Supportive Care for People with Dementia and their Families
Darrell Owens, DNP, ANP-BC, GNP-BC, ACHPN
Practice Chief
Primary, Palliative and Supportive Care
UW Medicine at Northwest Hospital

WHAT IS DEMENTIA?

• An acquired syndrome of decline in memory and other cognitive functions sufficient to affect daily life in an alert patient
• Progressive and disabling
• *Not* an inherent aspect of aging
• Different from normal cognitive lapses
THE EPIDEMIOLOGY OF DEMENTIA

- 6%–8% of people ≥65 yr have Alzheimer dementia (AD)
  - Prevalence doubles every 5 yr
  - Nearly 45% of those aged 85+ have AD
- Vascular dementia co-occurs with an estimated 15%–20% of AD cases — “mixed dementia”
- Lewy body dementia (LBD) — second most common cause of dementia

THE IMPACT OF DEMENTIA

Economic
- $604 billion annually for direct costs of medical and social care and informal care
- Medicare, Medicaid, private insurance provide much of the direct costs — remaining costs with families and/or caregivers ($202.6 billion)

Emotional
- Direct toll on patients
- Nearly half of caregivers suffer psychological distress, especially depression
ETIOLOGY

- Alzheimer disease
  - Amyloid plaques/oligomers
  - Tau neurofibrillary tangles
- Lewy body and Parkinson dementia
  - Cytoplasmic α-synuclein inclusion bodies
- Frontotemporal dementia
  - Tau or ubiquitin proteins
RISK FACTORS FOR DEMENTIA

Protective Factors

Definite: unknown

Possible
• NSAIDs
• Antioxidants
• Intellectual activity
• Physical activity
• Statin

Risk Factors

Definite
• Age
• Family history
• APOE4 allele
• Down syndrome

Possible
• Head trauma
• Fewer years of formal education
• Late-onset major depressive disorder
• Cardiovascular risk factors (hypertension, diabetes, hypercholesterolemia, obesity)

THE GENETICS OF DEMENTIA

Early onset (<60 years old)
• Amyloid precursor protein (APP)
• Presenilin proteins (PS1 and PS2)

Late onset
• Apolipoprotein E gene (APOE 2/3/4) — chromosome 19
  ➢ APOE4 — two alleles confers greatest risk in dose-related fashion
  ➢ APOE2 — protective
• Single-nucleotide polymorphisms
  ➢ Clusterin (CLU-C), complement component receptor 1 (CR1), and phosphatidylinositol binding clathrin assembly protein (PICALM)
ASSESSMENT: HISTORY

Ask both the patient and a reliable informant about the patient’s:

• Date of onset of current condition and nature of symptoms
• Medical history
• Current medications & medication history
• Patterns of alcohol use or abuse
• Living arrangements

ASSESSMENT: PHYSICAL

Examine:
• Neurologic status
• Mental status
• Functional status

Include:
• Quantified screens for cognition
  ➢ For example, Folstein’s MMSE, Mini-Cog, SLUMS, MoCA
• Neuropsychologic testing
### Screening Instruments for Evaluating Cognition

<table>
<thead>
<tr>
<th>Name</th>
<th>Items/Scoring</th>
<th>Domains assessed</th>
<th>Web link (accessed Oct 2012)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mini-Cog</td>
<td>2 items Score = 5</td>
<td>Visuospatial, executive function, recall</td>
<td><a href="http://geriatrics.uthscsa.edu/tools/MINICog.pdf">http://geriatrics.uthscsa.edu/tools/MINICog.pdf</a></td>
</tr>
<tr>
<td>SLUMS</td>
<td>11 items Score = 30</td>
<td>Orientation, recall, calculation, naming, attention, executive function</td>
<td><a href="http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam_05.pdf">http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam_05.pdf</a></td>
</tr>
<tr>
<td>MoCA</td>
<td>12 items Score = 30</td>
<td>Orientation, recall, attention, naming, repetition, verbal fluency, abstraction, executive function, visuospatial</td>
<td><a href="http://www.mocatest.org">www.mocatest.org</a></td>
</tr>
<tr>
<td>Folstein MMSE</td>
<td>19 items Score = 30</td>
<td>Orientation, registration, attention, recall, naming, repetition, 3-step command, language, visuospatial</td>
<td>For purchase: <a href="http://www.minimental.com">www.minimental.com</a></td>
</tr>
</tbody>
</table>

### Assessment: Laboratory

**Routine**
- CBC
- Na+
- BUN/Cr
- Fasting glucose
- RPR
- TSH
- Vitamin B₆ level

**Optional (based on clinical exam and suspicion)**
- Liver function
- Folic acid
- Homocysteine/methylmalonic acid
- Urinalysis / Toxicology
- CSF analysis
- HIV testing
ASSESSMENT: BRAIN IMAGING

Consider imaging when:
• Onset occurs at age <65 years
• Neurologic signs are asymmetric or focal
• Clinical picture suggests normal-pressure hydrocephalus
• Patient has had recent fall or other head trauma

Consider:
• Noncontrast computed topography head scan
• Magnetic resonance imaging
• Positron emission tomography

DIFFERENTIAL DIAGNOSIS

• Normal aging
• Mild cognitive impairment
• Delirium
• Depression
• Alzheimer disease
• Vascular dementia
• Lewy body dementia
• Other (frontotemporal dementia, alcohol, Parkinson disease, neurosyphilis)
NORMAL AGING

• No consistent, progressive deviations on testing of memory
• Some decline in processing and recall of new information: slower, harder
• Reminders work—visual tips, notes
• Absence of significant effects on ADLs or IADLs due to cognition

DEPRESSION VS. DEMENTIA (1 of 2)

The symptoms of depression and dementia often overlap:
• Impaired concentration
• Lack of motivation, loss of interest, apathy
• Psychomotor retardation
• Sleep disturbance
DEPRESSION VS. DEMENTIA (2 of 2)

• Patients with primary depression are generally unlike those with dementia in that they:
  - Demonstrate ↓ motivation during cognitive testing
  - Express cognitive complaints that exceed measured deficits
  - Maintain language and motor skills

• ~50% presenting with reversible dementia and depression progress to dementia within 5 yr

ALZHEIMER DISEASE

• Onset: gradual

• Cognitive symptoms: memory impairment core feature with difficulty learning new information

• Motor symptoms: rare early, apraxia later

• Progression: gradual, over 8–10 yr on average

• Lab tests: normal

• Imaging: possible global atrophy, small hippocampal volumes
**VASCULAR DEMENTIA**

- **Onset:** may be sudden/stepwise
- **Cognitive symptoms:** depend on anatomy of ischemia, but dysexecutive syndrome common
- **Motor symptoms:** correlates with ischemia
- **Progression:** stepwise with further ischemia
- **Lab tests:** normal
- **Imaging:** cortical or subcortical changes on MRI

**LEWY BODY DEMENTIA**

- **Onset:** gradual
- **Cognitive symptoms:** memory, visuospatial, hallucinations, fluctuations
- **Motor symptoms:** parkinsonism
- **Progression:** gradual, but usually faster than AD
- **Lab tests:** normal
- **Imaging:** possible global atrophy
FRONTOTEMPORAL DEMENTIA

- **Onset**: gradual, usually age <60
- **Cognitive symptoms**: executive, language, and behavioral dysfunction, including disinhibition and hyperorality
- **Motor symptoms**: none; may be associated with ALS in rare cases
- **Progression**: gradual but faster than AD
- **Lab tests**: normal
- **Imaging**: atrophy in frontal and temporal lobes

THE GENERAL PROGRESSION OF DEMENTIA (1 of 2)

<table>
<thead>
<tr>
<th>Stage 1: No cognitive impairment</th>
<th>Unimpaired individuals experience no memory problems, and none is evident to a health care professional during a medical interview.</th>
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<tbody>
<tr>
<td>Stage 2: Very mild cognitive decline</td>
<td>Individuals at this stage feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses, or other everyday objects. However, these problems are not evident during a medical examination or apparent to friends, family, or coworkers.</td>
</tr>
<tr>
<td>Stage 3: Mild cognitive decline</td>
<td>Early-stage Alzheimer disease can be diagnosed in some, but not all, individuals. Friends, family, or coworkers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview.</td>
</tr>
<tr>
<td>Stage 4: Moderate cognitive decline (mild or early-stage Alzheimer disease)</td>
<td>At this stage, a careful medical interview detects clear-cut deficiencies. The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations.</td>
</tr>
</tbody>
</table>
THE GENERAL PROGRESSION OF DEMENTIA (2 of 2)

Stage 5: Moderately severe cognitive decline (moderate or mid-stage Alzheimer disease)

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential.

Stage 6: Severe cognitive decline (moderately severe or mid-stage Alzheimer disease)

Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with customary daily activities.

Stage 7: Very severe cognitive decline (severe or late-stage Alzheimer disease)

This is the final stage of the disease when individuals lose the ability to respond to their environment, to speak, and ultimately to control movement.

NONPHARMACOLOGIC MANAGEMENT (1 of 2)

• Cognitive rehabilitation
• Supportive individual and group therapy
• Physical and mental activity
• Regular appointments every 3–6 months
• Family and caregiver education and support
• Attention to safety
  ➢ Need for supervision, wandering, driving etc.
NONPHARMACOLOGIC MANAGEMENT (2 of 2)

• Environmental modification
  ➢ Orientation and memory measures such as clocks, calendars, to-do list, visual clues, simple and compassionate communication style

PHARMACOLOGIC MANAGEMENT

• Treatment should be individualized

• Cholinesterase inhibitors: donepezil, rivastigmine, galantamine
  • Memantine

• Other cognitive enhancers

• Antidepressants

• Psychoactive medications
CHOLINESTERASE INHIBITORS
(1 of 2)

• Slow breakdown of acetylcholine

• Clinical trials demonstrate modest delay in cognitive decline compared with placebo in AD

• GI side effects common
  ➢ Mitigated by slow titration curve
  ➢ Maximum dosing of donepezil 23 mg/day creates significant side effects without evidence of improving global function

• No evidence of difference in efficacy among drugs

CHOLINESTERASE INHIBITORS
(2 of 2)

• Use in other dementias
  ➢ Widespread use in vascular dementia not recommended
  ➢ Behavioral disturbances in Lewy body dementia can benefit from treatment
  ➢ Rivastigmine is FDA-approved for mild to moderate dementia in Parkinson dementia
  ➢ Treatment in frontotemporal dementia may worsen agitation
MEMANTINE

- Neuroprotective effect is to reduce glutamate-mediated excitotoxicity
- Modest *benefit* on cognition, ADLs, and behavior in AD
- Limited effect on cognition and no evidence to support widespread use in vascular dementia
- FDA-approved for moderate to severe AD
- Common adverse events: constipation, dizziness, headache

![Figure 1](image-url)

*Figure 1: Neuropsychiatric Clusters in Dementia*

- Aggression: Aggressive resistance, Physical aggression, Verbal aggression
- Agitation: Walking aimlessly, Pacing, Trailing, Restlessness, Repetitive actions, Dressing/undressing, Sleep disturbance
- Apathy: Withdrawn, Lack of interest, Amotivation
- Depression: Sad, Tearful, Hopeless, Low self-esteem, Anxiety, Guilt
- Psychosis: Hallucinations, Delusions, Misidentifications

SYMPTOM MANAGEMENT (1 of 2)

• Psychoactive medications
  ➢ Behavioral disturbances best managed nonpharmacologically, eg, reducing overstimulation, environmental modification

• Antidepressants
  ➢ Depressed mood, low appetite, insomnia, fatigue, irritability, agitation
  ➢ Possibly effective for disinhibition and compulsive behaviors
  ➢ Caution: falls and anticholinergic effects that may worsen confusion (ie, paroxetine)

SYMPTOM MANAGEMENT (2 of 2)

• 1st/2nd-generation antipsychotics
  ➢ Limited evidence of efficacy and increased risk of all-cause mortality in dementia
  ➢ Should be used with caution in targeting delusions, hallucinations, and paranoia — frequently attempt to taper off

• Valproic acid and carbamazepine
  ➢ Possible options, but with limited evidence and increased risk of mortality

• Benzodiazepines and anticholinergic medications should be avoided
RESOURCES FOR MANAGING DEMENTIA (1 of 2)

• Specialist referral to:
  ➢ Geriatric psychiatrist
  ➢ Neurologist
  ➢ Neuropsychologist

• Social worker
• Physical therapist
• Nurse

RESOURCES FOR MANAGING DEMENTIA (2 of 2)

• Attorney for will, conservatorship, estate planning

• Community: neighbors & friends, aging & mental health networks, adult day care, respite care, home-health agency

• Organizations: Alzheimer’s Association, Area Agencies on Aging, Councils on Aging

• Services: Meals-on-Wheels, senior citizen centers
THE FINAL STAGE OF DEMENTIA/ VERY SEVERE

- Unable to recognize anything at this point
- Loss of writing skills and languages
- Needs complete help with feeding
- Incontinence
- No control over muscle movement

Hospice Care

- Approximately 13% of patients enrolled in hospice have a dementia diagnosis
- The number of patients with dementia accessing hospice increased by 33.6% over the past several years
- Patients on hospice with dementia have a slightly longer length of stay
- Barriers include providers and families not viewing dementia as a terminal illness
**Functional Assessment Scale (FAST)**

1. No difficulty either subjectively or objectively.
2. Complains of forgetting location of objects. Subjective work difficulties.
3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.
4. Decreased ability to perform complex tasks, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5. Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised).
6. Occasionally or more frequently over the past weeks. * for the following:
   A) Improperly putting on clothes without assistance or cueing.
   B) Unable to bathe properly (not able to choose proper water temp).
   C) Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue)
   D) Urinary incontinence
   E) Fecal incontinence
7. A) Ability to speak limited to approximately ≤6 intelligible different words in the course of an average day or in the course of an intensive interview.
   B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview.
   C) Ambulatory ability is lost (cannot walk without personal assistance.)
   D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.)
   E) Loss of ability to smile.
   F) Loss of ability to hold up head independently.


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**Palliative Performance Scale (PPS)**

<table>
<thead>
<tr>
<th>%</th>
<th>Ambulation</th>
<th>Activity and Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Level of Conscious</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Full</td>
<td>Normal activity, no evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90</td>
<td>Full</td>
<td>Normal activity, some evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80</td>
<td>Full</td>
<td>Normal activity with effort, some evidence of disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70</td>
<td>Reduced</td>
<td>Unable to do normal work, some evidence of disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60</td>
<td>Reduced</td>
<td>Unable to do hobby or some housework, significant disease</td>
<td>Occasional assist necessary</td>
<td>Normal or reduced</td>
<td>Full or confusion</td>
</tr>
<tr>
<td>50</td>
<td>Mainly sit/tile</td>
<td>Unable to do any work, extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or confusion</td>
</tr>
<tr>
<td>40</td>
<td>Mainly in bed</td>
<td>Unable to do any work, extensive disease</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full, drowsy, or confusion</td>
</tr>
<tr>
<td>30</td>
<td>Totally bed bound</td>
<td>Unable to do any work, extensive disease</td>
<td>Total care</td>
<td>Reduced</td>
<td>Full, drowsy, or confusion</td>
</tr>
<tr>
<td>20</td>
<td>Totally bed bound</td>
<td>Unable to do any work, extensive disease</td>
<td>Total care</td>
<td>Minimal sips</td>
<td>Full, drowsy, or confusion</td>
</tr>
<tr>
<td>10</td>
<td>Totally bed bound</td>
<td>Unable to do any work, extensive disease</td>
<td>Total care</td>
<td>Mouth care only</td>
<td>Drowsy or coma</td>
</tr>
<tr>
<td>0</td>
<td>Death</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>
SUMMARY (1 of 2)

- Dementia is common in older adults but is *not* an inherent part of aging
- AD is the most common type of dementia, followed by vascular dementia and dementia with Lewy bodies
- Evaluation includes history with informant, physical & functional assessment, focused labs, & possibly brain imaging

SUMMARY (2 of 2)

- Primary treatment goals: enhance quality of life and maximize function by improving cognition, mood, behavior
- Treatment may involve both medications and nonpharmacologic interventions
- Community resources should be used to support patient, family, caregivers