

Dementia & Developmental Disabilities

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Definitions

- The failure or loss of power (Webster).
- Greek word for “out of mind”.
- The presentation of demonstrable impairment in memory functioning associated with other cognitive or personality changes that interferes with daily activities and social relationships (DSM IV).

Definitions Continued

- **The development of multiple cognitive deficits manifested by both memory impairment and one or more of the following cognitive disturbances:**

Aphasia- language disturbance.

Apraxia- impaired ability to carry out motor activities, despite intact motor function.

Agnosia- failure to recognize or identify objects despite intact sensory functioning.

Disturbance in Executive Functioning- planning, organizing, sequencing, or abstracting.

Facts

- A physical and mental disease (DSM IV Axis I and Axis III).
- Over 30 medical conditions can manifest as dementia and some of these are reversible and treatable.

Prevalence

- 5.7 million U.S. Citizens and that number is expected to triple in the next 50 years.
- 10% of the U.S. Population 65 and above and this number doubles every 5 years after age 60.
- With the exception of Down’s Syndrome, adults with Intellectual Disabilities are at the same risk for Alzheimer’s Disease as adults in the general population , about 6% for persons age 60 and older.

Prevalence Continued

- Individuals with Down’s Syndrome develop Alzheimer’s Disease at alarming rates: 25% by age 40 and 65% by age 60 and above.
- It is estimated that there are 140,000 adults with Intellectual Disabilities affected by dementia.

Common Dementias

- Alzheimer's (50% of all dementias).
- Vascular (30% of all dementias).
- Lewy Body.
- Parkinson's.
- Frontotemporal.
- For a more complete list with descriptions see the attached Alzheimer's Association handout.

Reversible Dementias

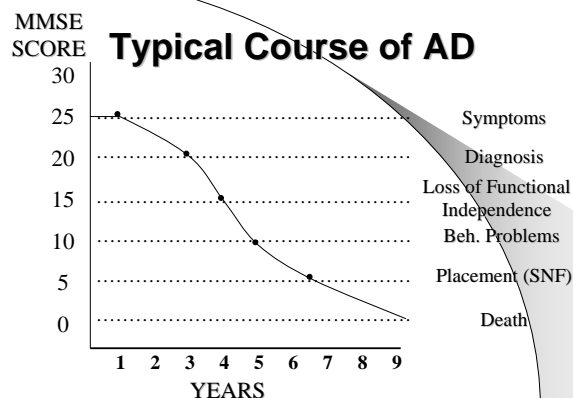
- Depression (Pseudodementia).
- Reactions to medications/street drugs (Delirium).
- Clinical imbalances (e.g., poor nutrition, illnesses such as Pernicious Anemia/vitamin B-12 deficiency, sodium or calcium imbalance, or increased thyroid levels).
- Heart and lung problems that deprive the brain or adequate nutrition or oxygen.

Reversible Dementias-Continued

- Head injuries.
- Exposure to pollution (e.g., lead, mercury, carbon dioxide, some pesticides).
- Chronic Alcoholism.
- Some illnesses like Meningitis.

Diagnosis

- Most frequently made by exclusion.
- Presence and progression of illness is marked by decline in baseline functioning.



Global Deterioration Scale (GDS)

- This scale divides the functional decline of dementia into 7 stages of decreasing ability.
- Why might this be more useful in describing the ID population with dementia?

GDS Continued

Most standardized assessment tools are not normed for use in the DD/ID population. The Mini Mental (Folstein) scores are strongly influenced by age and education level. They rely on ability to read, communicate verbally, draw and follow directions. The baseline score for the individual with DD/ID are skewed lower pre-morbidly.

GDS Continued

- Changes in the individual's functional ability may be the best clue to significant changes and diagnosis for this population.
- Some facilities utilize video tapings of the individual to track significant functional changes.

GDS Continued

Stage 1: No Cognitive Decline

- Experiences no problems in daily living.

GDS Continued

• Stage 2: Very Mild Cognitive Decline

- Forgets names and locations of objects.
- May have trouble finding words.

GDS Continued

• Stage 3: Mild Cognitive Decline

- Has difficulty traveling to new locations.
- Has difficulty handling problems at work.

• Stage 4: Moderate Cognitive Decline

- Has difficulty with complex tasks (Finances, shopping, planning dinner for guests).

GDS Continued

• Stage 5: Moderately Severe Cognitive Decline

- Needs Help to Choose Clothing.
- Needs Prompting to Bathe.

GDS Continued

- **Stage 6: Severe Cognitive Decline**
 - Needs help putting on clothing.
 - Requires assistance bathing and may have a fear of bathing.
 - Has decreased ability to use the toilet or is incontinent.

GDS Continued

- **Stage 7: Very Severe Cognitive Decline**
 - Vocabulary becomes limited, eventually declining to single words.
 - Loses ability to walk and sit.
 - Becomes unable to smile.

GDS Continued

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Typical Problems

- Reduced Communication.
- Paranoia- filling memory voids with scary thoughts.
- Aggressive and/or Agitated Behavior- often because their brain doesn't process information or because they cannot express their needs, feelings, or pain/discomfort.

Treatment/Management Strategies

- Except for the reversible dementias, there is no cure at present time.
- Medications have been effective at slowing the process down and treating side effects.
- Change is extremely disorganizing for people challenged by dementia.
- Be respectful and loving.

Strategies Continued

- Ensure that all basic needs are met.
- Remember that dementia is a physical disease that causes communication problems.
- Be a detective to figure out behaviors and what works today.
- Assess for pain frequently.

Strategies Continued

- Decrease environmental stimulation.
- Re-familiarize resident to you and their environment as needed.
- Keep directions simple-one step at a time.
- Provide consistency in schedule, activities, and sequence.

Strategies Continued

- Provide lots of positive feedback and genuine praise.
- Be gentle, not forceful.
- Provide reassurance, this can be a scary reality.

Communication Strategies

- Be aware of your verbal and nonverbal messages.
- Kindness and friendliness are essential.
- Greet your residents.
- Provide lots of reassurance.
- Validate feelings.
- Increase environmental information and cues (memory boxes, familiar items, calendar).

Communication Continued

- Minimize the confusion of environmental changes.
- Speak slowly, calmly and with a deeper voice.
- Avoid shouting.

Communication Continued

- Avoid repeating words unnecessarily.
- Unless the person is blind, speak primarily when you can be seen.
- Approach the person from the front.
- Ask “yes-no” questions.
- Avoid the stress of pressing the person to remember something.
- Find different ways to ask questions (2-choices).
- Don’t argue or talk down to the resident.

Communication Continued

- Use the person’s name and remind them of your name.
- Orient the person to the next shift member’s name.
- If you are allowed to wear a nametag or pin, wear one that older eyes can actually read.
- Use humor and be willing to laugh with the person.

Communication Continued

- Be empathic-remember they are probably trying their best to deal with a horrible illness.
- Keep things simple.
- Remember- the person you are entrusted to care for could be you or someone you love someday.

Strategies For Providing Care

- Personal care involves close contact...we don't always know the person's history of trauma. Trust is a gift to be earned.
- Know the resident and their routines including ADL sequence, rate, and current abilities as they change.

Providing Care Continued

- Try to identify the best time for care.
- Consider the prudent use of medications before care is given.
- Give one-step directions in a sequence.

Providing Care Continued

- Pause before the person becomes agitated so that things end on as good a note as possible.
- Be empathic and prepare the resident if something is going to hurt. Ask them if they are ready.
- Use praise and thank the person for their cooperation.
- Use "elbow check range" awareness.
- Allow independence by placing warm washcloths and towels within the person's reach for their use.

Environmental Triggers To Behavior Problems

- Loud startling noises (door slams, overhead pages, loud cell phones, and raised voices).
- Confusing sounds (talking on a cell phone when the resident thinks you are talking or caring for them, and unusual cell phone ring tones).
- Overcrowded conditions can be scary.

Environmental Triggers Continued

- Bright lights being turned on in the middle of the night.
- Wheelchair or walker bumping cars.
- Not being prompted, or being left out of something the person likes.
- Close physical proximity.

Environmental Triggers Continued

- Unfriendly facial expressions and/or voices.
- Staff not approaching from the front or from where they are looking.
- Personal care without an announcement.
- Rapid movements.
- Staff speaking a foreign language.
- Poor lighting.

Be Aware Of Behavioral Cues That Signal Difficulties

● Verbal cues include:

- Change in volume of speech.
- Tone of voice.
- Word choice.
- Threats.

Behavioral Cues Continued

● Nonverbal cues include:

- Hand movements.
- Arm flapping.
- Nonsense vocalizations (change).
- Pacing and/or rocking.
- Wandering.
- Repetitive movements.
- Withdrawal or isolation.
- Attempts to stand/walk, if unable

Dealing With Noncompliance

● Use Therapeutic Directives

- *Be polite, firm and friendly when making requests
- *Be in a face-to-face position
- *Use the person's name then 3-5 words with gestures (model) to make a request

Noncompliance Continued

- *Allow 5-10 seconds then prompt again
- *Praise or express appreciation for small steps towards cooperation
- If this fails...

Wait...Then Use Behavioral Momentum

- Identify 2-3 things the person will do.
- Request the most likely one and thank them.
- Request the second one and thank them.
- Request the third and thank them.
- Then...request the target behavior and thank them.
- If this fails...

Try Successive Approximation

- Identify target behavior.
- Reinforce/praise tiny steps in the direction of the targeted behavior.
- Reinforce/praise a slightly larger step towards the targeted behavior.
- Repeat...
- If this succeeds...thank them for being helpful.
- If this fails...

Remember...

- Not all things are going to work all of the time.
- Sometimes we need to back off and re-approach the person later or have a different care giver try.
- Brainstorm with coworkers and be sure to share tribal knowledge with other staff.

Activities

- What does the person like to do? (Ask family and friends).
- Of short duration. End activity before the person becomes bored or tired.
- Familiar (sorting, folding, coloring, busy box).
- Repetitive.
- Individualized.
- Small groups based on functional level.
- Stable schedules and routines.

Activities Continued

- Flexible participation.
- Use of appropriate sensory activities.
- Limit stimulation.
- Consider a “snoozling room ” (calm, meditation room with aromatherapy).
- Errorless content.
- Broad base of participants.

Thank You for Attending!

Enjoy the conference!