My Family Member Has Dementia: What Do I Do Now?

Understanding and Communicating with Persons with Dementia

Kim P. Petersen MD
Verona, Wisconsin

Prevalence of Different Dementias

- Alzheimer's Disease: 60%
- Lewy Body Dementia: 15%
- Mixed Dementia: 10%
- Vascular Dementia: 5%
- Others: 10%
Mild Cognitive Impairment

Key Features of Mild Cognitive Impairment

- Increasing **Memory Lapses**
  - Confirmed by someone else
- Progressive **subtle decline in performance of daily activities**
- Change from baseline **judgment ability**
- **Poor performance on formal neuropsych memory testing**

Common Behaviors of MCI

- Awareness of deficits/ change from baseline
- Increased anxiety and irritability
- New onset of depression/ apathy
- Frustration with inefficiencies/ inaccuracies in accomplishing IADLs
- Tendency to withdraw, protect oneself from challenging situations
Alzheimer’s Disease

Key Features of Alzheimer’s Disease

- **Amnesia:** Difficulty learning and retaining new information
  - Damage to the Hippocampus
  - Almost always the first symptoms

- **Executive Function Impairment:**
  Difficulty making a plan and carrying it out; difficulty making good decisions
  - Frontal lobe dysfunction

Key Features of Alzheimer’s Disease

- **Aphasia:** Language impairment; word finding difficulties
  - Damage to the Temporal lobes
  - More prominent in some patients, less in others

- **Apraxia:** Difficulty way-finding; doing multiple step projects; disoriented to time and place; difficulty understanding the value of numbers; difficulty using tools or appliances
  - Disease involving the Parietal lobe
  - Patients look “demented”
Key Features of Alzheimer’s Disease

- **Agnosia**: Difficulty understanding the purpose of objects; difficulty interpreting what is seen
  - Late-stage symptoms
  - Involves association areas & multiple brain systems

Key Behaviors of Alzheimer’s Disease

- Delusions
- Misidentifications
- Depression & anxiety
- Apathy
- Wandering
- Agitation with catastrophic reactions
- Disinhibition

Lewy Body Dementias
Lewy Body Dementia

- Frequency: 15 – 20% of all dementias
  - Second most common dementia
  - Men more affected than women

- May be mixed with other dementias
  - Often misdiagnosed

- Shorter duration than AD: 6 – 10 years

Diagnosis of Lewy Body Dementia

- Progressive dementia

- Core features:
  - Fluctuating cognition & attention
  - Recurrent visual hallucinations
  - Motor features of parkinsonism

  - 2 core features = probable LBD
  - 1 core feature = possible LBD

Supporting Diagnostic Features of Lewy Body Dementia

- Repeated falls
- Syncope: transient loss of consciousness
- Delusions
- Auditory hallucinations
- Mild memory impairment in early stage
- REM sleep disorders
  - Restless leg syndrome
  - Somnambulism—sleep walking
- Depression
- Neuroleptic sensitivity
Common Behavioral Problems - Lewy Body Dementia

- Periods of acute confusion, “brown-outs”
- Agitation, paranoia from being told that hallucinations are unreal
- Confused about people's identity
- Depression and irritability
- Difficulty with visual-spatial tasks - e.g. inability to find the bathroom, especially when acutely confused
- Sleep disturbance and restless legs

Vascular Cognitive Impairment & Vascular Dementia

- Risk factors:
  - Hypertension or prolonged hypotension
  - Heart diseases
  - Diabetes, especially Type II
  - Obesity
  - Elevated lipids
  - Smoking
Causes of Vascular Cognitive Impairment

- Multiple large strokes
- Single strategic stroke
- Hemorrhage
- Small vessel disease
  - Most common cause of VCI
  - Lacunar infarcts
  - White matter disease
- Ischemic-hypoxic dementia
  - Prolonged lack of oxygen

Mild Cognitive Impairment: Subcortical Vascular Type

- History of vascular risk factors
- Dysexecutive syndrome
  - Goal formation and initiation of activity
  - Planning and organizing
  - Sequencing
  - Executing
  - Set-shifting
  - Self-maintenance
  - Abstraction ability

Mild Cognitive Impairment: Subcortical Vascular Type

- Mild memory deficit
  - Less severe than AD
  - Benefits from cueing

- Mood disorders:
  - Apathy
  - Depression
  - Mood lability
  - Irritability
Vascular Dementia

- Progression of cognitive and functional impairment
  - Spotty cognitive deficits
  - Often co-existing with AD
    - Accelerates AD pathology
  - MRI evidence of stroke or white matter disease

Vascular Dementia

- Neurological Signs
  - Abnormal gait
  - Psychomotor retardation
  - Increased reflexes
  - Localized neurological signs
  - Urinary incontinence

Common Behavioral Problems - Vascular Cognitive Impairment

- Episodes of unexplained confusion
- Apathy, loss of interest in activities, social withdrawal, negativism, lack of self-confidence
- Self-neglect
- Moving and thinking slowly: Irritability and agitation when rushed
- Poor decision making
- Treatment-resistant depression, sleep disturbances, anorexia
- Perseveration
Frontal Temporal Dementias

Key Features of Frontal-Temporal Dementia
- **Personality changes, not primarily a memory disorder**
- **Change in judgment ability:** can’t learn from mistakes, shows lack of concern about serious problems
- **Personality changes:** loses social skills, lack of empathy, hypersexual
- **Perseveration:** does the same thing over and over
- **Changes in language ability:** either decreased speech or fluent aphasia - lots of words without meaning, stereotyped responses, becomes mute
- **Hyperorality:** puts everything in mouth, craves sweets

Staging Alzheimer’s Disease & Brain Changes with Each Stage
Reisberg Cognitive Stages

- Groups cognitive deficits into 7 stages of severity
  - 1: normal adult
  - 2: mild cognitive impairment
  - 3 & 4: early AD
  - 5 & 6: middle stage of AD
  - 7: late AD

Reisberg Clinical Dementia Stages

- **Stage 1**—no cognitive decline
- **Stage 2**—very mild decline
  - complaints of forgetfulness
  - forgets names
  - loses items
  - no objective deficits in work or social life

Brain Changes in Stage 2

- Significant cell loss in Hippocampus
  - Loss of ability to form long-term memories
  - Neurochemical changes promoting anxiety and depressed mood
- Depends more on habits and rituals to cover up memory loss
- Increasing fear of possible dementia
- Denial often used to cope
How Caregivers Can Help

- Recognize and discuss memory changes
- Encourage a complete “checkup”
  - Look for depression symptoms
- Restructure and simplify lifestyle
- Organize home/work environment
- Reassure loved one’s value and personhood

Reisberg Clinical Dementia Stages

- **Stage 3**—mild decline
  - Remembers little of passage from a book
  - Difficulty finding words
  - May get lost in unfamiliar places
  - Anxiety common
  - Uses poor judgment

Brain Changes in Stage 3

- Numerous brain networks in the memory system affected; inefficient, fail to connect
  - Hippocampus, parietal lobe, frontal lobe
  - Language changes begin—“word finding”
  - Day-to-day variation in function; medical and drug issues greatly affect, driving self-protective denial & cover-up of symptoms
How Caregivers Can Help

- Empathize with their frustrations
  - Know their anger/anxiety/frustration is coming from the disease
- Repeat, repeat; don’t say “I told you that”
- Fill in the word if they can’t find it
- Ask them to join in an activity—don’t ask if they want to join—it will usually be “no”
- Do financial work together
  - Put limits on checking/credit cards
  - Get emotional support for yourself

Reisberg Clinical Dementia Stages

- **Stage 4**—moderate decline
  - clear cut deficits
  - concentration deficits
  - decreased knowledge of recent events
  - difficulty traveling alone
  - difficulty handling finances
  - remains oriented to time and person

Brain Changes in Stage 4

- Major damage to Hippocampus and Frontal Lobe connections
- Parietal and Temporal lobe dysfunction increasing
- Low brain serotonin levels leading to depression symptoms
- Obvious to person they have memory trouble, but may also “forget they’ve forgotten”
How Caregivers Can Help

- Needs to have a Memory Assessment and diagnosis at this stage
- Recognize, validate and support person’s frustration and fear of memory loss
- “Play to their cognitive strengths”—concentrate on longer-term memories
- Use much more humor
- Safety first, including driving ability
- Get all advanced planning for $$ and healthcare done

Reisberg Clinical Dementia Stages

- **Stage 5**—moderately severe decline
  - can no longer live without assistance
  - forgets address & phone number
  - forgets names of close family members
  - disoriented to time and place
  - remembers own name, spouse & children
  - trouble dressing, bathing
  - needs assistance with meals & toileting

Brain Changes in Stage 5

- Major cell loss in parietal lobe and disconnection with frontal lobe
  - Memory–association areas affected
- Increasing confusion about daily life
  - Withdrawal, self-absorption, immature behavior the norm
- Long-term memory systems damaged
- Unable to access memory systems for orientation, language, judgment and life history
How Caregivers Can Help

- Needs 24-hour supervision
- Help when needed but don’t infantilize
  - Assist rather than “take over”
  - Focus on strengths
- Never criticize or say “no”  Repeat, repeat
- One-step directions; limit choices
- Get support from peers & have “time outs”
  - Day-Club for appropriate activities & socialization

Reisberg Clinical Dementia Stages

- **Stage 6**—severe decline
  - Occasionally forgets spouse’s name
  - Largely unaware of all recent events
  - Retains sketchy knowledge of past life
  - Unaware of surroundings, season, year
  - Sleep patterns disrupted
  - Personality changes
  - Behavioral changes

Brain Changes in Stage 6

- Almost complete frontal lobe deterioration
  - Causes behavioral, personality & psychiatric changes
- Temporal lobe damage increasing leading to loss of language ability
- Motor symptoms develop including repetitive motions, restlessness, balance & gait problems
- Life is a total confusion but they don’t know what’s happened or why
How Caregivers Can Help

- Move & react very slowly—give more time for person to respond
- Offer frequent reassurance—helpful approach
- Explain before doing a task and do one step at a time
- Relate to the person’s feelings, not words
- Use lots of appropriate touch and music
- Think “out of the box” to understand why they are doing what they are doing—don’t just react

Reisberg Clinical Dementia Stages

- Stage 7—very severe decline
  - late dementia
  - inability to communicate
  - incontinent of urine and stool
  - needs total assistance
  - may be unable to walk
  - focal neurological signs
  - death

Brain Changes in Stage 7

- Total loss of most networks; un-coordination of thought patterns
  - More like brain of young infant
- Visual-association system affected leading to loss of ability to recognize who or what things are
- Brain disconnect with bladder & bowels
- Swallowing difficulty leading to choking risk
- Loss of motor coordination; walking ability lost
How Caregivers Can Help

- Palliative model of care
- Use touch, music, non-verbal methods to communicate
- Person will require total care
  - Decide on limits of medical treatment
  - Withdraw unnecessary medication & procedures
  - Respect person’s wishes regarding medical directives
- Make it a “good death”

Communication—the Key to Enhanced Relationships

Improve YOUR Communication Skills
General Communication Principles

Set the Stage
- Quiet environment
- Even bright lighting
  - Avoid strong backlights
- Reduce clutter and distraction
- Turn off the television!
  - Disasters portrayed on tv may seem real and immediate

Earn attention
- Make eye contact
- Use touch, if appropriate
- Sit if the person is sitting
  - Be at the same level
- Smile genuinely
- Greet the person
- Use the person’s preferred name
- Introduce yourself
- Be willing to come back, if this isn’t a good time

Vocal Quality
- Lower pitch
- Calm
- Slow down
- Don’t use Elderspeak
  - Sing-songy voice, childish intonation and language, “Imperial we”
- If a person is hard of hearing, consider using a pocket talker or other assistive device
  - A loud voice may be perceived as angry or cross
General Communication Principles

- Non-Verbal Cues
  - "Center" and collect yourself, so your body language will be calm, positive, open
  - Smile with the eyes, as well as the mouth-mean it!
  - Open, non-threatening stance, hands relaxed, visible
  - Be aware of each person's personal space comfort zone

- Keep Language Simple

  - One step at a time
  - Add descriptors and gestures:
    - Please sit down in this chair right here
    - This blue chair
    - This blue rocking chair
  - Don't argue or confront
  - NEVER SAY NO!

Positive Language

- Let's explore the garden.
- I'm sorry, I must have bumped the table and spilled your juice.
- Let's us early-birds have some coffee.
- Let's go freshen up.

Negative Language

- Don't go out to the street
- Oops, you spilled your juice all over!
- You can't get up now- it's 4 a.m.
- I need to clean you up, you had an accident.
The Art of Questions

1. Who is this?
   • Open-ended question
2. Is this a picture of John Wayne?
   • Question that gives the answer
3. Gee, John Wayne looks serious here, don’t you think?
   • Make a commentary
4. How do you feel when you see this picture of John Wayne?
   • Creative question, with no right or wrong answer

Responding

• “Give me the …….the….you know…”
  □ It must be really frustrating when you can’t find the word you’re looking for.
• “I was in the Navy on an aircraft carrier…”
  □ What an interesting story– I love to hear you talk about being in the navy!
• “I want to go home…I want to go home..”
  □ I wish I could take you home

Early-Middle Stage Activities
Life Story Book

- Involve many family members in gathering mementos, pictures, etc.
- Many facilities and ADCs request that a *Life Story Book* be made when the person moves in or joins the group
- Use a three-ring binder and plastic sleeves
- File folders make durable pages for pictures
- Use copies of precious pictures
- May also make a *Life* Story box with 3-dimensional items

Reminiscence and “Life Review”

- Process, not product
- “Just do it!” -- Don’t worry about grammar, spelling, mechanics
- “Life Story Books”
- TR- Bios (Therapeutic/ Restorative Biographies- Gene Cohen)
- “Making Memories Together” game- GENCO GAMES

TimeSlips- Creative Storytelling Project

Developed by Anne Basting, PhD, the TimeSlips project has generated hundreds of stories and plays. The creative processes promotes communication, connection and joy in elders who are living with dementing illnesses.

www.TimeSlips.org
Music Therapy in Dementia
Meta-analysis of Study Results

- Persons with dementia can continue participating in structured music activities into late stage
- Instrument playing and dance/movement are most preferred live music activities
  - Singing participation declines in late stage dementia
- Modeling of expected responses helps to maintain participation

Music Therapy in Dementia
Meta-analysis of Study Results

- Individual or small groups (3-5) are optimum
- Social and emotional skills and communication are enhanced
- Music can enhance cognitive skills such as memory
  - Information presented in a song context enhances recall and recognition
- Effective alternative to medication for behavior management

Music Therapy Resources

- Alicia Clair, *Therapeutic Uses of Music with Older Adults*
- David Aldridge, ed., *Music Therapy in Dementia Care*
- Oliver Sacks, *Musicophilia: Tales of Music and the Brain*
Sensory Stimulation- All 5 senses

- Tactile toys
- Quilts/ fabric
- Bubble pipe
- Scarves
- Balloons
- Fountains, envirascapes
- Favorite perfumes/ aftershave
- Musical Instruments to play

Ideas for Late-Stage Dementia Activities

Montessori Based Activities for Late-Stage Dementia Residents

- Activities to maintain or regain tactile sensation, auditory, temperature and scent discrimination
  - Match the smell of an orange with the orange itself, eat the orange or drink orange juice
  - Sort sandpaper-covered blocks according to the coarseness of the sandpaper, from roughest to smoothest
  - Scooping activities: using a spoon to transfer ping pong balls from a plate into the wells of a muffin tin
Creative Adaptations for Persons with Severe Disability of Dementia

- Seek non-verbal creative tasks
  - music, art, movement
- Procedural memory often remains for most of the dementia journey
  - e.g. the motions for knitting, sanding a wooden piece
- Break task into small component parts
  - e.g. sorting fabric by color for quilt pieces
- Remember: process, not product
- Adaptations of activities for persons with severe disabilities from dementia challenge your creativity!

Reminiscence Therapy for Behavior Management

- Bath-time reluctance
  - Old-fashioned apron
  - Reminisce about Saturday night bath routine
  - Peanut butter sandwich
  - Getting dressed up to go out on a date or to a dance
  - Aromatherapy- favorite moisturizer, cologne or aftershave
- I want to go home- My mother’s waiting for me
  - Draw me a picture of your favorite room or place at home
  - Look at Life Story Book
- Agitated Behavior- Use large muscle groups
  - Tearing sheets and rolling bandages
  - Sanding wood blocks
  - Polishing candle sticks, wood tabletops
- Rummaging
  - Sort “quilt fabric” by color and pattern
  - Put nuts onto large bolts
  - Handbag rummage
  - Sorting socks, baby clothes sprinkled with baby powder

Collaboration-Working Together

- “Life savers”
  - Fanny pack
    - Grocery/ hardware store list
    - Hankies/ scarves to fold
    - Peppermints
    - Jewelry to sort
    - Hand lotion
    - Bandana
    - Stuffed animal
Collaboration - Working Together

- Job Box
  - Toys to sand
  - Fabric for bandages
  - Candlestick to polish
  - Old milking machine
  - Ledger books/ grade books/ restaurant order pads
  - Cross stitch hoops
  - Large knitting needles, crochet hooks
  - Old post cards to sort
  - Fishing bobbers to sort
  - Soda bottle with birdseed/ objects to find.

Multi-Sensory Stimulation

- Create a Spa:
  - Decorate the room like a resort with palm trees, umbrellas, beach posters, etc.
  - Facials, make-up, manicures and pedicures
  - Hair care
  - Massage and aromatherapy
  - Soothing music or environmental sounds
  - Juice bar
  - Do “Color profiles”
  - Take and develop photos of persons after their “Make-Over”
  - Exercise- yoga, tai chi, etc.

Spirituality

- Beloved religious items: Bible, rosary, Koran, Menorah
- Magazines from faith organizations
- Sacred music
- Designated place for meditation
- Outside meditation garden
Humor and Play

- Early Stage dementia persons may be fighting to keep up a façade of control.
  - May respond negatively to games that seem “childish” or “too easy.”
  - Facilitator needs to use a sensitive, playful approach.

- Middle and Later Stage dementia persons are letting go of past/future and living in the “here and now.”
  - Often lose their inhibitions
  - “Blossom” through play
  - When play is presented in a spirit of fun, love and respect, people don’t feel demeaned.

Play

- Support “Play” Behavior:
  - Play doh, fingerpaints, silly string, puppets, stuffed animals, mud pile
- Creative Dramatics, Make-Believe, Charades:
  - Make a collection of silly hats, clown noses, Groucho glasses
- Funny Board or Basket:
  - Laminate cartoons, amusing pictures and funny sayings for a bulletin board or laugh basket
Humor Everyday

- Funny Clothes
  - Wear amusing buttons, vests, jewelry

- Kids and Animals
  - Share funny children's books: *Alexander and the Terrible, Horrible, No Good, Very Bad Day* - Viorst; *Wilfrid Gordon McDonald Partridge* - Mem Fox
  - Bring in baby animals, pets

Activities for Smiles and Laughs

- Funny Videos from Years Ago
  - *I Love Lucy, Milton Berle, Red Skelton*

- Funny Videos for Children

- Therapeutic clowns

Summing Up

- Know the type of dementia and where the person is in the journey
  - Each person is unique

- Understand it’s the disease causing the cognitive and behavioral changes

- Improve & hone your communication techniques
  - Critical for the person with dementia

- Find joy and happiness in everyday
Questions?