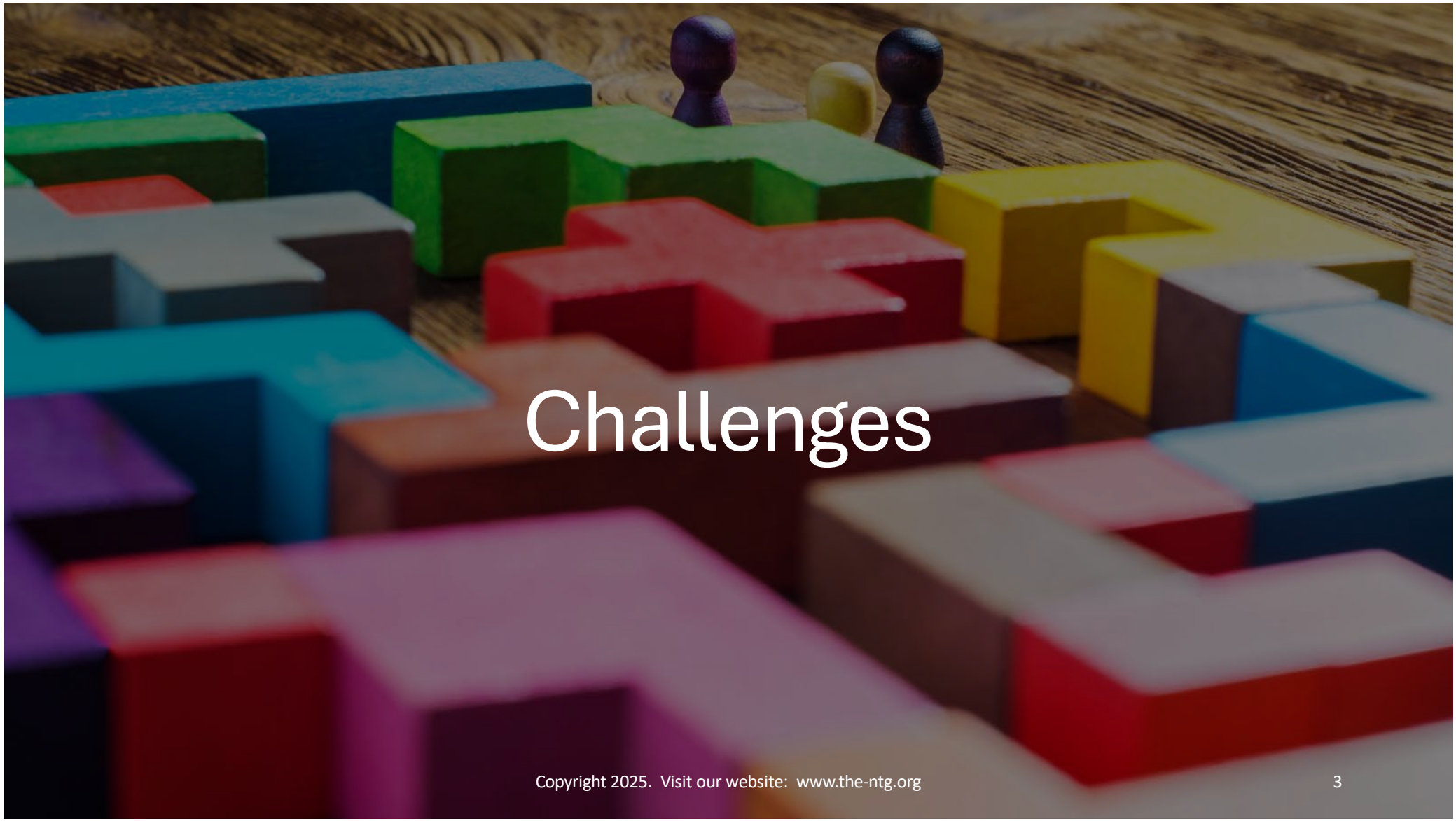
National Task Group on Intellectual Disabilities and Dementia Practices

Presented by
Kathryn G. Pears, MPPM

The 3 D's

Depression, Delirium & Dementia…Identifying the causes of change in function

Supported in part by grant No. 90ADPI0108-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. The grant was awarded to Catholic Charities Hawaii for the Alzheimer's Disease Programs Initiative.



Challenges to identifying change in function

- Diagnostic overshadowing – Attributing symptoms to the underlying disability (and overlooking potentially new causes)
- Few specialized health care practitioners
- Myth that 100% of people with Down syndrome will develop Alzheimer's
- Failure to do a "differential diagnosis"
  - Medications
  - Potentially treatable conditions (B12 deficiency, kidney/liver, hypothyroidism, hearing/vision, Lyme disease, etc.)

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Depression

Depression and Aging with a Disability

- Although adults with IDD are at high risk for depression as they age, depression is not a normal part of aging.
- Some people are ashamed to admit they are depressed because they see it as a sign of weakness or a character flaw
- Older adults tend to report more physical symptoms of depression such as difficulty sleeping and loss of appetite than younger adults
- When older adults lose their social supports and become isolated, they may be less likely to independently seek help for depression
- Depression is a treatable medical condition

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Symptoms of Major Depression

"SIG-E-CAPS"

- **S**leep disturbance (insomnia or hypersomnia)
- **I**nterests (anhedonia or loss of interest in usually pleasurable activities)
- **G**uilt and/or low self-esteem
- **E**nergy loss of energy, low energy, or fatigue)
- **C**oncentration (poor concentration, forgetfulness)
- **A**ppetite changes (loss of appetite or increased appetite)
- **P**sychomotor changes (agitation or slowing/retardation)
- **S**uicide (morbid or suicidal ideation)

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Comparing Depression & Dementia

Comparing Dementia & Depression		
	Depression	**Dementia**
Onset	Rapid or slow	Progressive, develops overs several years
Cause	Alteration in neurotransmitter function	Progressive brain damage
Duration	Months, can be chronic	Years to decades
Course	Usually recover within months; can be relapsing	Not reversible, ultimately fatal
Level of consciousness	Normal or slowed	Normal
Orientation	Usually intact	Correct in mild cases; first loses orientation to time, then place and person
Thinking	Distorted, pessimistic	Impaired, impoverished
Attention	Difficulty concentrating	Usually intact
Awareness	Diminished	Alert during the day; may be hyperalert
Sleep/waking	Hyper or hypo somnolence	Normal for age; cycle disrupted as the disease progresses

Slide courtesy of Lucille Esralew, Ph.D.

Depression or Dementia?

- Decline is faster with depression. Dementia is slow and insidious.
- People with depression are not usually disoriented, whereas people with dementia may be.
- People with depression have difficulty concentrating, whereas those affected by dementia, especially Alzheimer's disease, have problems with short-term memory.
- Writing, speaking, and motor skills aren't usually impaired in depression.
- *Depressed people are more likely to notice and comment on their memory problems, while those with Alzheimer's may seem indifferent or unaware of such changes.*

Slide courtesy of Lucille Esralew, Ph.D.

Just to further complicate matters…

- Depression tends to show an up-and-down pattern of decline that, with time and treatment, will show improvement and an eventual return to pre-morbid levels of functioning.
- Symptoms of Alzheimer's dementia tend to fluctuate in the early stages, but over time will show a progressive and nonreversible pattern of decline.
- Depression may co-occur with Alzheimer's dementia.
- When this is the case, prompt treatment of depression may preserve functioning for some time, even though a downhill course may be inevitable.
- The following symptoms can be seen in both depression and Alzheimer's dementia: loss of adaptive skills, disruption of sleep cycle, appetite change.

Slide courtesy of Lucille Esralew, Ph.D.

Delirium

Delirium or Dementia?

- Delirium and dementia are **not the same thing**.
- Delirium involves **“waxing and waning” symptoms**, meaning they get better and worse.
- Delirium often occurs in people with dementia, but episodes of delirium **don't always mean a person has dementia**.
- Confusion from delirium comes on much **faster** than dementia and is often temporary.

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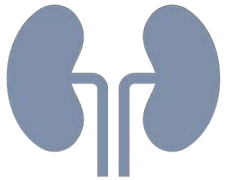
Delirium is a Medical Emergency

- Hyperactive, hypoactive, mixed
- Serious change in mental abilities
  - disorientation
  - confusion
  - communication difficulties
  - agitation
- Comes on fast (hours, days)
- Potential causes
  - Urinary tract infection, fecal impaction, pneumonia
    - Chest x-ray, complete blood count (CBC), urinalysis (with culture and sensitivity)
  - Think broadly…gallbladder, kidney stone, sepsis, medications, kidney/liver problems, dehydration

Main Points About Delirium

Symptoms of delirium are sometimes confused with symptoms of dementia but come on **suddenly** and are generally caused by an **underlying medical condition**.

Delirium is a **medical emergency**.



Although urinary tract infections are a very common cause, if **urinalysis is negative…keep looking!**

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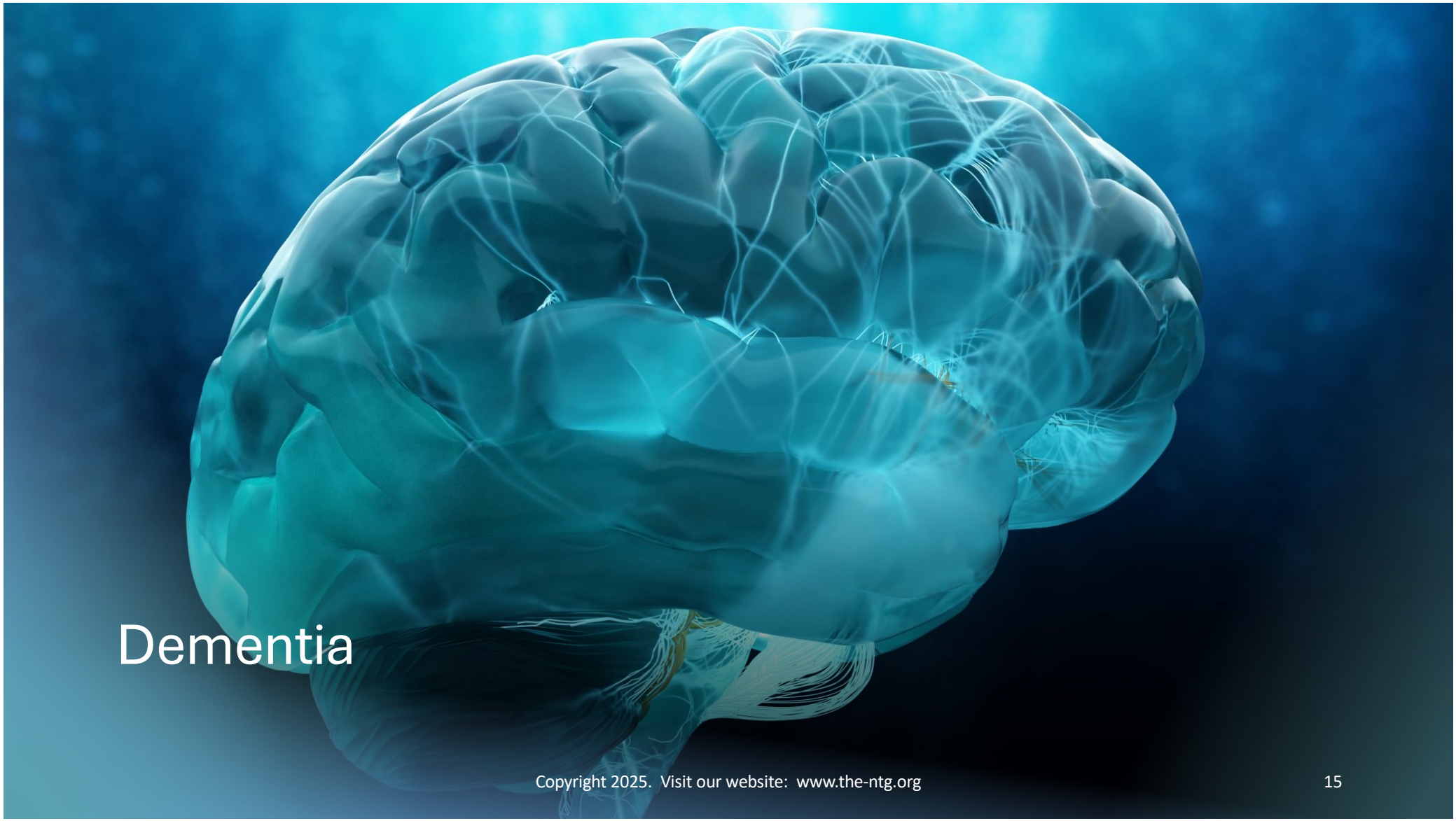

Dementia

What is Dementia?

- Is not a disease, an umbrella term to describe a group of symptoms
- Dementia refers to a **steady decline** in thinking ability and is a **permanent** condition that **worsens over time**
- Progressive damage and **loss of nerve cells in the brain**
- When **brain cells are damaged, they can't function and communicate** properly. This causes the symptoms of dementia
- **Irreversible causes** (ex. Alzheimer's disease, Lewy body, vascular, Frontotemporal)
- **Potentially treatable** (metabolic conditions, hearing/vision, medication-related, Lyme disease)

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Symptoms of Dementia

- Memory problems (non-Down syndrome)
  - recent events
  - older memories and events
  - names of familiar people and places
- Getting lost in familiar locations
- Impulsive, emotional
- Personality changes, loss of interest in previously enjoyed activities
- General confusion
- Loss of problem-solving skills
- Difficulty completing self-care tasks
- Loss of verbal skills
- Anxiety, agitation
- Seizures (Down syndrome)

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Risk for Adults with IDD

- **Down syndrome:** Increased risk specifically for Alzheimer's disease
  - Extra copy of chromosome 21
    - Carries a gene that produces a specific protein called amyloid precursor protein (APP). Too much APP protein leads to a buildup of protein clumps called beta-amyloid plaques in the brain. The presence of beta-amyloid plaques is one of the hallmarks of Alzheimer's disease.
  - Most will have *pathology* by age 40
  - That does not mean all will develop Alzheimer's disease
    - Estimates suggest that 50% or more of people with Down syndrome will develop dementia due to Alzheimer's disease as they age. (National Institute of Health)
- **IDD other than Down syndrome:** Thought to be the same as general population, but little research

Treatments

Medications: No good evidence these medications are effective for people with Down syndrome specifically. May have some benefit in IDD other than Down syndrome

- Aricept (donepezil), etc.
- Namenda (memantime)

Newly FDA approved treatments: Adults with IDD were not included in clinical trials

- Donanemab, Leqembi

Nonpharmacologic interventions vs. medication for behaviors

- Common causes of behavior: Environment, pain, caregiver interaction, asking more than can do, stress/anxiety/confusion, communication impairment
- Antipsychotics are a last resort. Start low and go slow.

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Main Points About Dementia

Degenerative condition and gets worse over time

Symptoms start out mild and get more severe as the condition progresses

Adults with Down syndrome have an increased risk, but not all will develop the symptoms

Individuals with Down syndrome were not included in clinical trials for newly approved treatments. Little good evidence that donepezil is effective for people with Down syndrome.

Antipsychotics should be a last resort after nonpharmacologic interventions have been tried

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Aging with Intellectual and Developmental Disabilities (IDD): How to Tell the Difference between Depression, Delirium, or Dementia: Recommended Assessment and Treatment

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Tips for telling the difference and what you can do

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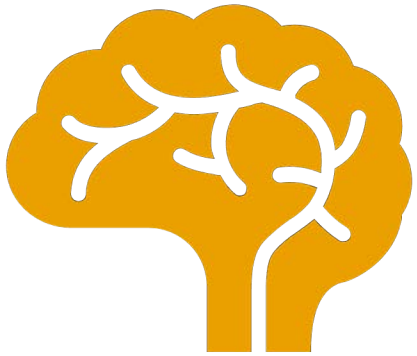
Brief Summary of Dementia, Delirium, and Depression



- **Dementia** –
- Many different types and causes for the symptoms of dementia
- Many types like Alzheimer's disease are regressive over relatively long periods of time with some exceptions like vascular dementia from a stroke
- Other underlying causes for decline may occur concurrently with a diagnosed dementia including Delirium and Depression
- **Delirium –**
- Rapid decline and changes in behavior usually due to a traumatic event such as hospitalization, surgery, and anesthetics. Treatable.
- **Depression –**
- Significant changes in behavior and function that may appear as withdrawal and confusion, Usually temporary if treated and may occur with multiple losses

Brief Summary of Differential Diagnosis

- **<u>Ruling out of underlying possible causes for decline and changes in function and behavior including</u>** –
  - Past medical conditions and diseases
  - Family medical history when available and appropriate
  - Common causes for decline in adults with IDD even if not part of past medical history
  - Worsening of pre-existing conditions and impairments such as visual and sensory.
  - Unwanted Side Effects of Medications and complete pharmaceutical review
  - Mental health and previous mental illness conditions including depression

Differential Diagnosis and your family member

- Family members and caregivers don't conduct a Differential Diagnosis, but should know what it is:
    1. An essential process for determining underlying causes for decline in function and change in behavior, including a type of dementia.
    2. Conducted by health care providers with information from medical records and family/staff/advocates who know the person.
    3. Multiple appointments and follow-up.
    4. Ideally with informed health care advocates who work in partnership with health care providers.

Differential Diagnosis:

The current function and behavior should always be compared to the individual over a lifetime and not to others in the general population or others with intellectual and developmental disability.

It is helpful for health care advocates (family, caregivers, others) to have information of the individual over a lifetime and to be able to identify changes in behavior and function.

The differential diagnosis is conducted by health care providers with information provided by the individual and those who know the individual including family.

It is conducted over a period of time including specialists and multiple appointments,, rarely in one appointment .

What can you do to help with a differential diagnosis?

Develop a working relationship, partnership with your health care providers.

If your family member is in a group home and/or a day program, talk with case managers, care staff, or others for assistance with health care appointments.

Ask for help from other family members to prepare for the appointment and attend the appointment with you.

Gather documentation for you and your family such as diagnosis of IDD, previous medical conditions, school or programs attended.

Photo albums, written life stories (templates available online, at least annual videoing.

Clues to Observing Symptoms of changes in function and behavior

A. Underlying causes can best be determined by

1. Monitoring changes not observed previously
2. Changes in function compared to lifelong functioning
    1. Previous learned skills and knowledge such as no longer performing Activities of Daily Living (ADLs) like showering.
    2. Ignoring or refusing to participate in usual interests.
    3. Activity and energy level increasing or decreasing significantly
3. Changes in behavior such as
    1. Interest and willingness to participate in activities

Steps of Health Care Advocacy for Family and Caregivers:

Observation of changes in function and behavior,

Prepare of and take documentation to appointment, such as tools like the EDSD,

Follow-up after the appointment,

Preparing for additional appointments as needed,

Communicating with other caregivers such as agency staff.

Why are life stories essential to differential diagnosis?


Helping health care providers understand the person over the lifetime and current changes is essential.

Capturing Life Stories Through Essence using documentation, photos, and/or videos:

1. **Shared moments of happiness and contentment through written material, photos, and/or videos.**
    1. **How were the emotions expressed?**
    2. **Multiple means of collecting**
2. **Causes for pain, fear, anxiety, and unhappiness?**
    - **a. How is anxiety expressed?**
    - **b. Ways to calm?**
    - **c. Calming physical and social environments?**

Understanding and documenting essence through Lifestories

Essential clues to determine possible underlying causes are established through access to baseline function, lifelong data, and understanding the essence of each adult.

Baseline information for diagnosis and quality of care.

Vocabulary.com defines essence as "whatever most sums up the heart and soul of something, the truest most indispensable qualities."


Essence – Knowing who is important and valued shared activities

Additional Suggestions to Capture Life Stories:

1. ***Favorite pets, relatives, neighbors, and school friends?***
2. ***Look at photos together of favorite places to visit, the former home, or activities.***
3. ***Photograph individuals enjoying favorite foods, clothing, favorite places or events and personal objects.***
4. ***Note favorite teams and sports activities. Are there favorite items associated with these favorites like a shirt or jacket he/she likes to wear?***
5. ***Favorite songs, musicals, and dance?***
6. ***Favorite holidays and celebrations? How were they celebrated? Old photos or videos of past holidays can help caregivers provide holidays that are fun and less stressful for everyone.***

Is it depression, delirium, or dementia?

Albert's Story

Albert

A 58 Years old man with Down syndrome living with his two aunts in their very large family home.

Referred for consult as refusing to attend his workshop program and weekend usual activities.

Because of pre-existing diagnosis of Down Syndrome assumed to have Alzheimer’s disease.

Information to gather:

Is this a change in behavior?

Why is Albert living with his aunts?

What is his recent history?

Previous history of refusal and mental illness?

Previous history of underlying conditions?

Any recent medical conditions or hospitalizations?

When you have some of the answers which is most likely; depression, delirium, or Dementia?

Dottie – 60 Years Old female with Down Syndrome and suspected dementia

- *Primary reasons for caregivers and health care providers believing she might have dementia was due to loss in weight,*
- *lack of interest in usual foods, refusal to eat*
- *extreme confusion in finding her way in familiar areas,*
- *and inability to conduct activities compared to her usual level of capability.*

- *Depression, Delirium, or Dementia? A Combination? Other possibilities?*

Questions asked and answered about Dottie:

- *After meetings and interviews it was determined from her past and recent history,*
  - *Dottie had exhibited similar symptoms in the past year, she was diagnosed with upper GI pain which occurred most often after meals and at night.*
  - *Dottie wasn't sleeping at night.*
  - *Dottie's mother had been recently placed in assistive living because of "late stages of Alzheimer's disease" and inability to care for her own needs.*
  - *Dottie's mother usually visited her day program daily to bring her favorite lunch. Dottie didn't understand why her mother was not visiting.*

What should be done next?

Is it likely depression, delirium, or dementia?

Do we know enough to make that decision?

Could it be a combination?

Is there enough information to conclude Alzheimer's disease?

Remember how important your information is to a differential diagnosis!

KNOWING UNIQUE INFORMATION ABOUT YOUR LOVED ONE.

PROVIDING CLUES TO ASSIST WITH YOUR HEALTH CARE PROVIDERS RECOMMENDATIONS AND DIAGNOSTIC DECISIONS

FOLLOW-UP AND CONTINUED DETERMINATION TO SEEK ANSWERS, MAKE A DIFFERENCE IN QUALITY OF LIFE AND HEALTH.

Questions and Answers?

Thank you for attending today's webinar!

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Resources

Bishop et al (February 2015), Guidelines for Dementia-Related Health Advocacy for Adults With Intellectual Disability and Dementia: National Task Group on Intellectual Disabilities and Dementia

HELEN's **March 2025 issue** features engaging articles, **Dementia Capable Care, IDD, and The Importance of Essence** By Kathleen M. Bishop, Ph.D.

Shih-Yin Lin &Frances Marcus Lewis (February 2015). Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future. Gerontologist, 55(2):237–244.

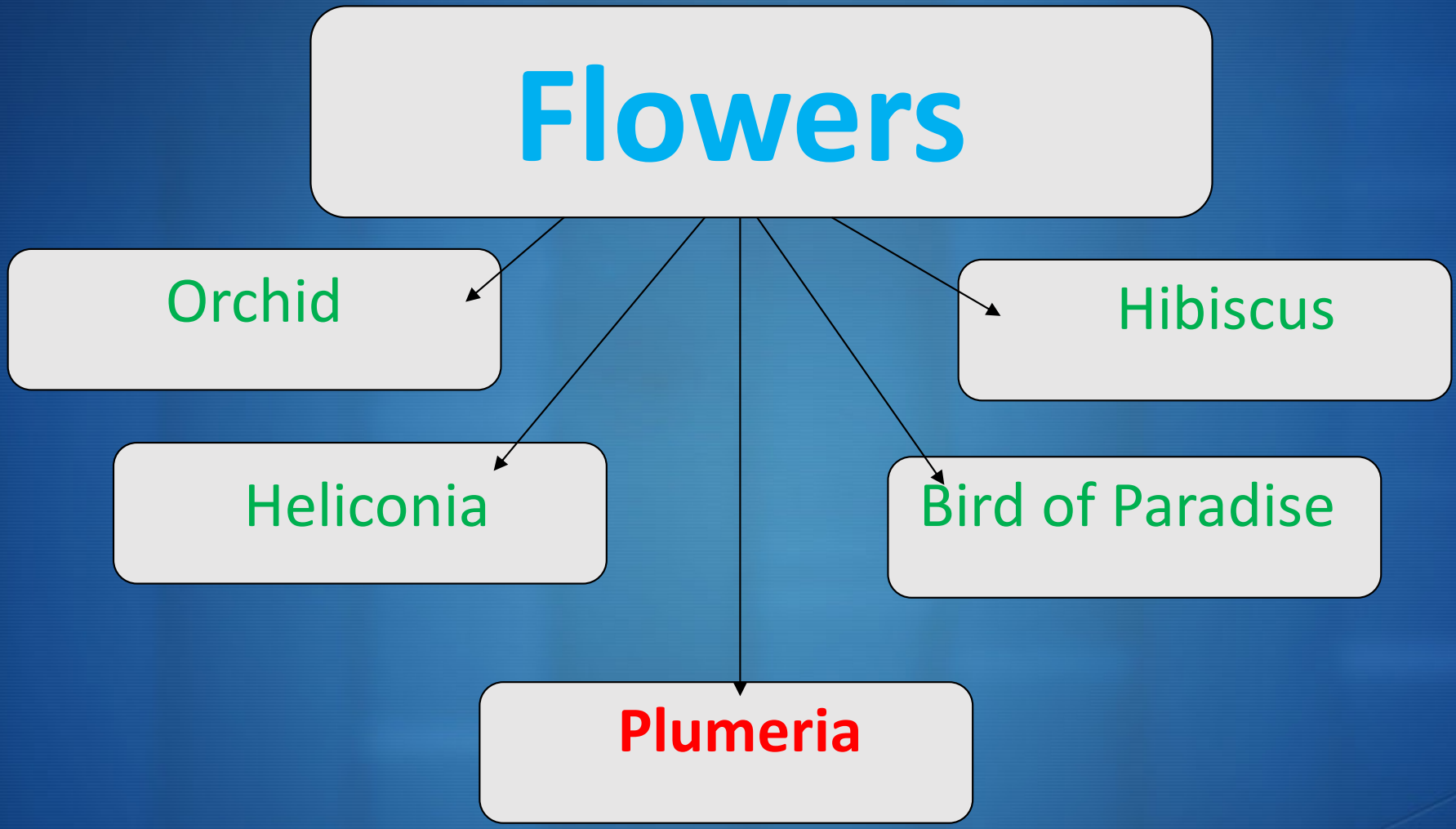
Differential Diagnosis

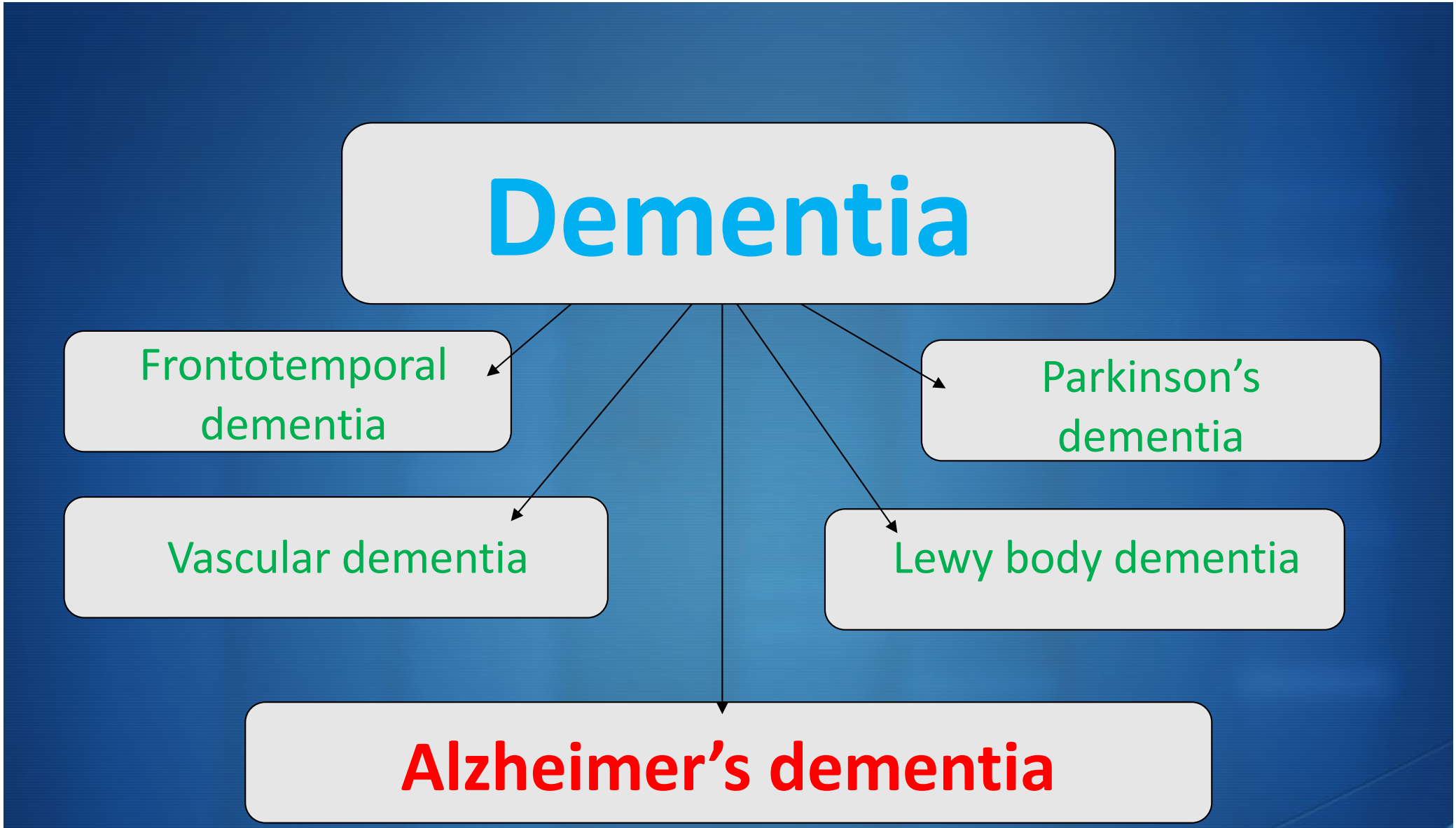
Ritabelle Fernandes, MD, MPH
Associate Professor, JABSOM, UH

for Catholic Charities Hawaii, April 17, 2025

Learning Objectives

- Understand the importance of a differential diagnosis
- Describe the tests that should be done for persons with memory problems
- Importance of medications review, including over-the-counter and supplements
- Discuss treatments both pharmacological and non-pharmacological approaches
- Describe types of dementia


Flowers
Orchid
Hibiscus
Heliconia
Bird of Paradise
Plumeria


Dementia
Frontotemporal dementia
Parkinson's dementia
Vascular dementia
Lewy body dementia
Alzheimer's dementia

Essentials of a Diagnostic Workup

- Rule out delirium – sudden confusion, inattention, medical emergency
  - UTI, impaction, pneumonia, medications
- Rule out depression/anxiety – has there been a recent significant life event
- Medication review – new meds, changes, interactions
- History and physical
- Lab tests
- MRI and/or CT scan (possibly)

Depression

- Apathy
- Persons could present with forgetfulness
- Persons may not be motivated or interested in engaging in conversations
- Depressed persons know the answers to the questions but may be silent
- Long term memory is intact
- Short term memory is intact

Always rule out potentially treatable conditions first!

- Stroke
- Side effects of medications
- Nutritional deficits and imbalances
- Hypothyroidism
- Alcohol and drug abuse
- Dehydration, malnutrition
- Cardiovascular disease
- Environmental challenges
- Sensory impairments
- Depression
- Lyme disease
- Normal pressure hydrocephalus

Sensory impairments can also mimic dementia

Seven Senses: responsible for our interaction with the external world.

1. Auditory (hearing)
2. Visual (sight)
3. Olfactory (smell)
4. Gustatory (taste)
5. Tactile (touch)

---

1. Proprioceptor (position) – the sensory feedback that informs us where the parts of our body are and how they are moving. Integrates input from the 5 senses.
2. Vestibular (balance) - related to and dependent on the proprioceptive system. The vestibular system is what gives us balance, allows us to stand and move through space without falling over.

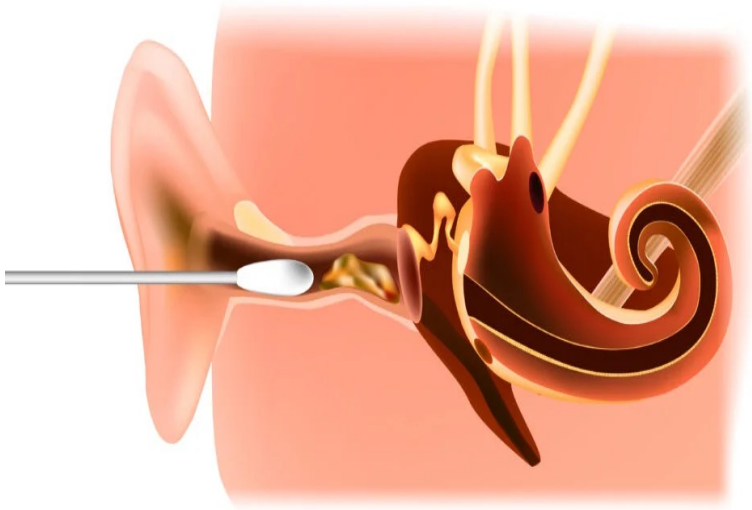
Hearing and vision

Get hearing and vision tested if you suspect the person is having a sensory problem.

- Often mistaken for symptoms of balance and movement problems, non-responsiveness, and social withdrawal.
- It is important to accurately determine sensory functional capabilities.

Deafness

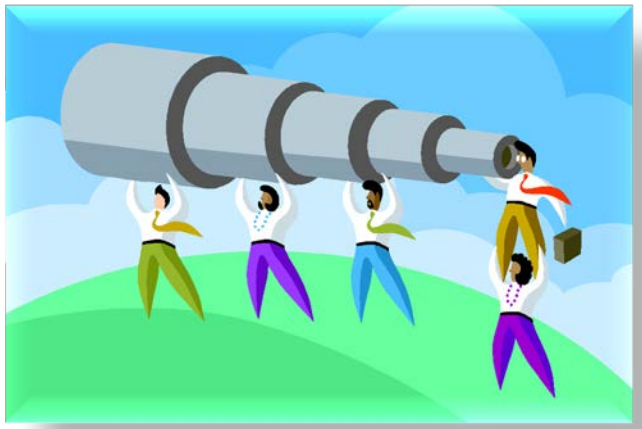
- Hearing loss can mimic dementia
- Ear wax is a very common problem



Vision changes

The following may all be affected by Alzheimer's Disease:

- Depth perception
- Color contrasts
- Acuity
- Motion versus stationary objects
- Object identification
- Delayed recall to visual stimulation
- Figure-ground differentiation
- Size and shape
- Visual memory



Over the Counter Medications

- $41 B dollar industry
- Unregulated
- Safety
- Efficacy
- Drug-drug interactions

Factors that increase the likelihood of Medications causing behavioral Changes

- Advancing age
  - Decreased kidney and liver function.
  - Increased potential for side effects.
  - Dosage guidelines developed for younger persons.
- Lifetime use of medications, especially psychotropic
- Polypharmacy
- Decreased fluid intake (due to incontinence)

Medications for Alzheimer's Disease

- **Leqembi** (Lecanemab)
- **Kisunla** (Donanemab)
- **Aricept** (Donepezil)
- **Namenda** (Memantine)
- **Exelon** (Rivastigmine)
- **Razadyne** (Galantamine)
- **Namzaric** (Donepezil + Memantine combination)

Environment

Would you have trouble finding your bedroom?

Can you suggest adaptations or modifications that might make it easier to navigate?

Non Pharmacological Approaches

Environmental cues:

Ex. Pictures on door

Familiar textures for matching.

Ex. On the seat for meals.

Lighting.

Contrasting colors.

Reduce unnecessary stimuli.