR DAILY LIFE

<https://memory.ucsf.edu/tips-daily-life>

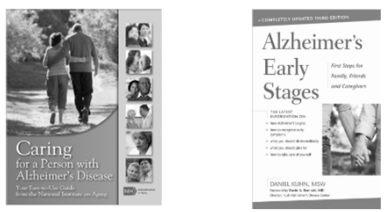


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NONPHARMACOLOGICAL MANAGEMENT

Recommended Publications – First Visit



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PRINCIPLES FOR NONPHARMACOLOGICAL MANAGEMENT OF ALZHEIMER'S

Insidious, neurodegenerative disease with no disease-modifying treatment, requiring monitoring over time

- Provide good primary care
 - Minimize medications
 - Optimize hearing and vision
 - Treat depression, pain, constipation, etc
 - Check annual CBC, CMP, TSH, B12, Vit D
- Empower/ educate the caregiver
 - Give them the available resources for managing the patient and keeping themselves healthy
 - Complete powers of attorney for health, finances
- Support the caregiver over time.


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Who are the Caregivers?



- 65% of older adults rely exclusively on family and friends for assistance
- 66% of caregivers are women, average age 49, married, and employed.
- Women are nearly half of all workers, and mothers are the primary breadwinners or co-breadwinners in two-thirds of American families.
- Four out of ten caregivers say they had no choice in becoming caregivers.
- Women caregivers are almost 6X as likely to suffer from depression or anxiety
- Women's physical health suffers
 - 2/3 don't take advantage of preventive health services

Sources: Family Caregiver Alliance, The Shriver Report.


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WHY IS IT SO HARD FOR PATIENTS TO RECEIVE CARE?


Perspective on what your loved one might be feeling

1. I don't feel comfortable asking for help
2. No one wants to be a burden on others.
3. It is hard to admit to needing care.
4. I'm afraid that I'll ask and no one will be there, or I will be abandoned.
5. I don't want to lose my privacy.
6. I don't want to feel vulnerable.
7. I don't want to lose my dignity.
8. I am the giver—not the other way around.


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CAREGIVING: DIGNITY AND ROUTINE




- Waiting on the caregiver increases awareness of helplessness, along with the "tedium of anticipation." Caregiver thinks "After all, she has all day and I have so much to do." By the time the caregiver arrives, the patient may respond in anger. The caregiver thinks "This is what I get in return?"
- Instead give the patient a realistic predictable schedule

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CAREGIVING: COMMUNICATION


- **Limit choices**
 - "Do want the red or the blue blouse?"
- **Getting into the patient's world:** Base communication on what the patient believes is real, do not correct or try to orient. Validate what the patient believes, focus on feelings.
 - Active listening
 - "You're missing your mother, is that right?"
 - Redirect the conversation to a new topic or activities
 - "While we are waiting, let's make some tea"


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CAREGIVING: GOOD ENOUGH

- **Moderation in help:** In trying to help, caregivers often take over a patient's life. The patient may respond with frustration and bitterness. Let the patient be as independent as possible.
- **Honor the patient's preferences:** When independence is threatened (or lost), what may seem trivial or inconsequential, may take on great importance to the patient.
- **Identify giving opportunities:** Counter the patient's feelings of indebtedness, passivity, and uselessness by accepting their offer to help (e.g. fold towels).





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CAREGIVING: MAXIMIZE STRENGTHS

- It is important to maximize our patient's strengths and minimize what is hard for the patient. Set up an environment where success is more likely and bumping up against memory problem is less likely.
- Day programs, if available, are great at doing that.







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CAREGIVING: ACTIVITIES

Pet Therapy, Music Therapy, Art Therapy, Exercise, Sing-along



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CAREGIVER: TAKING STOCK

Wellness is important not only for our patients but also for their families.

It is not possible for one person to perform all the duties required for their loved one

- Determine the needs of the patient
 - i.e. personal care, daily activities, medical, supervision, organizing home care, organizing medical care, managing finances
- Decide what needs you can or would like to meet on your own
- Determine what needs can or must be met by others
- Identify family and friends to whom you can turn for help
- Establish the need for outside professional help




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SUPPORT GROUPS ARE KEY


Partner with local senior services, social worker, hospital

- Group Purpose
 - Emotional Support
 - Social and personal support and networking
 - Information
 - Education
 - Invited Speaker
 - Skills Acquisition
- Group Audience
 - Caregivers
 - Friends, families, other interested
 - Employed caregivers
 - Patients
 - Newly-Diagnosed/ Early Onset




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CASE: BOB LARSON, CAREGIVER

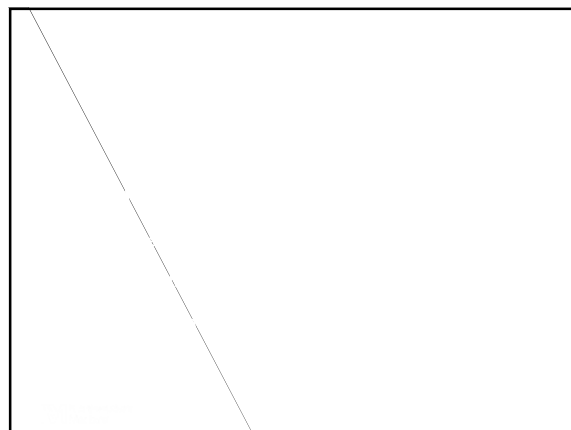


- Mr. Larson is embarking on a long challenging journey of caregiving. He has some solace in having a diagnosis for his wife of dementia.
- Not correcting Mrs. Larson when she thinks her brother is alive or when she says she wants to go home is frustrating, but he is learning.
- He told Mrs. Larson that now that he is retired, he does not have enough to do and so he wants to drive her around. She has stopped driving.
- Mr. Larson meets for coffee at the local café every morning with three other men whose wives are having trouble remembering.
- Friday nights his daughter brings the grand kids over and Mr. Larson goes bowling with his buddies.
- He looks forward to Mrs. Larson's visit with you every 3 months where he can give you a report of how she (and he) is doing




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1967 1990 1997
1998 1999 2000

William Utermohlen 1933-2007 (diagnosed 1995)

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