Getting Through COVID: Managing Behavioral Changes in Dementia

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What is Dementia?

Dementia (Major Neurocognitive Disorder) is an enduring decline in cognition that interferes with functioning in everyday living.

American Psychological Association

- Impairment will not improve
- Sufficient decline in cognitive functioning
- Change in cognitive functioning must be severe enough to make it harder for the individual to carry out activities of daily living
    - Managing finances
    - Managing medication
    - Making reasoned decisions
    - Preparing meals

If decline in cognitive abilities and difficulty functioning are severe enough = Dementia

- Major Neurocognitive Disorder)

If less cognitive impairment

- Mild Neurocognitive Disorder

Dementia is a General Diagnosis

- A diagnosis of Dementia does not tell you what is causing the decline

- Dementia can be caused by many diseases and any insult that has affected the brain.

- Knowing the cause tells us what to expect in the future.

Causes of Dementia

Neurodegenerative Diseases

- Alzheimer's disease
- Frontotemporal disease
- Lewy Body disease
- Parkinson's disease

Other Insults

- Vascular disease or insult
- Infection
- Traumatic brain injury

Alzheimer's Disease

- Most common form of dementia
- Typically diagnosed after age 65
- Early onset form late 30's and up

Nerve cells within the brain

- Lose their function
- Become unable to communicate with other nerves
- Eventually die

This causes changes in cognition and behavior

Parts of Brain Affected

Middle temporal lobes first

- Rapid forgetting

Frontal lobes and subcortical parts of brain

- Problems with executive functioning

Progression of AD

Initial Symptoms

- Primarily temporal lobe forgetting

1. Forgetting
2. Trouble Naming things & people
3. Losing or Misplacing things

Behavioral Change:

- Frustration
- Irritability
- Some lack of insight

Forgetting

Executive Functioning

Alzheimer's disease progresses gradually

- Forgetting followed by executive functioning problems

Executive functioning changes:

- Focusing without distraction
- Planning and sequencing
- Solving problems
- Comprehending complex information
- Multitasking
- Focus on unimportant details and missing the big picture

Executive Function Changes

Cognitive problems worsen

- Marked forgetting of recent events
- Repeating oneself
- Trouble planning things
- Difficulty carrying out multi-step tasks
- Unable to focus on one conversation in group

Behavioral Change due to Forgetting

- Continued irritability
- Thought processes are less clear and linear
  - Poor decision making
  - More susceptible to scam artists
- Confused more often
- Paranoid and suspicious
  - Can't find jewelry – daughter stole it / someone broke in

Behavioral Change due to Executive Functioning

- Quickly overwhelmed / overstimulated in groups
  - Leads to withdrawal from family gatherings
  - Irritability with grandchildren
- Insight declines further
  - May become angry
- Repetitive behavior
- Sleep changes
  - More agitated and confused in evening night
- Wandering

Strategies for Behavioral Change

Irritability & Anger

- Respond calmly
- Remove person from situation
- Look for cause
- Limit distractions (quiet, calm environment)
- Shift focus to another activity with you

Strategies for Behavioral Change

Forgetting and Confusion

- Respond with a brief explanation
- Give the same answer to the same question each time, calmly
- No need to correct / Make suggestions
  - "I think that is your granddaughter Julie"
  - Verses "That's not your daughter Emma!"
- Talk about things they remember / Pictures they recall

Paranoia

- It is ***real*** to them
- Stay calm
- Listen and be reassuring
- Don't argue or try to convince
- Offer a simple answer…
  - Then switch the focus to another activity

Overwhelmed and Overstimulated

- Follow a routine each day
- Create a calm environment
- If family gathering, understand that the individual will need time away
- Have a safe and quite place where they can go
- Explain to family and friends simply
- Avoid making a big deal over this

Repetitive Behavior

- Same question?
  - Give same simple answer each time
  - Write down on a white board
  - Then redirect to new activity
- Look for reason behind the repetition
  - Around certain people?
  - Certain time of day?
  - Certain environment?
- Stay calm and don’t try to explain differently
- Engage the person in an activity

Sleep Changes

Possible Causes

- End of the day exhaustion (cognitive fatigue)
- Poor lighting and shadows can be confusing and frightening
- Caregivers may be frustrated (LONG day) and they sense it
- Difficulty separating dream from reality causes disorientation

Sleep Changes

Strategies

- Keep home well lit in evening
- Comfortable home
  - Comfortable temperature
  - Home safe with locks on doors
- Keep a routine for evening and bedtime
- Identify triggers
  - Television
  - Children visiting
- Take care of yourself too

Wandering

Possible Causes

- Confusion
  - Trying to "go home" even if already there
  - Difficulty finding familiar places like bathroom or bedroom
- Restless
  - Paces or makes repetitive movements
- Asking the whereabouts of family or friends
  - Goes looking
- New environment
  - Become confused or lost
- Sometimes there's a real need that the person can't figure out how to meet

Wandering

Strategies

- Have routine for daily activities
- Identify times of day most likely to wander
- Reassure the person if feel lost or disoriented
- Ensure all basic needs are met
  - Gone to bathroom?
  - Hungry or thirsty?
- Avoid busy places that can be confusing (grocery stores, shopping malls)

Wandering

- Place door locks out of sight (top or bottom)
- Make doorknobs less accessible
  - Cover with curtain or childproof knobs
  - Paint knobs with same color as door
- Place bell or alarm on door to know when opened
- If wandering – 24 hour assistance (don't leave alone)
- Car keys hidden
- Night wandering
  - Night lights
  - Restrict fluids two hours before bed
  - Use bathroom just before bed

Frontotemporal Disease

- In people under age 60, most common cause of dementia
- Most often diagnosed disease among 45-64 year olds

Nerve cells within the brain

- Lose their function
- Become unable to communicate with other nerves
- Eventually die

This causes changes in cognition and behavior

Part of the Brain Affected

- Frontal lobes
- Anterior Temporal lobes

Causes different cognitive and behavioral changes than in Alzheimer's

Types

1. Behavioral Variant FTD
2. Primary Progressive Aphasia
3. FTD with motor neuron disease

...first two

Behavioral Variant FTD

- Emotional flatness / Decreased reactivity
- Apathy
- Decreased social skills
- Inability to initiate activities
- Lack of insight / Self-awareness
- Selfishness
- Disinhibition around things they enjoy or want
  - Eating sweets
  - Sexual comments

Primary Progressive Aphasia

Type One

- Can't say what you want to say
- Can't come up with the words
- Lose the concept of things (what is a bird)
- Reading declines
- Simple math declines

Type Two

- Difficulty **producing** language fluently (motor problem)
- Worse on telephone
- Develop Parkinsonian symptoms

Primary Progressive Aphasia

Eventually develop

- Disinhibition
- Apathy
- Emotional flatness
- Lack of insight

Frontotemporal Behavioral Changes

- Aggression
- Apathy
- Social withdrawal
- Compulsive Behavior
- Confusion &
  non-linear thinking
- Delusions
- Difficulty swallowing
- Language problems
- Hallucination
- Sexual disinhibition

Compulsive Behavior

- Hoard items
- Check locks and doors repeatedly
- Count over and over

Strategies:

- Ignore if not harming anyone
- Involve person in another activity

Language Problems

- Use short sentences; get to the point
- Speak clearly
- Avoid negative, complicated sentences
  - Say "I ran" not "I didn't walk"
- Speak slowly
- Give person time to respond in spite of long pauses
- Maintain eye contact so they can use facial expression
- Decrease distractions when speaking

Sexual Disinhibition

- Due to lack of insight, lack of impulse control and inability to "read" others' responses

Strategies

- State firmly what behavior is not acceptable
- Avoid situations that "trigger" the behavior
- Tell family and friends about this
- Print "business cards" (see UCSF Frontotemporal pages)

Unique Behavioral Changes

Capgras Syndrome & Reduplicative Paramnesia

- Irrational beliefs that a familiar person or place has been replaced by an exact duplicate or imposter
- May come and go suddenly
- Most common in Lewy body Dementia, but can occur in Alzheimer's disease

Strategies

- Know that this is not personal or about your relationship
- Facial recognition part of brain switches off and on

When it occurs…

- Misidentified person leave the room for a while
- Help person who is confused to leave the house for a while, then return
- Sometimes clears their recognition
- If not, be calm and reassuring
- Don't argue
- Wait for recognition to normalize

Bibliography

- Alzheimer's Association Website
- *The Behavioral Neurology of Dementia* by Bruce Miller & Bradley Boeve
- *The 36-hour Day* by Nancy Mace MA & Peter Rabins, MD, MPH

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Questions?