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Managing Dementia: Promoting Function and Maintaining Independence

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Objectives

- Review dementia, including overview and diagnosis
- Review expected changes in memory, thinking, mood and function
- Explore techniques to minimize common challenges
- Discover approaches and interventions for caregivers to use in promoting ADLs and safety

What is Dementia?

- A general term for a decline in cognition and behavior that impacts one's ability to function independently in everyday life (American Psychiatric Assoc. 2000).
 - Caused by gradual loss of working brain cells
 - Not a normal part of aging
 - Can be permanent or reversible
 - There are 50 types of dementia.

Statistics

- 1 in 3 seniors will die with dementia (2016)
- Over 9 million Americans live with some form of dementia
- By 2050, an estimated 16 million will develop dementia
- \$160 billion in costs to Medicare and Medicaid (2016)
- 60% of caregivers rate emotional stress high or very high
 - ~ 40% of caregivers report symptoms of depression

Common Types of Dementia

- Alzheimer's disease
- Vascular dementia
- Lewy body dementia
- Parkinson's disease dementia
- Frontotemporal dementia
- Mixed dementia



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Alzheimer's Disease

- Most common type of dementia (60-80%)
- The 6th leading cause of death in the US
- Modern medical description by Alois Alzheimer in 1906, who found plaques and tangles in the brain
- Rare in earlier times because few people lived to a very old age

Progression of Alzheimer's Disease

- Duration of illness is generally 6 to 12 years
- The later the diagnosis, the shorter the lifespan
- Onset is usually after 65
- Before age 65, it's referred to as "early onset"

Brain Changes in Alzheimer's

- Cells die in vital areas of the brain as the result of neuritic plaques and neurofibrillary tangles
- Communication between parts of the brain is greatly reduced

Brain Changes in Alzheimer's

- **Hippocampus most affected**
 - Loss of memory
 - Loss of spatial orientation
- **Frontal Lobe**
 - Loss of executive function, inhibitions
- **Parietal and Temporal Lobes**
 - Disorientation in space
 - Loss of language
 - Loss of memory
- **Occipital Lobe**
 - Progressive loss of peripheral vision/binocular vision
- **Hypothalamus**
 - Loss of temperature regulation

Brain Changes in Alzheimer's

- Preserved in Alzheimer's
 - Emotions
 - Amygdala is the emotional center
 - Last are to be damaged
 - Capitalize on making connection with patients
 - Music and Rhythm
 - Stored opposite the language center
 - Often undamaged
 - Capitalize on for treatment

Vascular Dementia

- Also known as multi-infarct or vascular cognitive impairment
- Often due to series of small TIAs that block arteries
- Symptoms overlap with AD, however memory may not be as seriously affected
- May be focal loss, rather than global

Lewy Body Dementias

1. Dementia with Lewy bodies (DLB)
 - Problems with motor planning, memory, judgment and behavior
 - Severity and alertness of symptoms may fluctuate daily
 - As it progresses, physical symptoms similar to Parkinsonism: rigidity, bradykinesia
2. Parkinson's disease dementia (PDD)
 - 80% of PD patients will develop PDD
 - Physical symptoms followed by cognitive changes

Frontotemporal Dementias

- Includes Pick's disease, primary progressive aphasia, semantic dementia and others
- Minimal memory deficits are noted in early stages
- No pharmaceutical treatments available
- Common in individuals between 50-60 years old

Mixed Dementia

- Most common is AD and vascular dementia
- Can be any combination of dementia diagnoses
- Symptoms will be a composite of the mix

Reversible Dementias

Some Examples:

- Depression
- UTI
- Metabolic disturbances
 - Thyroid problems, vitamin deficiencies, liver disease, renal disease
- Medication side effects
- Excess use of alcohol
- Pneumonia
- Anemia

Keep In Mind...

- Problems with **new** learning or remembering **new** information
- **Old** memories remain intact
- We call these memories **residual memories**
- The client's ability **to access** residual memory erodes



Keep In Mind...

- Episodic memory
 - Memories of things you have personally experienced
 - Things you have done, people you have seen
 - Highly impacted in AD; may remain intact in PDD/LBD
- Semantic memory
 - Everything else you know: learned knowledge
 - Highly impacted in AD
- Procedural memory
 - Memories based on repetitive activity
 - Action based
 - Can be achieved with extra time
- Declarative memory
 - Memories of facts and events
 - Refers to those memories that can be consciously recalled
 - Sometimes called explicit memory

Example of Episodic Memory

- Recalling details of how you learned about a relative's death.
- Recalling neighbors where you use to live
- Recalling a ski vacation last winter

Examples of Semantic Memory

- Knowing that grass is green
- Knowing names of colors
- Knowing what a dog is

Examples of Procedural Memory (Motor Skills)

- Walking
- Talking
- Play piano
- Ride a bike

Examples of Declarative Memory

- Knowing one's address
- Giving someone directions to the store
- Recalling the route to a nearby park



Health professionals discuss dementia in "stages," which refers to how far a person's dementia has progressed. Defining a person's disease stage helps physicians determine the best treatment approach and aids communication between health providers and caregivers.

Determining Stages of Dementia

- Fast Scale
- Allen Cognitive Scale
- Global Deterioration Scale



Allen Cognitive Scale

- Developed by Claudia Allen OTR
- Identifies 6 cognitive levels and 4 modes of function with each level
- Best Practice recommends using 2 of the following to obtain level
 - Allen Cognitive Level Screen
 - Allen Diagnostic Module
 - Routine Task Inventory



Global Deterioration Scale

- Dr. Barry Reisberg
- Neuro Retrogenesis
 - Abilities are lost in the opposite direction they were learned
 - Treatment plan should follow that bath
Feeding ->toileting ->dressing ->grooming
(do not attempt grooming if person is no longer feeding)
- There are 7 specific stages of dementia progression
- Collectively, these stages are called the **Global Deterioration Scale**



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Stage by Stage Characteristics and Interventions

GDS Stage 1

- No dementia
- Function normally
- Possible short-term memory problems that increases with stress.

Stage 1 Intervention

- No communication concerns
- No treatment needed

GDS Stage 2

- No dementia, very mild cognitive decline
- Normal forgetfulness (ex: names, where keys are)
- Generally no problems functioning at work, home, or leisure activities
- No one knows there may be a problem

Stage 2 Interventions

Compensatory strategies for memory & organization

High Tech

- Digital voice recorder
- Programmable watch
- Cell phone

Low Tech

- Checklist
- Calendar
- Daily planner

Stage 2 Communication

- Provide written instructions
- Have a close friend or family member attend office visits
- Repeat back instructions to make sure understood
- Reminder calls for appointments (text messages, email, google calendar)

GDS Stage 3

I know, but nobody else does

- Mild cognitive decline with early confusion
- Increased forgetfulness
- Decrease in concentration
- Work performance starts to suffer
- Beginning of word finding problems
- The individual realizes that what is happening to his memory is not due to stress
- Decreased reading comprehension

STAGE 3 INTERVENTIONS

- Starting caregiver education
- Consider in home assistance or move in with a family member
- Home and community safety (Life Alert, SMART HOMES, virtual home care apps)
- Spatial considerations (orientation and wayfinding)
- Environmental adaptation
- Touch technology
- Routine exercise

Stage 3 Communication

- Use concrete, simple language
- Minimize instructions
- Written reminders in appropriate places
- Delay providing information about procedures until just prior to event

GDS Stage 4

Lost in Space: “What is happening?”

- The cat is out of the bag...it is obvious to others that the individual has dementia
- Difficulty with routine home maintenance
- Person often is depressed as he/she mourns the future
- Learned “helplessness can occur”
- Starts isolating self from others and avoids challenging situations.
(denial used as a defense mechanism)
- May be agitated
- Decline in executive functioning

Stage 4 Interventions

- Often the stage where placement first occurs
- Home safety adaptations
- Introduce signs and landmarks to facilitate Wayfinding
- Good with repetitive familiar tasks
- Can still learn new tasks given cueing and practice
- Teach new ways to ambulate and transfer to different surfaces with demonstration and repetition
- Comprehensive caregiver education is needed

Stage 4 Communication

- Word recall problems
- Repetitive questioning
- Person continues to be socially appropriate



GDS Stage 5

Dressed and ready, with nowhere to go

- Individual is unaware of having a problem with their memory
- Oriented to own name and usually spouse and children's names
- Disoriented to time, place, address, and telephone number
- Repetitive questioning
- Retains new information for about 5 minutes
- Unable to travel independently

Stage 5 (continued)

- May wander away
- May be agitated and hoard things
- Beginning of loss of visual fields
- Safety and fall concerns. May not be aware of tripping hazards such as a step or change in terrain
- Needs some assistance with ADLs such as picking out appropriate clothing.
- Independent with eating and toileting

Stage 5 Interventions

- Environmental modifications for safety and fall prevention
- Compensatory strategies for participation in functional activities
- Provide visual and verbal cueing / physical prompting and assistance

Stage 5 Intervention (continued)

- Purposeful and meaningful activities
 - Sorting money
 - Folding clothes
 - Matching cards
 - Reminiscent boxes
 - Old photographs

Stage 5 Communication

- Familiar, upbeat, pleasant tone of voice
- Simple, concrete language
- Limit choices to 2
- Respond to questioning
- Validate and distract
- Relate to client's world (refer to social history)

GDS Stage 6

- Severe cognitive decline
- Forgets names of children and spouse
- Disoriented to the immediate environment
- Pacing back and forth
- Usually lose peripheral vision and depth perception
- Decline in walking with falls

Stage 6 (continued)

- Will wear dentures, eyeglasses, and hearing aides for a short period of time; often loses them
- May look disheveled and often layers clothing due to feeling exceedingly cold
- May stop feeding themselves due to not knowing how to start
- Toileting assistance / incontinence

Stage 6 Interventions

- Do not change the setup of the environment
- Maintain consistency
- Confine ambulation to safe, level areas
- Supervise walking on stairs
- Remove distractions from view
- Remove hazards
- Respond better to visual and tactile cues
- Use signs and messages
- Caregiver education regarding agitation, behavior management

Stage 6 Communication

- Loss of functional language / “word salad”
- Recognize nonverbal communication
- Validate, distract, and redirect
- Get into their view and touch them before you give instruction
- Simple language, single step statements
- Calm tone, gentle, touch, smile
- Allow up to 90 seconds response time

GDS Stage 7

- Late dementia
- Tend to be dominated by their senses
- Unable to express needs verbally, so you have to be a detective and observe behaviors
- Loss of motor skills
- Unable to walk independently needing a wheelchair to prevent falls
- Contractures of extremities

Stage 7 (continued)

- Needs significant or total help with dressing, bathing, grooming, eating
- Incontinent
- Lose ability to taste and smell food, except with heavy seasoning or sweets
- Return of primitive reflexes (grasping and rooting)
- Significant weight loss and dysphagia

Stage 7 Interventions

- Caregiver education
- Fall prevention
- Positioning in bed and/or wheelchair
- Basic ADLs (finger food diet)
- Maintenance program development
- Sensory stimulation

Stage 7 Communication

- Single step instruction
- No choices
- Nonverbal communication
 - Read it: look for pain, which client cannot express
 - Use light touch to calm
 - Be aware of tone, approach
 - Smiling is key
- 90 second response time

Additional Interventions Across All Stages

Fall Reduction/Prevention

- Therapy
 - Strengthening
 - Balance activities
 - Postural remediation
- Environmental optimization
 - Furniture walking (relax the rules)
 - Wayfinding
 - Clutter reduction
- Home Exercise Program with caregiver support or in a group



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Environmental Modifications

- Control the environment
- Simplify the space
- Provide a calm atmosphere
- Eliminate or minimize background noise
- Provide sufficient lighting
- Sufficient warmth, eliminate drafts

Interventions for Behavioral Issues

SUNDOWNING

Bathing

Eating

Toileting

Dressing

Sundowning

- Late day confusion
- Usually worsens as the disease progresses and peaks in the middle stages.
- **Symptoms:** aggressiveness, delusions, hallucinations, pacing, elopement, increased difficulty with tasks that can be done earlier in the day.
- **Causes:** decreased activity in afternoon, decreased lighting, disrupted sleep cycle.

Sundowning Strategies

- Address hunger, thirst, pain, toileting
- Allow mini rest breaks throughout the day
- Decrease over stimulation
- Intermittent times of physical activity throughout the day
- Evening routine
- Provide adequate lighting

Bathing Behaviors

- **Behaviors:** refusal, yelling, hitting
- **Causes:** cold or discomfort, forgets what it is, embarrassed, fearful, unfamiliar

Bathing Strategies

- Pre - organize all items in bathroom
- Pre- adjust temperature in bathroom and water
- Safety equipment (grab bars, shower chair)
- Cover mirrors
- Avoid being confrontational
- Maintain the familiar
- Dignity and privacy

Eating Behaviors

- Poor appetite, refusing to eat, holding food in mouth, difficulty swallowing and chewing
- **Causes:** pain, poor fitting dentures, fatigue, medication, agitation, constipation, communication, depression, and lack of physical activity

Eating Strategies

- Routine physicals and dental care
- Eat when most alert
- Provide physical assistance / adaptive equipment
- Physical activity
- Nonverbal communication
- Don't rush
- Minimize distractions

Toileting Behaviors

- Incontinence
- Refusal
- **Causes:** UTI, constipation, prostate gland, GI, decreased sensation, wayfinding, mobility, communication, embarrassment, distracted

Toileting Strategies

- Toileting routine
- Easy to manage clothing
- Provide physical assistance / AE
- Visual cues and signs
- Limit coffee, soda, tea
- Incontinence pads
- Physical activity
- Proper diet / fluid intake

Dressing Behaviors

- Refusal
- Layers / inappropriate clothing
- Yelling, hitting

Dressing Strategies

- Simplify choices
- Simplify the task
- Comfortable and simple clothing
- Be flexible

Innovative Care for Persons with Dementia

- Dementia Villages
- Amsterdam (2007)
- Canada (2014)
- Italy (2016)
- Florida (in the making)

Innovative Care for Persons with Dementia (continued)

- SMART homes
- Key chain sensors
- Wrist band sensors
- Silent sensors
- Motion sensors

Pharmacological Interventions

- Brain of person with Alzheimer's disease
 - Has lower levels of acetylcholine. Acetylcholine helps send messages between nerve cells
 - Have loss of nerve cells that use acetylcholine.
 - Falling acetylcholine levels and progressive loss of nerve cells are linked to worsening symptoms.
- Cholinesterase inhibitors
 - Aricept, Exelon and Razadyne
 - Prevent the breakdown of acetylcholine
 - Increase concentration of acetylcholine

Pharmacological Interventions

- Leads to increased communication between nerve cells
 - Temporarily alleviates or stabilizes some symptoms
 - All three cholinesterase inhibitors work in similar way
 - One might work better than another for certain individual in terms of side effects
 - Also very effective for Lewy body dementia and PDD in treating agitation, apathy and psychotic symptoms

Pharmacological Interventions continued:

- Namenda:
 - Used to treat moderate to severe Alzheimer's disease
 - Blocks the toxic effect of excess glutamate
 - Regulates glutamate activation
 - Protects brain cells by blocking effects of excess glutamate
- Glutamate:
 - Brain chemical that sends messages between nerve cells
 - Is released in excessive amounts when brain cells are damaged by AD
- Antipsychotics: i.e. Risperdal (risperidone)
 - To eliminate or reduce psychotic symptoms, delusions and hallucinations
 - Have calming, sedative effect
- Antidepressants:
 - Can be effective for behavioral and psychological symptoms



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Generic	Brand	Approved For	Side Effects
Donepezil	Aricept	All stages	Nausea, vomiting, loss of appetite and increased frequency of bowel movements
Galantamine	Razadyne	Mild to moderate	Nausea, vomiting, loss of appetite and increased frequency of bowel movements
Memantine	Namenda	Moderate to severe	Headache, constipation, confusion, dizziness
Rivastigmine	Exelon	Mild to moderate	Nausea, vomiting, loss of appetite and increased frequency of bowel movements
Memantine + donepezil	Namzaric	Moderate to severe	Headache, diarrhea, dizziness, loss of appetite, vomiting, nausea and bruising



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Questions?

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