Understanding Alzheimer's Disease

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Wednesday, April 8, 2015
www.siumed.edu/alz

History of Alzheimer's Disease Programs in Illinois

- September 1985 -- Alzheimer's Disease Research Act: Created Alzheimer's Disease Research Fund (Tax Check-Off)
  - http://www.idph.state.il.us/fundop.htm (was due Jan 17, 2014 at 5 pm)
- January 1986 -- Alzheimer's Disease Assistance Act: Created Two Regional Alzheimer's Disease Assistance Centers
    - Southern Illinois University School of Medicine, Center for Alzheimer's Disease and Related Disorders
    - Rush Alzheimer's Disease Center
  - Third Site Added in 1997
    - Northwestern University Medical School

What is a Primary Provider?

- A licensed hospital or medical center that provides medical consultation, evaluation, referral and treatment to victims of Alzheimer disease under an agreement with a regional center.
- Currently there are 35 sites in the SIU School of Medicine 93 county area

Save the Dates: Our Upcoming Educational Events

Springfield, IL

- **Tuesday, May 19, 2015 – Risk and Protective Factors and Early Interventions Conference**
- **Wednesday, May 27, 2015 – Community Health Education: Healthy Brain Aging**

Registration flyers are posted at:
www.siumed.edu/alz

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Cognitive Changes in Healthy Adults

- Memory
  - Modest decline in short-term memory
- Verbal intelligence
  - Stable at least until the seventh decade
- Processing speed
  - Declines throughout adult life

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Frequency of Memory Problem Complaints in Healthy Older Adults

- Names 83%
- Where you put things such as keys, etc... 60%
- Telephone numbers you just checked 57%
- Words 53%
- Knowing whether you've already told someone something 49%
- Things people tell you 49%
- Faces 42%
- Directions to places 41%
- Begin to do something and forget what you're doing 41%
- Losing the thread of the conversation 41%
- Remember things you've done such as lock door 38%
- Appointments 34%
- Telephone numbers used frequently 29%

Bolla et al. *Arch Neurol. 1991;48:61-64.*

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"It takes a lot of patience on your part as well as on your supporters. Life is never going to be the same as the person becomes afflicted. I don't think that as it passes that you and those around you will ever quite be the same. There are so many facets to this disease." - Judy

"Sometimes it can be embarrassing. Sometimes people will treat you differently because they think you're worse off than you are. They don't understand what you're dealing with. Difficult to express ourselves sometimes. They talk around you, not to you." - Marie

"I've been very fortunate. My wife is outstanding! It wasn't just this, I've had other physical problems. Couldn't ask for anyone better. I really don't care whether people know or not (that I have AD)."
- Jack

"I feel okay because my husband loves to take care of me. He likes to help too much. I feel that he is doing too much. If he would let me do some of the cooking, that would be better. I feel good about myself!" - Marge

"Sometimes it's pressure on other people who don't understand you forget and get upset with you. Some people don't have patience. They talk down to you. Others who want to do your things for you." - Marie

"I used to sew all the time. I started when I was three years old. I used to make my own clothes, but now I don't do it and I don't know if it's that I can't or I won't." - Diane

"At home, putting laundry away, I forget what I'm doing. Don't know what I was trying to do. Can't remember where I put something." - Don

"There's a financial side to AD. Being diagnosed, I knew I had to step down from my job." – Mike
(Young onset, age 57)

"If you haven't been there, you don't know what it's like. It's hard to stop trying to find the words or what you need to say. You have to stop and think about, stop and try to find out what to do. You just have to be patient. No point in getting upset. I can remember some things, can't remember others." - Jean

"I usually say or do what I want and whatever happens, happens. If I don't like it, I just let it go. Sometimes my grandchildren ignore me." - Dianne

If I ask my wife a question, and she says I've already asked it, it makes me frustrated, then it makes me mad. I'm not doing this to make you mad, why don't you just answer my question? – Jim A

Sometimes I won't ask a question or start a conversation because I know it will start an argument. – Jim A

I'll tell a friend about my disease and they say, "oh, you're just busy or very active; that's just normal." But I know it's not like when I used to forget something when I worked as a teacher. I can't explain it. It's like being in a cloud. – Bonnie

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I'm doing the best I can. – Carolyn

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"I have lost myself." – Auguste D
Dr. Alzheimer's 1st patient
November 26, 1901

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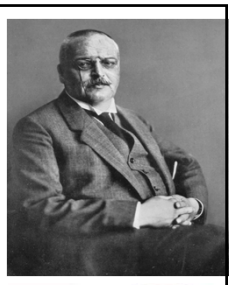
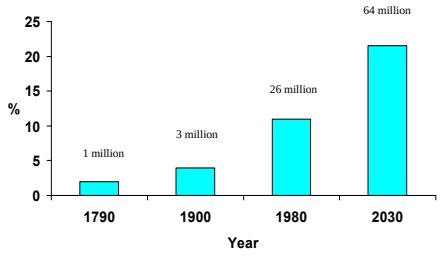
Alois Alzheimer (1864-1915)



On the occasion of the 37th Meeting of Southwest German Psychiatrists held in Tübingen in November 1906, Alois Alzheimer reported on a 51-year old female patient (Mrs. Auguste D.) who had been admitted to the Frankfurt hospital in November 1901 with signs of dementia. The title of his lecture was "Über eiene eigenartige Erkrankung der Hirnrinde" (On a Peculiar Disorder of the Cerebral Cortex). In 1907 his presentation appeared in print. Later on, at the suggestion of Emil Kraepelin, presenile dementia was designated “Alzheimer's disease”.

Percentage of U.S. Population 65 years of age and older



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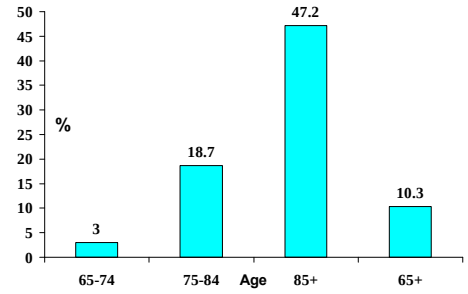
Prevalence of Alzheimer’s Disease In a Community Population



Evans et al. JAMA 1989;262:2551-2556

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What is Alzheimer's Disease?

- Progressive, degenerative disease
- Affects brain
- Impairs memory, thinking, behavior
- Most common form of dementia

What is Dementia?

- Decrease in mental ability from a prior level of intellectual function
- Many causes
  - Metabolic imbalances
  - Head trauma
  - Cerebrovascular events
  - Depression
  - Neurodegenerative diseases

Key differences between early signs of disease and normal aging include:

Normal Aging	Potential Signs of AD
• Forgets part of an experience	• Forgets entire experiences
• Often remembers later	• Rarely remembers later
• Is usually able to follow written/spoken directions	• Is gradually unable to follow written/spoken directions
• Is usually able to use notes as reminders	• Is gradually unable to use notes as reminders
• Is usually able to care for self	• Is gradually unable to care for self

Possible signs that patient has an underlying dementia

- Patient is a poor historian or seems “odd”
- Patient is inappropriately dressed or inattentive to appearance
- Patient fails to appear for appointments or arrives at the wrong time or wrong day
- Patient repeatedly and apparently unintentionally fails to follow directions (for example, medications)

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Possible signs that patient has an underlying dementia

- Patient has unexplained weight loss or has vague symptoms such as weakness or dizziness
- Patient seems to be unable to adapt or experiences functional difficulties under stress (for example, illness or death of spouse)
- Patient defers to caregivers to answer questions.

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10 Warning Signs of Alzheimer’s Disease

1. Memory changes that disrupt daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

1. Memory loss

- Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.
- ***What's normal***? Forgetting names or appointments occasionally.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

2. Difficulty doing familiar tasks

- People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps to prepare a meal, place a telephone call or play a game.
- ***What's normal***? Occasionally forgetting why you came into a room or what you planned to say.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

3. Problems talking or writing

- People with AD often forget simple words or substitute unusual words, making their speech or writing hard to understand. For example, they may be unable to find their toothbrush and instead ask for "that thing for my mouth.
- ***What's normal***? Sometimes having trouble finding the right word.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

4. Confusion about time and place

- People with AD can become lost in their own neighborhoods, forget where they are and how they got there, and not know how to get back home.
- ***What's normal***? Forgetting the day of the week or where you were going occasionally.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

5. Loss of judgment

- Those with AD may dress inappropriately, wearing several layers on a warm day or too little clothing in the cold. They may show poor judgment about money, like giving away large sums to a scam artist.
- ***What's normal***? Making a questionable or debatable decision from time to time.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

6. Problems with abstract thinking

- Someone with AD may have unusual difficulty performing complex mental tasks, like forgetting what numbers are and how they should be used.
- ***What's normal***? Finding it challenging to balance a checkbook.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

7. Misplacing things

- A person with AD may put things in unusual places, such as an iron in the freezer or a wristwatch in the sugar bowl.
- ***What's normal***? Misplacing keys or a wallet temporarily.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

8. Changes in mood or behavior

- Someone with AD may show rapid mood swings – from calm to tears to anger – for no apparent reason.
- ***What's normal***? Occasionally feeling sad or moody.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

9. Changes in personality

- The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.
- ***What's normal***? People's personalities do change somewhat with age.

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10 Warning Signs of Alzheimer's Disease © Alzheimer's Association

10. Loss of motivation

- A person with AD may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.
- ***What's normal***? Sometimes feeling weary of work or social obligations.

Alzheimer's Disease Statistics

- Today, every 67 seconds someone in America develops AD; by 2050, every 33 seconds
- Approximately 5.2 million Americans with AD
- Expect 11-16 million in US by 2050
- One-third of all seniors who die in a given year have been diagnosed with Alzheimer's or another dementia
- Life expectancy may be 2-20 years or more
- Between 2000-2010, % of deaths from heart disease, stroke, and prostate cancer↓16%, 23%, and 8%, respectively, while % from AD↑68%

Alzheimer's Association, 2014 Alzheimer's Disease Facts and Figures, *Alzheimer's & Dementia*, Volume 10, Issue 2.

Alzheimer's Disease Statistics

- Annual cost in this country today is over $200 billion; by 2050 it will be $1.1 TRILLION
- Over 70% of people live at home
- Almost 75% of home care provided by family and friends
- About 70% of all nursing home residents have cognitive impairment, 50% of assisted living residents have AD or another dementia, over 50% of adult day service participants have AD or another dementia, as well as about 25% of all elderly hospital patients
- Dementia is **the most** expensive malady in US, ahead of heart disease & cancer!

Diagnosis of Alzheimer's Disease

- No single clinical test to identify Alzheimer's disease
- Confirmation requires examination of brain tissue
- Comprehensive evaluation includes:
  - Complete health history
  - Physical examination
  - Neurological and mental status assessments
  - Blood and urine analysis, EKG, chest x-rays, EEG, CT scan, PET scan

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What are other causes of memory problems?

Some medical conditions cause confusion and forgetfulness. The signs may look Alzheimer's disease, but they are caused by other problems. Here are some medical conditions that can cause serious memory problems:

- bad reaction to certain medicines
- emotional problems such as depression
- not eating enough healthy foods
- too few vitamins and minerals in your body
- drinking too much alcohol
- blood clots or tumors in the brain
- head injury, such as concussion from a fall or accident
- kidney, liver, or thyroid problems

From the Alzheimer's Disease Education and Referral (ADEAR) Center publication *Understanding Alzheimer's Disease*

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DSM-5™ Neurocognitive Disorders

Delirium

- Other Specified Delirium
- Unspecified Delirium

Major and Mild Neurocognitive Disorders

- Major Neurocognitive Disorder
- Mild Neurocognitive Disorder

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DSM-5™
Neurocognitive Disorders

Major and Mild Neurocognitive Disorders

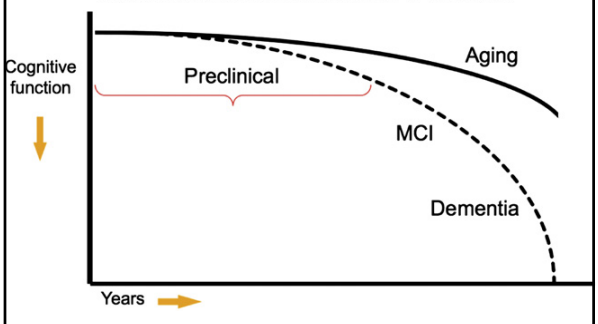
- Major or Mild Neurocognitive Disorder Due to Alzheimer's Disease
- Major or Mild Frontotemporal Neurocognitive Disorder
- Major or Mild Neurocognitive Disorder With Lewy Bodies
- Major or Mild Vascular Neurocognitive Disorder
- Major or Mild Neurocognitive Disorder Due to Traumatic Brain Injury
- Substance/Medication-Induced Major or Mild Neurocognitive Disorder

DSM-5™
Neurocognitive Disorders

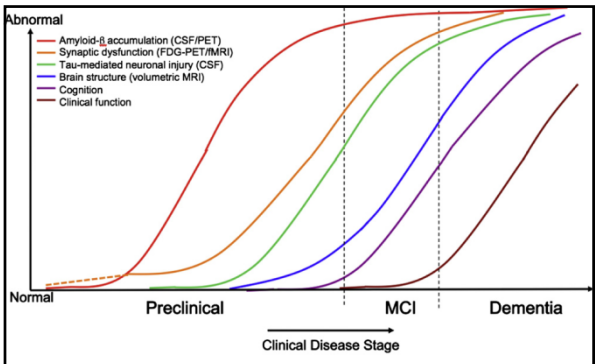
Major and Mild Neurocognitive Disorders

- Major or Mild Neurocognitive Disorder Due to HIV Infection
- Major or Mild Neurocognitive Disorder Due to Prion Disease
- Major or Mild Neurocognitive Disorder Due to Parkinson's Disease
- Major or Mild Neurocognitive Disorder Due to Huntington's Disease
- Major or Mild Neurocognitive Disorder Due to Another Medical Condition
- Major or Mild Neurocognitive Disorder Due to Multiple Etiologies
- Unspecified Neurocognitive Disorder

The continuum of Alzheimer's disease



From R.A. Sperling et al. Alzheimers Dement 2011;7:280-292.



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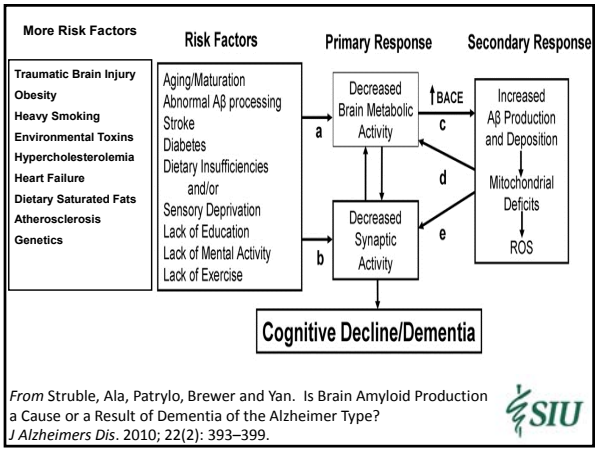
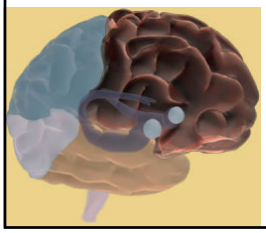


From Struble, Ala, Patrylo, Brewer and Yan. Is Brain Amyloid Production a Cause or a Result of Dementia of the Alzheimer Type? *J Alzheimers Dis*. 2010; 22(2): 393–399.

www.aboutalz.org

What Happens to the Brain? - Frontal

Normal – Personality; Reason; Movement; Speech; Attention Span; Alertness; Safety



AD – Change in Personality; Cannot Plan/Poor Judgment; Short Attention Span/Can't Concentrate; Easily Distracted; Can't Initiate Activity; Not Alert

What to Do – Give Step by Step Directions; Use Cues or Prompts to Start an Activity; Reduce Hazards in the Environments; Reduce Distractions

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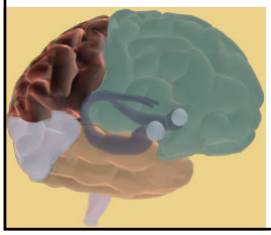
What Happens to the Brain? - Parietal

Normal – Perceptions; Senses (Temperature, Touch, Pain, Space); Language



AD – Can't Understand Input from Senses; Can't Follow Auditory or Visual Cues; Can't Recognize Familiar Objects by Touch; Doesn't Understand Purpose of Objects

What to Do – Assist with Cueing; Use Gestures, Body Language, Demonstrate; Use "Hand-in-Hand" Technique; Use Prompt to Show Purpose of Object

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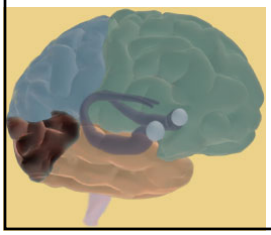
What Happens to the Brain? - Occipital

Normal – Vision; Interprets Information from the Eyes for Orientation, Position, Movement



AD – Loss of Depth Perception; Loss of Peripheral Vision; Difficulty Processing Rapid Movements

What to Do – Approach from the Front; Eye Contact; Use Slow Movements; Avoid Floor and Wall Designs that Could be Misinterpreted (A Black Floor Tile Could Appear to be a Hole

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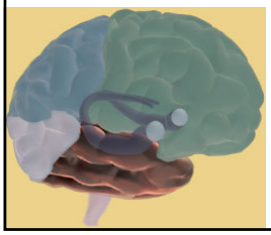
What Happens to the Brain? - Temporal

Normal – Hearing; Memory; Language; Ability to Draw



AD – Aphasic (Impaired Language) – Expressive (Inability to Speak); Receptive (Inability to Understand)

What to Do – Early Stages: Fill in Missing Words
Later Stages: Prompt with Gestures, Body Language, Physical Prompts, Hand-in-Hand

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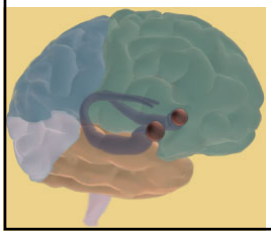
What Happens to the Brain? - Amygdala

Normal – Emotions; Anger, Sex, Fear



AD – Angry Outbursts; Inappropriate Sexual Behaviors; Afraid

What to Do – Distract; Reassure; Redirect with Activities, Music, etc.

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&MUSIC memory

www.musicandmemory.org

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Art Express:

An art expression class for persons with memory loss and their caregivers

A program of

SIU School of Medicine

Center for Alzheimer's Disease and Related Disorders

and the

University of Illinois at Springfield

Human Development Counseling Program

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I Remember Better When I Paint

Treating Alzheimer's Through the Creative Arts

"The creative arts are a doorway. Once that doorway is opened, things are tapped that are genuine and active and alive that don't get tapped in our normal day social interactions -- when we sit at a table and make conversations over a meal…."

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Quotes from Art Express participants

- "I look forward to it every week. It's like sunshine in here, no matter what it looks like outside."
- "I really enjoy coming to this class. I think it's my favorite part of the week."
- "I love doing this. It just clears my mind of all the worries and the effort to remember everything. I can just paint for a while."
- "I think I have come a long way because of this class. It helps me think outside the box."

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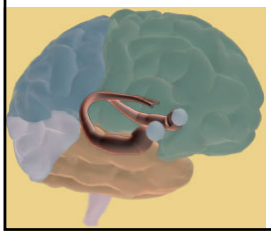
What Happens to the Brain? - Hippocampus

Normal – Memory: Processes Short Term Memory, Stores New Memory; Learning



AD – Loss of Short Term Memory; Asks Repetitive Questions; Gets Lost Easily; No Sense of Time; Easily Confused; Loses Things

What to Do – Reassure; Validate; Answer Questions, Even if Repeated; Redirect; Move Slowly Between Tasks; Allow Time for Adjustment

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Alzheimer's Disease -- Treatment Update

- tacrine (Cognex®) FDA approved - 1993
- donepezil (Aricept®) FDA approved - 1996
- rivastigmine or ENA 713 (Exelon®) FDA approved – 2000; patch came out two years ago
- galantamine (Razadyne®) FDA approved – 2001 (Trade name was Reminyl® prior to July 1, 2005)

Boosts acetylcholine (brain neurotransmitter)

Stimulates nicotine receptors (Razadyne®)

- memantine (Namenda®) FDA approved – October 2003

Regulates glutamate, another brain neurotransmitter

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Alzheimer's Disease -- Treatment Update

- Cerefolin®NAC
  - "An orally administered prescription medical food for the dietary management of certain metabolic processes identified with early memory loss."
  - Cerefolin®NAC caplets are indicated for the distinct nutritional requirements of individuals under a physician's treatment for neurovascular oxidative stress and/or hyperhomocysteinemia; with particular emphasis for those individuals diagnosed with or at risk for mild to moderate cognitive impairment, vascular dementia, Alzheimer's disease and/or recurrent or ischemic stroke.
  - Ingredients: L-methylfolate 5.6 mg; Methylcobalamin 2 mg; N-acetylcysteine 600 mg
- Medical foods do not have to undergo premarket review or approval by FDA and individual medical food products do not have to be registered with FDA.

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Alzheimer's Disease -- Treatment Update

- Axona™
  - "Study of the ketogenic agent AC-1202 in mild to moderate Alzheimer's disease: a randomized, double-blind, placebo-controlled, multicenter trial" published in Nutrition & Metabolism.
  - Ingredients: Medium chain triglyceride designed to safely elevate serum ketone bodies, providing the brain an alternative energy source
  - Studied 152 patients at 23 sites in the US, 80% taking another AD drug
  - Results: Correlation for APOE4¯and dose

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Alzheimer's Disease -- Treatment Update

- Ginkgo biloba
  - antioxidant
  - anti-inflammatory
  - anti-coagulant
- Study published in 1997 showed mild positive effect for some patients, but large dropout rate
- Study published in 2012 showed that long-term use of standardized ginkgo biloba extract did not reduce the risk of progression to AD compared with placebo.

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Other Disorders - Lewy body dementia (LBD)

- Two distinct but related types of dementia
  - Dementia with Lewy bodies
  - Parkinson's disease with dementia
- Second most common cause of dementia after AD
- Affects more than 1.5 million people and their families
- Accounts for 20-25% of all dementias

McKeith I. Dementia with Lewy bodies. In Miyoshi K, Morimura Y, Maeda K, eds. ***Neuropsychiatric Disorders***. New York, NY: Springer; 2010:247-254.

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Other Disorders – Dementia with Lewy bodies

- Dementia before motor symptoms
- Impaired self care skills (bathe, toilet, stand and walk independently, eat, brush teeth)
- Rapid progression (? Literature conflicting)
- Attention and concentration fluctuates
- Recurrent visual hallucinations / delusions
- Repeated falls and syncope
- Transient loss of consciousness
- Depression

❖Sensitive to neuroleptics (Haldol, Thorazine, Prolixin)

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Other Disorders - Parkinson's disease with dementia

- Motor skill impaired before dementia
- Memory impaired / Language impaired
- Visuo-spatial function impaired
- Executive function impaired
- Reduced attention
- Hallucinations (often drug induced)/ Delusions
- Apathy

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Other Disorders - Vascular dementia

- Stroke with obvious impairment
  - Abrupt onset
  - Motor signs
  - Aphasia
- Multiple “mini strokes”
  - Gradual onset
  - Symptoms depend on infarct areas

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Other Disorders - Frontotemporal dementia

- Personality changes
- Executive dysfunction
- Hyperorality
- Visual-spatial preserved

Treatment

- Planning
  - Medical and social management
  - Reevaluate and change as disease progresses
- Medication
  - Agitation
  - Anxiety
  - Unpredictable behavior
  - Improved sleeping patterns
  - Depression

Treatment

- Physical exercise
  - Social activities
  - Nutrition
  - Health maintenance
- Calm and well-structured environment
  - Problem with adapting to change
- Positive attitude
  - Never argue
  - Sweet as pie, 24 hours per day, 7 days per week

Illinois Cognitive Resources Network (ICRN)

- ***Vision Statement:*** The **ICRN** will make Illinois a national leader in the development and implementation of effective community-based models for adults to access research, education, training, and support services to promote cognitive health and quality of life.
- Visit our web site at: http://www.ilbrainhealth.org

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Staging Dementia – Five Stages

Allen Cognitive Levels

1. **Normal – 6.0**
2. **Early – 5.0**
3. **Early-Middle – 4.5-4.0**
4. **Late-Middle – 3.5-3.0**
5. **Late – 2.0-1.0**

From Allen CK, Earhart CA & Blue T (1992). *Occupational Therapy Treatment Goals for the Physically and Cognitively Disabled.* Rockville, MD: American Occupational Therapy Association.

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Early Stage

(Level 5.0: Signs Begin to Show)

- **Relatively able and independent**
- **Problems with short-term memory**
- **Problems losing track in complicated tasks**
- **Problems with planning, problem-solving and judgment (Executive functions)**
- **Should be able to manage most concrete tasks**
- **May affect "quality" of performance – may behave impulsively or hesitantly**

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Early-Middle Stage
(*Level 4.5: A Time of Increasing Problems*)

- **Seems to perform normally, but errors creep in**
- **Will keep a goal but may need reminders**
- **More easily distracted; needs help staying on track; readily redirected**
- **Language still works to give information**
- **Problems begin to show with thinking – handling abstract ideas is harder**
- **Easily frustrated; may be impulsive**

Early-Middle Stage
(*Level 4.0: Impairments More Noticeable*)

- **Limited attention & easily distracted – reacts to pressure; abstract thought very weak**
- **Simple and familiar tasks with few steps**
- **Knows there's a goal, but needs reminders**
- **Clear trouble with memory, language, orientation, perception and attention**
- **Performance quality poor**
- **Needs help organizing tasks**
- **Needs short, concrete directions – visual cues**

Early Stage (*Can Do Abilities*)
Approximate developmental age comparison = 4 – 12 years

- **Aware of the goal of an activity**
- **Thrives on routine and familiar**
- **Able to sequence self through steps**
- **Basic problem solving ability**
- **Partial new learning, especially if highly valued activity**

From Kim Warchol, Dementia Care Specialists

Late-Middle Stage (*Level 3.0: Person Experiences General Confusion*)

- **All thinking powers seriously affected**
- **Very confused. Hard to understand what's happening or what's wanted of him/her**
- **No purpose; order with help**
- **Needs help starting ad staying with all tasks**
- **Very concrete – visual and tactile cues**
- **Step by step help**
- **Very easily distracted, frustrated, upset, confused. Don't rush or pressure. Reassure.**

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Middle Stage (*Can Do Abilities*)

Approximate developmental age comparison = 18 – 36 months

- **Uses hands to hold and manipulate objects**
- **Follow one step commands to be sequenced**
- **Notes cause and effect**
- **Better fine motor coordination**
- **Strong long-term memory**

From Kim Warchol, Dementia Care Specialists

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Late Stage (*Level 2.0: Functioning with Minimal Abilities*)

- **Powers of thinking virtually gone**
- **Purpose and order are no more – have to come entirely from outside**
- **May or may not relate to objects**
- **Needs total care**
- **Goals of care are comfort**
- **Involvement, at this stage, is almost entirely passive**

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Late Stage (*Can Do Abilities*)

Approximate developmental age comparison = 12-18 months

- **Sit**
- **Stand**
- **Walk**
- **Gross motor skills**
- **Few word vocabulary**
- **Gross grasp on food and drink**
- **Follows one step inconsistently**

From Kim Warchol, Dementia Care Specialists

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Late Stage

(*Level 1.0: In Bed and Unresponsive*)

- **Little or no consciousness or awareness**
- **Sleeps much of the time**
- **Total care**
- **Comfort is the goal**

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Late/End Stage (*Can Do Abilities*)

Approximate developmental age comparison = 0 – 12 months

- **Respond to stimulation**
- **Smile**
- **Facial expressions**
- **Swallow**
- **Limited movement of extremities**
- **Eye tracking**

From Kim Warchol, Dementia Care Specialists

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Palliative Care

- Palliative approaches are preferred by
  - **71% of families**
  - **61% of physicians**
  - **55% of health care professionals**
- Hospice has traditionally rejected people with AD because of the "6 month rule"
- Medicare now has guidelines for defining terminal status in AD

Volicer L, Hurley A. *Hospice Care for Patients with Advanced Progressive Dementia.* New York, NY: Springer Publishing Company; 1998.

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Qualifying a person with AD for hospice
New information as of 2006

- **Unable to ambulate without assistance**
- **Unable to dress without assistance**
- **Unable to bathe properly**
- **Urinary and fecal incontinence**
- **Unable to speak or communicate meaningfully**
- **And suffer from at least one complication**
  - **Aspiration pneumonia, Upper UTI's, Recurrent fever after antibiotics**
  - **Signs of a recent stroke**
  - **Decubitus ulcers (multiple stages 3-4)**
  - **Difficulty swallowing or refusing food**

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Medications Associated with Cognitive Dysfunction

- **Benzodiazepines**: valium, ativan
- **NSAIDs**: ASA, ibuprofen, indomethacin, naproxen, sulindac
- **Antidepressants**: TCAs, SSRIs
- **Anticonvulsants**: PHT, VPA, CBZ, PHB
- **Antihypertensives**: B-blockers, Ca-channel blockers
- **H2 receptor antagonists**: cimetidine, ranitidine
- **Antibiotics**: Cephalexin, metronidazole, fluoroquinolones
- **Anticholinergics**: Benztropine, trihexiphenidyl
- **Antiarrhythmics**: disopyramide, quinidine, tocanaide, amiodarone
- **Antiparkinsonagents**: L-DOPA, pergolide, bromocriptine
- **Muscle relaxants**: Baclofen, cyclobenzaprine, methocarbamol
- **Others**: antihistamines/decongestants, digoxin, steroids, narcotics

Fick et al. *Arch Intern Med. 2003;163:2716-2724.*

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Medications Associated with Cognitive Dysfunction

- The American Geriatrics Society has an entire web page dedicated to the *Updated Beers Criteria for Potentially Inappropriate Medication Use in Older Adults (2012*), with tools and education resources located at:

http://www.americangeriatrics.org/health_care_professionals/clinical_practice/clinical_guidelines_recommendations/2012

Medications: "Start Low and Go Slow"

- Start with low doses
- Increase dosage slowly
- Always be wary of side effects

General Differences Between Delirium & Dementia

Delirium	Dementia
• Develops rapidly	• Develops slowly
• Fluctuating course	• Slowly progressive course
• Potentially reversible	• Not reversible
• Profoundly affects attention	• Profoundly affects memory
• Focal cognitive deficits	• Global cognitive deficits
• Usually caused by systemic medical disease or drugs	• Usually caused by Alzheimer or cerebrovascular disease
• Requires immediate medical evaluation and treatment	• Requires nonemergency medical evaluation & treatment

Differentiating Depression from Dementia

CLINICAL FEATURES	DEPRESSION	DEMENTIA
Onset	Acute	Insidious
Past Affective Episodes	Common	Uncharacteristic
Self-reproach	Common	Uncharacteristic
Diurnality	Worse in morning	Worse at night
Memory Deficit	Equal for recent & remote	Greater for recent than for remote

Differentiating Depression from Dementia

CLINICAL FEATURES	DEPRESSION	DEMENTIA
Other Cognitive Deficits	Circumscribed	Global
Response to Cognitive Testing	"Don't know"	Near miss
Reaction to Mistakes	Tend to give up	Catastrophic

Differentiating Depression from Dementia

CLINICAL FEATURES	DEPRESSION	DEMENTIA
Practice Effects	Can be coached	Consistently poor
Response to Sleep Deprivation	Improvement	Worsening (?)

The Philosophy of Dementia Care

- The philosophy of Dementia Care calls for a paradigm change that moves from the patient/problem/sick model of care to one of person/ability and enabled/wellness support model.
  - A shift in focus from
    - The patient to the person with dementia
    - Illness to wellness
    - Problems to Possibilities
    - Inabilities to Retained Abilities
    - Doing "to" or "for" to doing "with"

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The Philosophy of Dementia Care

- The opposite of **self-directed living** (person-centered care) is task-oriented care
- If things are happening for the convenience of staff members, it is **NOT self-directed living**
- Each person needs to know each person
- We should want the rest of their lives to be the best possible; if not, you (and your staff) are in the wrong job(s)!
- Foster a culture of **everyone** working for success for **all**

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"What Works Best for People With Dementia?"

"The following is a list of the main factors found in this study that assist in facilitating communication:

- Work from the assumption that the *person* is still there.
- Avoid concrete questions that will require the person to take in facts and respond to these.
- Ask questions about meaning (*invite* the person to respond, by tone of voice and welcoming attitude).
- Connect with the person spiritually and emotionally. This means being present to the person, using all the skills of person-centred care, such as appropriate touch, eye contact, and a welcoming and unhurried approach to conversation.

Elizabeth MacKinlay (2012): Resistance, Resilience, and Change: The Person and Dementia. Journal of Religion, Spirituality & Aging, 24:1-2, 80-92.

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"What Works Best for People With Dementia?"

- Allow time for the person to respond—a long time (sometimes up to five to six seconds).
- Allow periods of silence and be comfortable in that.
- Call the person by name, and then pause before asking the question.

Put simply, all of these factors lead to affirmation of the dignity of the person in dementia."

Elizabeth MacKinlay (2012): Resistance, Resilience, and Change: The Person and Dementia. Journal of Religion, Spirituality & Aging, 24:1-2, 80-92.

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Analyze the symptom (behavior)?

- Description of incident
  - Was the environment too noisy or stimulating in another way?
  - Were too many people present?
  - Was the task too complicated?
  - Was communication effective?
- Date and time of incident
- What happened immediately before the incident?
- Who was there?
- What stopped the symptom?

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Poor Environment

- Environment is too large
- Too much clutter or stimulation
- No signs, labels, or other cues
- Inadequate lighting, confusing sensory environment
- Changes in the environment
- New or unfamiliar environment

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Difficult Tasks

- Task is too complicated
- Steps are combined
- Task is not modified for increasing impairments
- Task is new or unfamiliar

Poor Communication

- Caregiver is in a negative mood
- Too many distractions
- Asking complicated questions
- Speaking too fast, too high
- Using unfamiliar words, abstract concepts
- Caregiver not using active listening

Poor Physical and Emotional Health

- Medications
- Impaired vision or hearing
- Acute or Chronic illness
- Dehydration
- Constipation
- Depression
- Fatigue
- Physical discomfort
- Pain

Pain and AD

- People with AD experience pain and discomfort at the same level as people without dementia (Morrison et al, 1998)
- Think about pain before treating agitation with tranquilizers!
- Treat presumptively. Does the person have a painful condition or pace?
- Schedule pain medication, not on demand

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Pain and AD

- If the pain is intermittent, the person may "deny" pain
- Watch for "guarding," screaming, calling out, striking out when approaching the pain site
- Think about the person who is on their feet the whole day

SIU

Rules for Redirecting Challenging Behaviors

- **S**TOP and THINK
- **L**ook for the Reason; the Trigger
- **B**e Flexible
- **U**se Disease-Appropriate Communication
- **D**istract
- **U**se Flattery and Compliments
- **R**eassure; strive for feelings of security

SIU

Rules for Redirecting Challenging Behaviors

- **B**e Calm
- **B**e Pleasant
- **E**nter the Person's World (validate the feelings, go along, etc.)
- **M**ake Sure the Person Can See You Before You Touch Them
- **B**e Creative

SIU

Rules for Redirecting Challenging Behaviors

- **T**reat Person with Dignity (allow them to "save face")
- **B**e Aware of Body Language (yours and theirs)
- **U**se Positive Statements
- **S**ing Rather Than Talk
- **T**ry New Approaches When Necessary
- **L**et Other Staff Members Know What Works

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Why do they search?

- May need to use bathroom
- May be hungry
- May be thirsty
- May have physical discomfort
- May want exercise

SIU

Why do they search?

- May indicate worsening of confusion secondary to:
  - Dehydration
  - Infection
  - Congestive heart failure
  - Medication side effects
- May be in response to:
  - Uncomfortable temperature
  - Excess stimulation
  - Sensory deprivation
  - Uncomfortable clothing

Why do they search?

- May be :
  - Seeking fulfillment of unmet psychological needs
    - Need to relate to others
    - Need to feel safe
    - Need to feel useful
  - Acting out habitual routine
    - Daily walk
    - Shopping
    - Going to work
  - Type of person who handles stress by being physically active
  - Simply lost (can't find room or bathroom)

Communication Tips

1. Get the person's attention.
2. Maintain a calm tone and speak slowly.
3. Provide reminders and help with problems.
4. Give him or her more time to answer. It may take up to a minute for the person to form a response.
5. Ask simple questions that can be answered with a yes or no. Answer questions the same way.
6. Accept silence.

People with Severe Dementia Exhibit Episodes of Lucidity

- 57% of people with severe dementia with difficulties with communication
  - Person unexpectedly says or acts in a way that surprises caregiver and seems to be much more aware of their situation than usual
  - Had higher orientation scores and expressed more emotions than others
  - Took more outdoor walks with caregivers
  - Closer contact changed caregivers' expectations and enhanced communication

Normann et al (2006) Journal of Clinical Nursing 15, 1413-1417

SIU

Communication Do's

- **R**eassure; *strive for feelings of security*
- **S**how Kindness, Love, Appreciation
- **U**se Simple, Single-Meaning Statements
- **B**e Calm
- **B**e Pleasant
- **E**nter the Person's Reality *(go along, etc.)*
- **S**mile
- **A**pproach from the Front

SIU

Communication Do's

- **C**onsider Physical Needs, Comfort
- **B**e Conscious of Body Language *(yours and theirs)*
- **I**dentify Yourself Often
- **M**ake Eye Contact
- **S**how Respect
- **A**llow Person to Maintain Dignity
- **U**se touch
- **A**cknowledge the Person's Feelings (*Validation*)

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Communication Do's

•**M**ake the Most of the Person's Abilities *(usually social skills)*
•**E**xplain what you are doing or are going to do
•**E**xpect repetitive behaviors & questions *(repeat an answer that reassures)*
•**R**edirect/Distract *to end inappropriate behaviors*
•**B**e Creative (*try out your ideas)*
•**T**alk about Familiar Things
•**C**ue the Person *(provide clues & prompts)*

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Communication Do's

•**U**se Positive Language
•**A**llow the Person Time to Process Information
•**L**imit Noise
•**S**ay "Thank You" *for cooperation, attempts to help, etc.*
•**S**ing -- *especially when talking doesn't get through*
•**U**se Good Manners
•**C**ompliment and Encourage Any Attempts to Communicate
•**U**se What You Know about the Person's Past
•**D**ish Out "Good Vibes" (*Lay the groundwork to make your next encounter - and your job! - a pleasant one.)*

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Communication Don'ts

- **D**on't Talk or Take Action without **THINKING** first
- **D**on't Try to Convince
- **D**on't Try to Explain Reality
- **D**on't Argue
- **D**on't Try to Use Reason
- **D**on't Raise your Voice
- **D**on't Frown
- **D**on't Scold

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Communication Don’ts

- **D**on't Tease
- **D**on't Take Everything Literally “*Where is my mother?”* may mean *“I need to feel safe and loved.”*
- **D**on't Ask a Lot of Questions.
- **D**on't Use Complex Statements or Questions
- **D**on't Approach from Behind
- **D**on't Use “Don't” *(avoid negative statements to stop behaviors)*

Communication Don’ts

- **D**on't Use Language that Could Be Misinterpreted as Romantic or Sexual *(sweetie, honey, etc.)*
- **D**on't Talk About the Person as if He or She Isn't There
- **D**on't Corner the Person
- **D**on't Crowd the Person
- **D**on't Call in Reinforcements
- **D**on't Be Offended
- **D**on't Ignore the Person's Feelings
- **Don't Give Up!** ***(Keep trying to find the thing that works!)***

Online Communication Resource

- **The Gerontological Society of America**
  www.geron.org

Communicating With Older Adults: An Evidence-Based Review of What Really Works; 2012.

How to Help Them Eat Well in the Later Stages

- Serve meals at the same time each day
- Make the eating area quiet to reduce distraction
- Offer just one food at a time
- Use colorful plates so the person can see the food
- Control between meal snacks

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How to Help Them Eat Well in the Later Stages

- Give finger foods such as cheese, mini sandwiches, fresh fruits, vegetables, chicken bites. Pita bread sandwiches may be easier to handle.
- Give high-calorie, healthy foods such as milk shakes with added protein, other blended drinks
- Use healthy fats such as olive oil in cooking. Try using extra butter, mayonnaise, oils if the person needs more calories.

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How to Help Them Eat Well in the Later Stages

- Keep certain foods out of reach for those on diabetic or low-salt diets. Limit salt, ketchup, etc.
- Serve larger portions at breakfast
- Use supplements to add vitamins, minerals and other important nutritional needs to the person's diet

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Swallowing Problems

- Cut food into small pieces and make it soft enough to eat
- Offer soft foods such as ice cream, yogurt, soups, milk shakes, fruit sauces, pudding, gelatin, etc.
- Grind food or liquify it with blender or food grinder
- Cold drinks are easier to swallow than hot drinks

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Swallowing Problems

- Limit milk if it tends to get caught in the throat
- Small sips from a cup are better than straws
- Thin liquids such as tea, coffee, water or broths are harder to swallow. Use ice cream, sherbet or thickeners to make liquids easier to swallow.
- Don’t hurry the person since it takes time to chew and swallow each mouthful before the next bite

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Swallowing Problems

- The person should be upright for feeding and for at least 20 minutes after the meal
- Have the person keep neck forward and chin down when swallowing
- Gently stroke the person’s neck in a downward motion and say “swallow” to remind the person to swallow the food or drink
- Find out if pills can be crushed or taken in liquid form

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Dental Problems

- Make sure dentures are properly fitted
- Check the person's mouth for problems such as:
  - Food pocketed in the cheek or on the roof of the mouth
  - Sores
  - Decayed teeth
  - Lumps

Non-Pharm Interventions for Behavioral Symptoms of Dementia

- **Cognitive/Emotion-oriented Interventions**
- **Sensory Stimulation Interventions**
- **Behavior Management Techniques**
- **Other Psychosocial Interventions**
- **Various Interventions Targeting a Specific Behavioral Symptom**

http://www.hsrd.research.va.gov/publications/esp/Dementia-Nonpharm.pdf
Published March 2011

Key points to remember

From Zoe Dearing, Alzheimer's Association

- When interacting with someone with a dementia, work heart-to-heart, not brain-to-brain.
- Whatever you are doing, it should be about how you make them feel while involved in a task, not about the task itself.
- When thinking about physical discomfort (including pain), consider other areas of the person's life where they might be feeling pain, such as emotionally and spiritually.
- People need to feel loved, valued and acknowledged.

alzheimer's association

- **Founded in 1980, based in Chicago, nationwide network of chapters with 300 offices**
- **Vision: A World Without Alzheimer's Disease**
- **Work: People and Science**
- **Nationwide Contact Center operates 24:7**
- **Largest non-governmental source of Alzheimer research (over $165 million since 1980)**
- **Nation's largest library dedicated to AD**
- **Advocacy efforts at federal, state and local levels**

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alzheimer's association

- **4 chapters serve Illinois**
  - **Offices in Bloomington, Carbondale, Chicago, Dixon, Joliet, Peoria, Quincy, Rockford and Springfield**
- **Local programs and services**
  - **Helpline**
  - **Support Groups**
  - **Education**
  - **Safe Return**

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Web Sites For Information About Alzheimer's Disease

SIU Center for Alzheimer's Disease and Related Disorders
http://www.siumed.edu/alz

Rush Alzheimer's Disease Center
http://www.rush.edu/radc

Northwestern University Cognitive Neurology and Alzheimer's Disease Center
http://www.brain.northwestern.edu

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Web Sites For Information About Alzheimer's Disease

Alzheimer's Association – National
http://www.alz.org
National 24 hour Helpline: (800) 272-3900
Alzheimer's Association – Greater Illinois Chapter
http://www.alz.org/illinois
Alzheimer's Association – Central Illinois Chapter
http://www.alzillinois.org
Alzheimer's Association – St. Louis Chapter
http://www.alzstl.org
Alzheimer's Association – Greater Iowa Chapter
http://www.alz.org/greateriowa

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Web Sites For Information About Alzheimer's Disease

Ageless Design – Alzheimer's Daily News
http://www.agelessdesign.com/news-alz.htm

Alzheimer's Disease Education and Referral (ADEAR)
http://www.alzheimers.org

ClinicalTrials
http://clinicaltrials.gov/ct/gui/c/a1b/screen/SimpleSearch

PubMed, a service of the National Library of Medicine
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi

Alzheimer Research Forum
http://www.alzforum.org

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