# AGING, DEMENTIA, AND INTELLECTUAL/DEVELOPMENTAL DISABILITIES

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# WHAT IS DEMENTIA?

**According to the Alzheimer's Association in 2014:**

- **Dementia is not a specific disease.**
- **It is an overall term that describes a wide range of symptoms that are associated with a decline in memory and thinking skills.**
- **It can become severe enough to interfere with a person's ability to perform every day activities.**

# HOW DO WE CLINICALLY DEFINE DEMENTIA?

**Dementia is defined in the *Diagnostic and Statistical Manual of Mental Disorders*-Fifth Edition (DSM-5) as "Evidence of a significant decline from the previous level of performance in one or more cognitive domains."**

**The cognitive domains include:**

- **Attention**
- **Executive functioning with planning, judgment, and self-monitoring**
- **Learning and memory**
- **Language**
- **Motor skills**
- **Socialization**
- **Self-care**

# HOW DO FAMILIES AND CAREGIVERS DEFINE DEMENTIA?

**“A living death”**

**“You are living in the past, forget the present, and there is no future”**

**Training and preparedness are key factors for caregivers as they face the complex challenges involved in caring for someone who has been diagnosed with dementia.**

# DEMOGRAPHICS

**National researchers offer the following estimates about Down syndrome and dementia:**

**22% for adults 40 to 60 years of age**

**56% for adults 60 years of age and older**

# WHAT IS THE RELATIONSHIP BETWEEN DEMENTIA AND INTELLECTUAL DISABILITY?

- **Longevity has increased for all individuals including those diagnosed with an intellectual disability (ID). As greater numbers of people are surviving into older age, there is a higher risk of developing dementia.**

- **This is uniquely true for those diagnosed with certain disorders, such as Down syndrome. These individuals have a four times higher risk of developing Alzheimer's disease due to genetic factors.**

# ASSESSMENT OF DEMENTIA IN INTELLECTUAL DISABILITY

- Assessment of dementia in the context of an intellectual disability (ID) is complex because of the many explanations that can account for cognitive deficits and decline.
- These include pre-existing intellectual difficulties, physical illnesses, and co-occurring mental health issues that can masquerade as dementia.
- As a result, dementia may progress before the initial diagnosis is made.

# ASSESSMENT OF DEMENTIA IN INTELLECTUAL DISABILITY

- **There is no consensus about the optimal test battery to use in detecting dementia in persons with an intellectual disability (ID).**
- **We must understand that the diagnosis of dementia is a *process* of recognizing and accounting for the decline from the individual's previous or *baseline* level of functioning.**
- **This underscores the importance of establishing an individual's capabilities well before the onset of any possible changes.**

# THE DIFFERENCE BETWEEN FORGETFULNESS AND DEMENTIA

According to national research,

<u>individuals with age-related memory problems</u>:

- Forget parts of experiences
- Often remember parts of the experiences later
- Can usually follow directions and care for themselves

whereas, <u>individuals with dementia:</u>

- Forget the whole experience
- Rarely remember it later
- Are eventually unable to follow directions or care for themselves

# THE DIFFERENCE BETWEEN DEPRESSION AND DEMENTIA

**According to the American Medical Association,**

**<u>With Depression:</u>**

- **Onset takes weeks to months**
- **Mood is low or apathetic**
- **The illness responds to treatment**
- **The individual is concerned with their memory loss**
- **The individual may neglect self-care**

# THE DIFFERENCE BETWEEN DEPRESSION AND DEMENTIA

**According to the American Medical Association,**

**<u>With Dementia:</u>**

- **Onset takes months to years**
- **Mood fluctuates**
- **Course of the disease is chronic and deteriorates over time**
- **The individual may hide their memory loss or be unaware of it**
- **Self-care progressively worsens**

# DSM-5 DEFINITION OF NEUROCOGNITIVE DISORDERS (NCD)

- Neurocognitive disorders are clusters of signs and symptoms where the underlying cause might be one of the following conditions:
  - Delirium
  - Dementia
  - Amnesia
  - Traumatic brain injury
- NCD is the preferred terminology used by younger practitioners. The term dementia may be retained for continuity by patients and practitioners who are accustomed to it.

# TWO NCD CATEGORIES

1. **Minor Cognitive Impairments:**

- Mild memory problems that do not interfere with everyday activities
- Individuals who are often *aware* of their forgetfulness
- Minor cognitive impairments that may not necessarily progress to dementia

2. **Major Cognitive Impairments or Dementia:**

- Significant problems with memory that interfere with everyday activities
- Individuals are often *not aware* of their forgetfulness
- This category progressively worsens

# DSM-5 DEMENTIA CLASSIFICATIONS

**Types of Major Neurocognitive Disorders:**

- **Alzheimer's**
- **Vascular**
- **Lewy body**
- **Frontotemporal**
- **Hydrocephalus**
- **Traumatic brain injury**
- **Substance/medication-induced**
- **Prion (transmittable disease)**
- **Parkinson's & Huntington's disease**
- **Multiple etiologies**

- ***Cortical or Subcortical***
- ***Common or Rare***

# DEMENTIA OF THE ALZHEIMER'S TYPE

- It occurs when biochemical problems inside the brain cells form abnormal proteins called amyloid plaques and neurofibrillary tangles.
- Alzheimer's is the most common cause of dementia. It accounts for more than 65% of dementias in the elderly.
- It is twice as common in women because they have a longer life expectancy.
- In the early stages, individuals with Alzheimer's disease are often better groomed and neater than those with other types of dementia.

# OTHER TYPES OF DEMENTIA

# VASCULAR

- Also known as multi-infarct dementia.  It is a cognitive deterioration related to cerebrovascular disease.
- Risk factors include strokes, heart disease, high blood pressure, diabetes, high cholesterol, and smoking.
- Both vascular dementia and Alzheimer's dementia can occur together.
- The decline in vascular dementia may be gradual. It can have a "patchy" or fluctuating course that can be frustrating to caregivers and treatment providers.
- Vascular issues are the second most common cause of dementia among the elderly, especially in men after the age of 70 years old.

# LEWY BODY

- Cognitive deterioration due to changes in the upper parts of the brain.
- Signs and symptoms may include:
  - Sleep disturbances
  - Psychosis (e.g., Hallucinations and Delusions)
  - Slowed movements, rigidity, and tremors
  - Gait imbalance
  - Visual-Spatial problems
  - Short-term memory may be preserved
- Lewy Body is the third most common dementia. The age of onset is typically after 60 years old.

# FRONTOTEMPORAL
## (FORMERLY PICK'S DISEASE)

- A hereditary disorder that affects the frontal and temporal lobes of the brain.
- It brings about marked changes in personality.
- Behaviors often become disinhibited and repetitive.
- May affect the ability to produce and comprehend language.
- Age of onset is typically younger between 55 to 65 years.
- Frontotemporal accounts for up to 10% of dementias

# MIXED DEMENTIA

- It is characterized by the abnormalities associated with more than one type of dementia.

- The most common mixed dementia is Alzheimer's and Vascular.

# DEMENTIA ASSOCIATED WITH TRAUMATIC BRAIN INJURY (TBI)

- Common characteristics include:
  - Difficulties remembering or learning new information
  - Poor attention and concentration
  - Problems organizing thoughts and planning activities

- Causes of head trauma may include:
  - Falls
  - Motor vehicle accidents
  - Self-injurious behaviors (SIB)

# HYDROCEPHALUS

- It is characterized by:
  - Gait disturbances (e.g., unsteady balance)
  - Memory loss
  - Urinary incontinence
  - Enlarged brain ventricles

- Interventions:
  - Surgical placement of a shunt

- Hydrocephalus accounts for 6% of dementia cases

# OTHER DEMENTIAS

- **Dementia related to Parkinson's Disease:**
  - **Characterized by slowness, rigidity, and tremors**

- **Korsakoff's syndrome:**
  - **Appears as problems learning new information, an inability to remember recent events, and gaps in long-term memory.**
  - **Thinking and social skills may be fairly unaffected**
  - **It is caused by a deficiency in vitamin B-1 from alcohol abuse, AIDS, chronic infections, or poor nutrition.**

# THE GENERAL CAUSES,

# RISK FACTORS,

# AND SIGNS AND SYMPTOMS

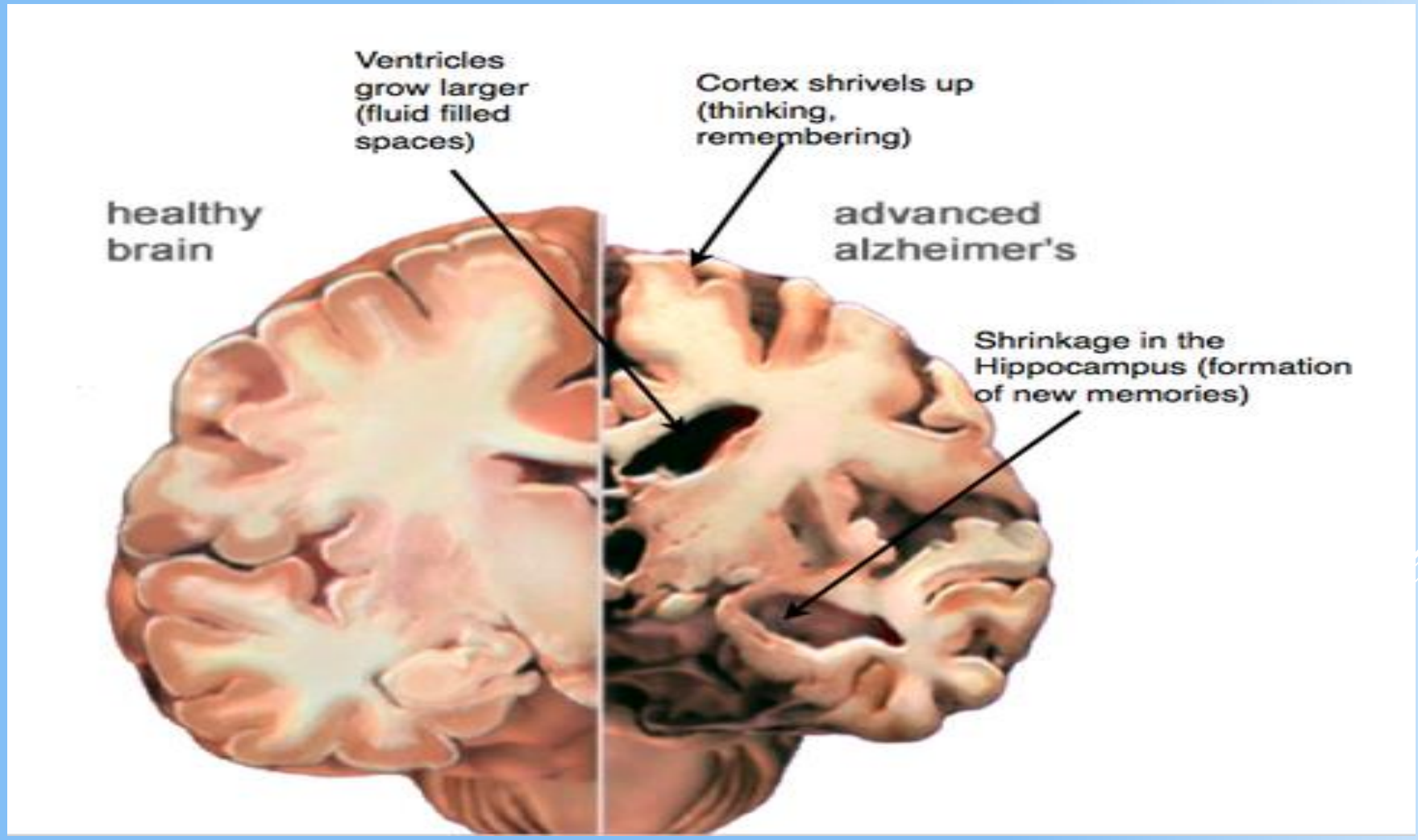
# OF DEMENTIA

# WHAT CAUSES DEMENTIA?

- **We have no reliable means of determining the etiology or specific cause for the various types of dementia.**

- **Although we have seen advances in medical science and technology, such as neuroimaging, the best confirmation of dementia remains an autopsy.**

# HEALTHY VIEW OF THE BRAIN
## (ALZ.ORG/BRAIN TOUR, 2014)



# RISK FACTORS FOR DEMENTIA

- Advancing age
- Diagnosis of Down syndrome
- Family history of dementia in first-degree relatives
- Traumatic brain injury and repeated head trauma
- Sleep disorders
- Thyroid disease
- Metabolic syndromes (e.g., obesity, diabetes, hypertension)
- Exposure to toxins (e.g., lead, aluminum, mercury)

# SIGNS & SYMPTOMS OF DEMENTIA FOR INDIVIDUALS DIAGNOSED WITH DOWN SYNDROME

- Loss of daily living skills is the hallmark feature
- Difficulty learning and retaining information
- Onset of seizures or an increase in seizure activity
- Urinary incontinence
- Return of early developmental reflexes

# DIAGNOSING DEMENTIA

# DEMENTIA SCREENING IN THE I/DD POPULATION

- **Always start with a comprehensive physical exam:**
  - **Blood work for thyroid and vitamin deficiencies**
  - **Review of medications for adverse side effects and negative drug interactions**
  - **Screens for infections**
  - **Vision and hearing checks**
  - **Bone density scans**
- **The cornerstone of dementia diagnosis is thoroughly comparing the past and present history of functioning to identify any areas of decline.**

# DEMENTIA SCREENING IN THE I/DD POPULATION

- **Completion of Psychological Assessments:**
  - IQ tests
  - Memory screens
  - Adaptive behavior measures
  - Specialized dementia scales based on caregiver interviews

- **Consultation:**
  - Testing completed by a neuropsychologist or gerontologist

# STAGES OF DEMENTIA

# PLEASE REMEMBER

- People may differ in the speed at which their abilities deteriorate. Some individuals with dementia may change from day-to-day, while others may decline slowly over a number of years.

- It is also important to remember that not all features of dementia will be present in every person, nor will every individual go through every stage.

- Caregivers often benefit from education and guidance about the challenges and changes that can be expected at each stage.

# EARLY STAGE OF DEMENTIA

## 2-4 Years

***This stage often becomes apparent in hindsight. The early signs of dementia may be subtle. It may be impossible to identify the exact time that it began.***

- Apathy and depression
- Problems with word finding and remembering names
- Loss of interest in hobbies or activities
- Unwillingness to try new things
- Difficulty adjusting to change
- Indecisiveness
- Taking longer with routine jobs
- Forgetfulness about details of recent events
- Repeating statements
- Responding to the loss of independence with agitation, irritability, or hostility

# MIDDLE STAGE OF DEMENTIA
## 2-10 YEARS

***Problems become more apparent and disabling.***

- **Very forgetful about recent events**
- **Confusing one family member with another**
- **Forgetting the names of friends**
- **Getting easily disoriented**
- **Missing social and environmental cues**
- **Tendency to get lost in familiar surroundings**
- **Substantial increase in falls and accidents**
- **Becoming easily distressed when frustrated**
- **Restlessness or aggression due to confusion, particularly in the evening (*Sundowning Effect*)**
- **Sleep patterns becoming disorganized**

# LATE STAGE OF DEMENTIA
## 1-3 YEARS

***During this end stage the individual requires total care.***

- **Inability to remember information, even for a few minutes**
- **Loss of speech and language (expressive and receptive)**
- **Immobility**
- **Incontinence**
- **Inability to recognize friends and family members**
- **Unable to recognize everyday household objects**
- **Vulnerable to medical complications**
- **Often results in coma and death**

# CAREGIVING TIPS,

# TYPES OF INTERVENTIONS,

# AND

# IDEAS FOR PREVENTION

# CAREGIVING TIPS

- **Be realistic with expectations for yourself and the individual**
- **Take a breaks as needed**
- **Eat well and exercise**
- **Accept that as the disease progresses, changes can occur daily and then hourly**
- **Get support from groups, helplines, family, friends, and other staff members in your work environment**
- **Don't be afraid to *ask for help!***

# INTERVENTIONS
## MEDICATIONS

**There are currently two types of anti-dementia medications:**

**1. Actelycholinesterase inhibitors are prescribed for mild-to-moderate symptoms. They are intended to *preserve* functioning or delay worsening. These include Cognex, Aricept, and Exelon.**

**2. Other medications that regulate glutamate can be prescribed to treat moderate-to-severe symptoms. For example, the medication Namenda.**

# INTERVENTIONS
## MEDICATIONS

### Considerations about Anti-Dementia Medications:

- Early diagnosis and prescribing are key. Unfortunately, dementia is typically not detected until the late stage for individuals with severe-to-profound I/DD.
- The effects of anti-dementia medications have not been thoroughly researched in the I/DD population.
- Individuals with I/DD often metabolize medications differently, which can decrease the effectiveness of anti-dementia medications.

# POSITIVE BEHAVIOR STRATEGIES TO ASSIST THOSE DIAGNOSED WITH DEMENTIA

*NON-PHARMACOLOGIC APPROACHES*

**Maintain a structured routine even on weekends and holidays.**

**Use consistent words and phrases for familiarity.**

**Regularly engage the individual in low stress activities.**

**Speak softly, slowly, and clearly.**

**Use simple sentences with only one-to-two steps when giving instructions.**

# POSITIVE BEHAVIOR STRATEGIES TO ASSIST THOSE DIAGNOSED WITH DEMENTIA

## *NON-PHARMACOLOGIC APPROACHES*

**Rooms should be reasonably bright.**

**The environment should contain sensory stimuli to reinforce orientation (e.g., holiday decorations).**

**Avoid abrupt changes in the environment and routine.**

**Frequently use soothing and reassuring words.**

**Ask others to provide the same style of guidance because it may increase cooperation.**

# POSITIVE BEHAVIOR STRATEGIES TO ASSIST THOSE DIAGNOSED WITH DEMENTIA

## *NON-PHARMACOLOGIC APPROACHES*

**Always tell the individual what your are doing before starting a task or activity.**

**Use gradual steps when trying to teach something new.**

**Building and maintaining skills is best done in the morning.**

**Redirect with distractions and substitutions.**

**Be flexible and accommodating.**

# PREVENTION

***It is impossible to stop the aging process. But, there are many things that improve health as one ages. For instance:***

**Eating well: Meet with a dietitian to learn healthy food choices.**

**Exercising: Have a doctor or physical therapist create an exercise program.**

**Keeping the mind active: Participate in activities that encourage thinking.**

**Seeing a physician for regular check-ups and special screenings.**

THIS CONCLUDES OUR TRAINING.

IF YOU HAVE SPECIFIC QUESTIONS REGARDING THE DDS INDIVIDUALS THAT YOU SERVE, PLEASE CONTACT PSYCHOLOGY STAFF, NURSE CONSULTANTS, OR CASE MANAGERS.

FOR ADDITIONAL RESOURCES, PLEASE REFER TO THE LINKS PROVIDED ON THE DDS WEBSITE.

WE APPRECIATE YOUR PARTICIPATION!