

Adults with Intellectual and Developmental Disabilities (IDD) and Dementia

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No Disclosures

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National Task Group on Intellectual Disabilities & Dementia Practices (NTG)

- Coalition of interested persons and organizations.
- Mission: Ensuring that the needs and interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and related dementias – as well as their families and friends – are taken into account as part of the National Alzheimer's Project Act (**NAPA**).
- **To access resources, visit www.aadmd.org/NTG**

Learning Objectives

1. Define intellectual and developmental disabilities (IDD)
2. Define dementia vs. Alzheimer's Disease
3. Describe signs and symptoms of the different types of dementia
4. List ways to prevent dementia
5. Identify ways to support people with IDD who also have dementia

DEFINITION: Intellectual Disability

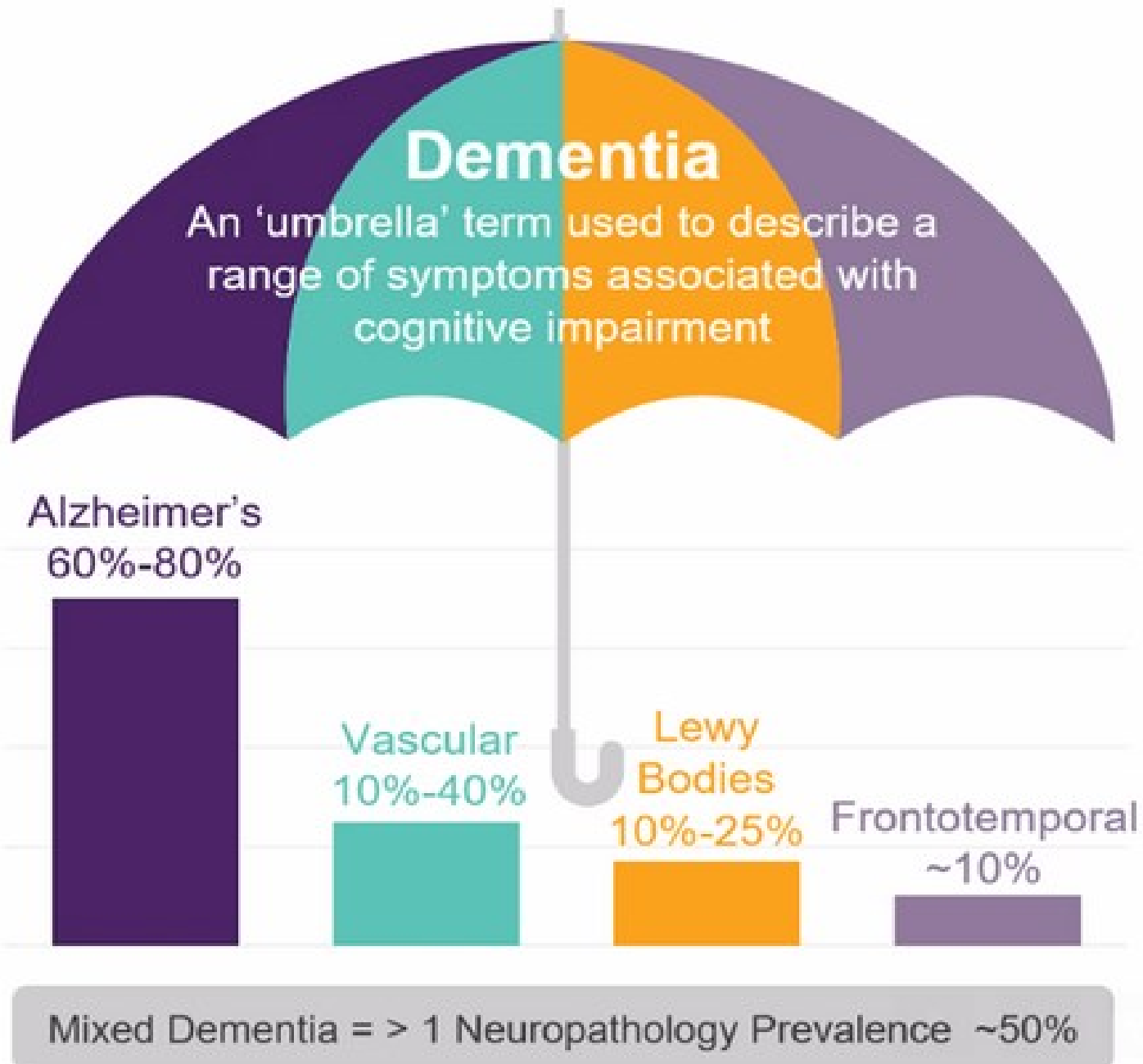
- An intellectual disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills
- This disability originates before the age of 22

DEFINITION: Developmental Disability

A Developmental Disability (DD) is an umbrella term that includes intellectual disability but also includes physical disabilities that occur before the age of 22 and are lifelong.

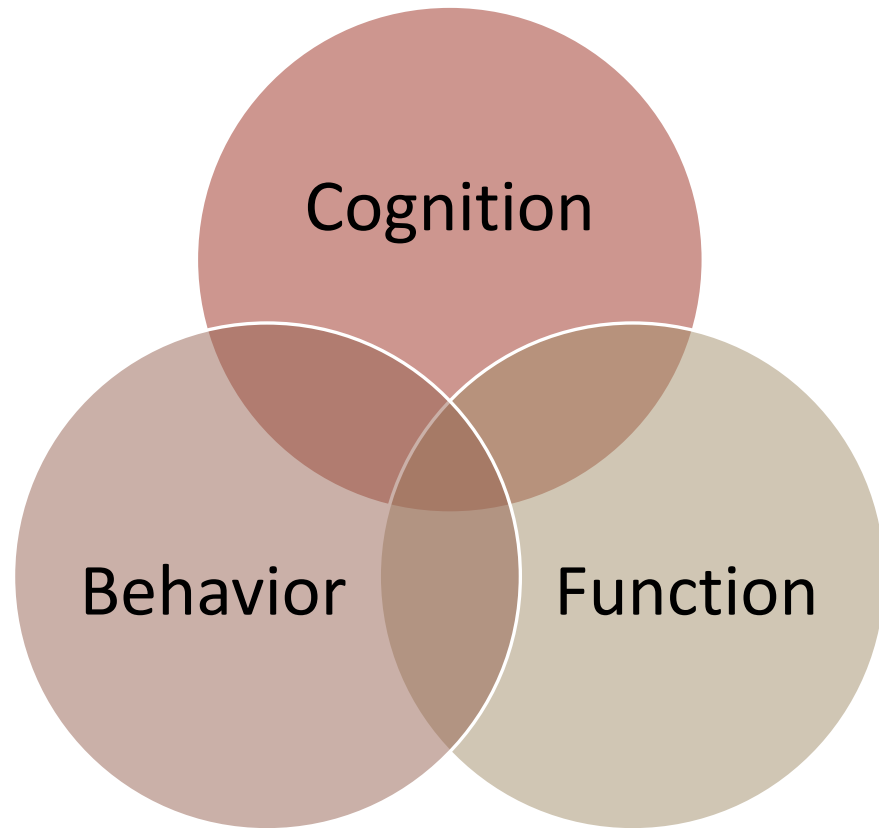
- Intellectual Disability
- Autism Spectrum Disorder
- Epilepsy
- Cerebral Palsy
- Neurological Impairments (e.g. spina bifida)
- Traumatic Brain Injury (TBI)

What is Dementia?



- A collection of symptoms related to cognitive decline
- Alzheimer's Disease is the most common
- Mixed dementia is increasingly common
- Some causes of cognitive decline are "reversible" and not truly dementia

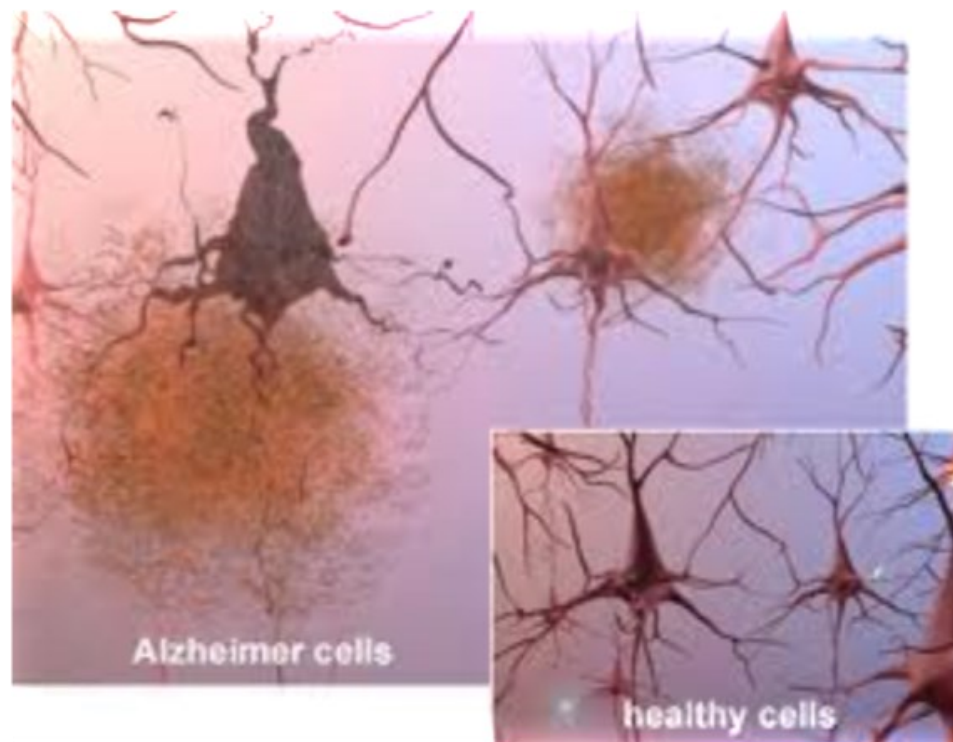
What does Dementia Impact?



- Memory
- Language skills
- Focus and ability to pay attention
- Reasoning & judgement
- Sensory perception
- Sequencing tasks

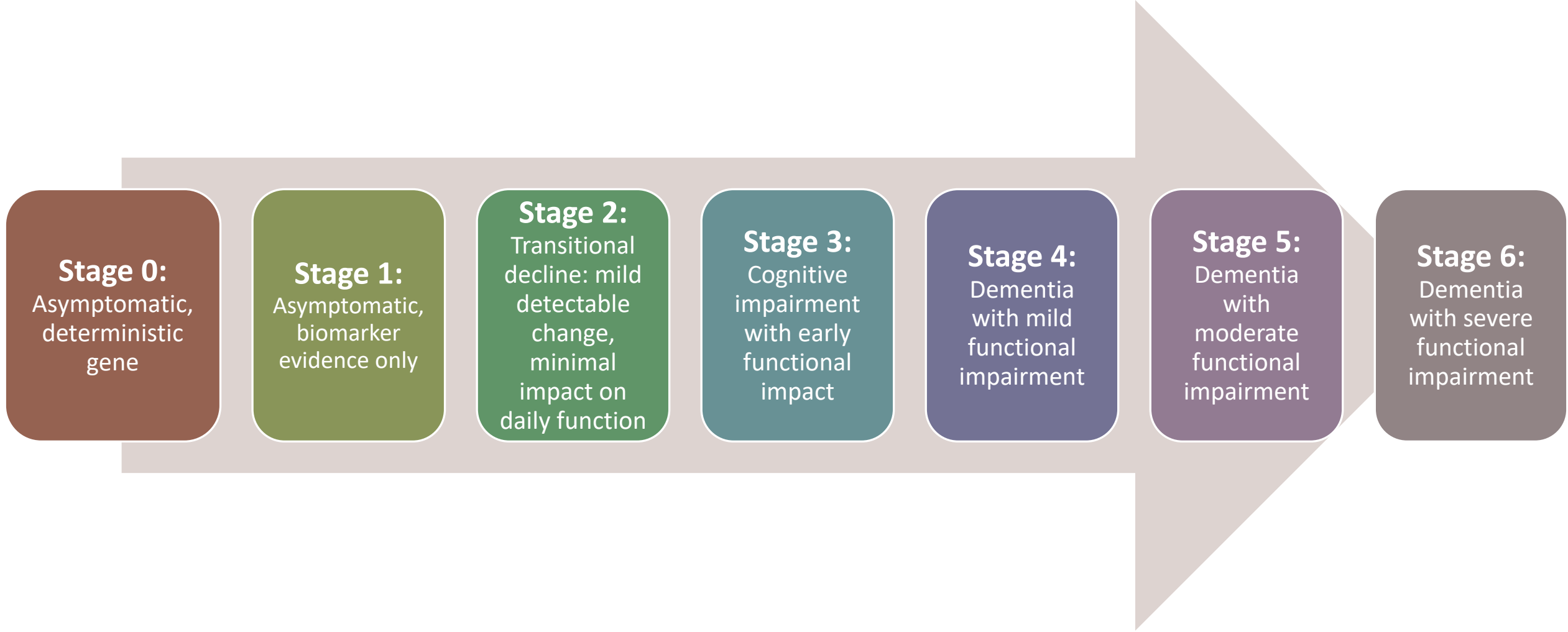
Alzheimer's Disease (AD)

- Most common form of dementia
- Gradual onset
- Early impact on short term memory
- Generalized brain atrophy
- Shrinks by 30% by time of death
- Accumulation of amyloid-beta protein fragments and abnormal forms of the protein tau



Mild Cognitive Impairment (MCI)

- Memory problems greater than those expected for age
- Do not experience the personality changes or other problems that are characteristic of AD
- Serious enough to be noticed by the individuals experiencing them or to other people...but *not severe enough to interfere with ability to function in daily life*
- Because the changes caused by MCI are not *severe enough to affect daily life*, a person with MCI does not meet diagnostic guidelines for dementia



2025 Dementia Facts & Figures - Alzheimer's Association

Symptoms of Stage 4

- **Memory problems** usually reported first
- **Difficulty planning & making complex decisions:** managing finances, chores, shopping, cooking, medications, driving
- **Difficulty with orientation and way-finding**
- **Visual-perceptual difficulties** (not hallucinations)

Symptoms of Stage 5

- **Reduced language and communication**
 - **Expressive** language changes - word finding difficulties, smaller vocabulary, shorter phrases, less spontaneous speech
 - **Receptive** language changes - difficulty understanding language and verbal instructions
- **Worsened fine motor control**
- **Decline in work productivity**
- **Changes in mood or emotion: reacting vs responding**

Symptoms of Stage 5 (continued)

- Progressive personality change
- Behavior changes (e.g., impulsivity, sexual disinhibition, anger, argumentative, hoarding)
 - Apathy is common in early stages (social withdrawal, loss of interest)
 - Agitation, restlessness, and wandering are common in later stages
- Poor judgment, insight, problem-solving

Symptoms of Stage 6

- Loss of ability to perform activities of daily living:
 - Dressing (grooming)
 - Bathing (hygiene)
 - Toileting (incontinence)
 - Walking (mobility)
 - Eating (feeding)

Mood: Agitation, restlessness, and wandering, apathy

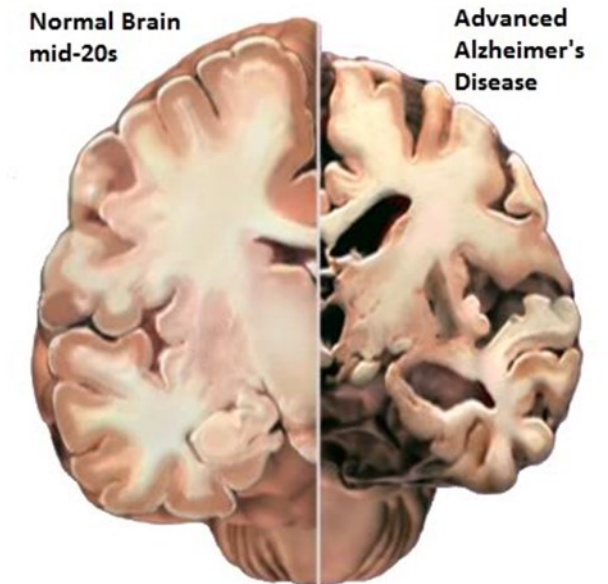
Clinical Features of Various Dementias

Alzheimer Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
<p>Memory, visual-spatial and language disturbances</p> <p>Indifference</p> <p>Delusions</p> <p>Agitation</p> <p>Behavioral changes</p>	<p>Personality changes</p> <p>Executive dysfunction</p> <p>Disinhibition</p> <p>Impulsivity</p> <p>Progressive loss of speech</p>	<p>Visual hallucinations</p> <p>Delusions</p> <p>Falls</p> <p>Syncope</p> <p>Parkinsonism</p> <p>Fluctuating memory</p> <p>Sensitivity to antipsychotic medications</p>	<p>Abrupt onset</p> <p>Stepwise deterioration</p> <p>Prominent aphasia</p> <p>Motor dysfunction</p> <p>Mood or behavior changes</p> <p>Severe depression symptoms</p>

Although the brain neuropathy will differ, caregivers need to note the nature of the behaviors exhibited.

Why is Dementia Type Important?

- Different types of dementia have different characteristics. It can be helpful to know that particular behaviors are part of the disease process and not “bad behavior”
 - Lewy body – visual hallucinations
 - Fronto-temporal – profound personality change, disinhibition
- The type of dementia impacts what medications are used:
 - Lewy body – sensitivity to certain antipsychotics
 - Fronto-temporal – symptoms may worsen with common Alzheimer’s medications such as donepezil
- Ensure that treatable causes of the symptoms have been ruled out before a diagnosis of dementia is given



Prevalence by Dementia Type

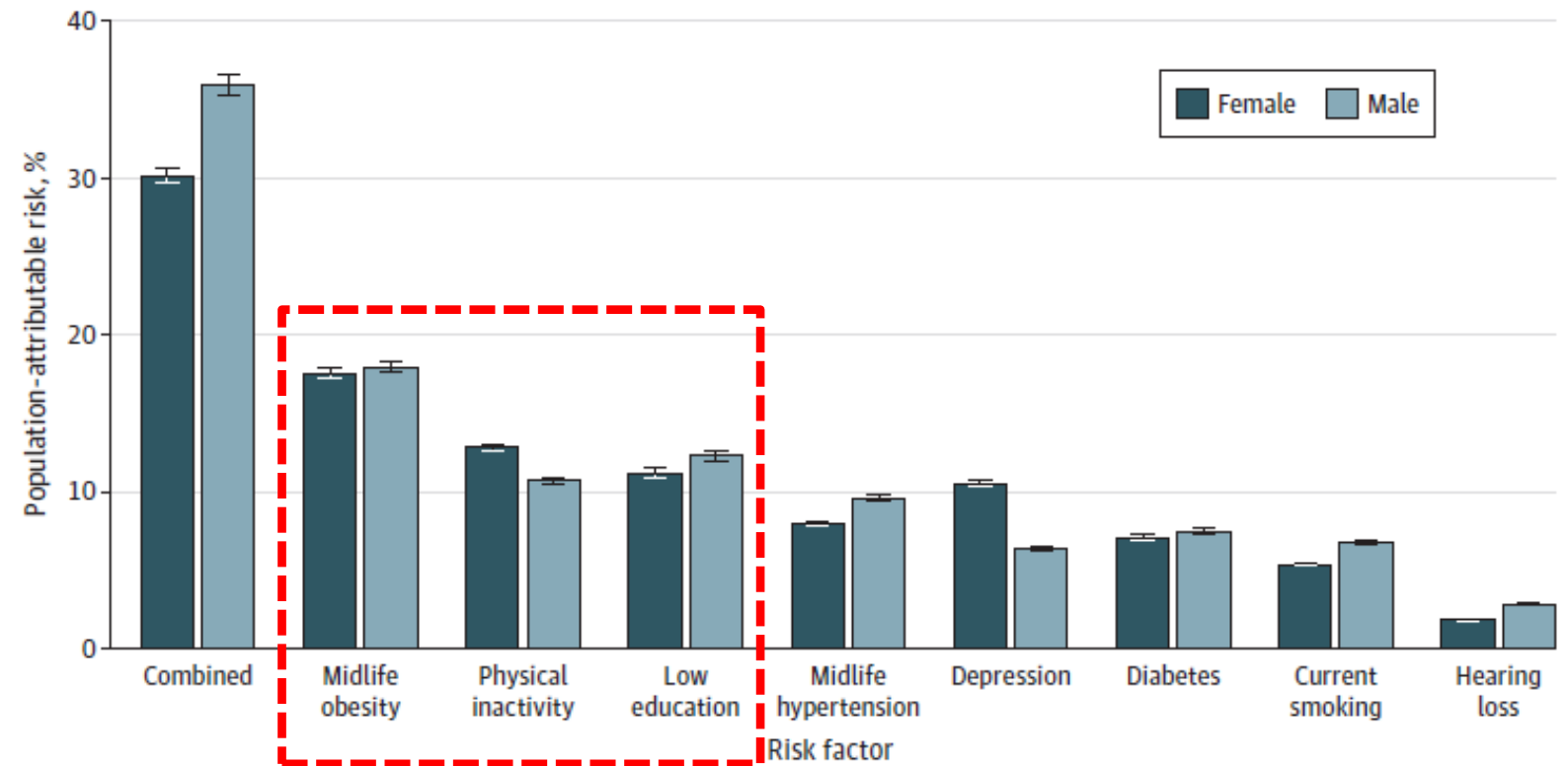
- **Becoming Older with Learning Disabilities (BOLD)** – study of dementia in adults with ID over age 60 in the UK (N=222)
 - Alzheimer’s Disease: 8.6%
 - Vascular Dementia: 2.7%
 - Lewy Body: 5.9%
 - Frontotemporal Dementia: 3.2%
- Largest cross-sectional study of dementia in ID

Strydom, A, Livingston, G, & Hassiotis, A. (2007). Prevalence of dementia in intellectual disability using different diagnostic criteria. *British Journal of Psychiatry*, 191, 150 – 157.

Risk Factors for Dementia

- Midlife obesity
- Physical inactivity
- Low educational attainment

Figure 1. Unadjusted and Combined Population-Attributable Risk for 8 Modifiable Dementia Risk Factors by Sex in the US, 2018



JAMA Neurol. 2022;79(6):584-591. doi:[10.1001/jamaneurol.2022.0976](https://doi.org/10.1001/jamaneurol.2022.0976)

Published online May 9, 2022.

What is brain health?

Brain health refers to how well a person's brain functions across several areas.

Motor function
Controlling movements and balance

Sensory function
Seeing, hearing, tasting, and smelling

Tactile function
Feeling and responding to sensations of touch, including pressure, pain, and temperature

Cognitive health
Thinking, learning, and remembering

Emotional function
Interpreting and responding to emotions



Six Pillars of Brain Health

3 Eat smartly

4 Be social

2 Seek out mental challenges

5 Get enough sleep

1 Get moving

6 Take control of your health



Down Syndrome (DS)

- DS occurs 1 in 750 live births.
- DS is caused by a genetic abnormality – an extra full or partial copy of chromosome 21 (Trisomy 21).
- The extra copy of genetic material alters the course of development and causes the characteristics associated with Down syndrome.



Alzheimer's Disease in DS

- Earlier onset than general population. Average age of onset is 58 and average length of progression is 4.6 years (NDSS, 2024)
- Management similar to general population
- No strong evidence that Alzheimer's drugs benefit
- Depression and thyroid disease can mimic dementia
- Normal age-associated deficits are common
- Often present with behavioral symptoms instead of memory loss
- Seizures are present in 75% of people with DS with dementia

Diagnosing Dementia

Diagnostic Overshadowing

- The tendency for clinicians to attribute symptoms or a change in behaviors of a person with ID to their underlying cognitive deficits and therefore under-diagnose the presence of co-occurring disease such as dementia.
- (Reiss, Levitan & Szyszko, 1982)

Traditional Screening Tools - Not Useful

- Traditional screening instruments for detecting dementia in the general population are designed for people with average baseline intelligence and are not useful for detecting cognitive impairment in adults with IDD.

Example:

- Mini-Mental Status Exam (MMSE; e.g., count backwards from 100's by 7s)
- St Louis University Mental Status Examination (SLUMS)
- Montreal Cognitive Assessment (MoCA)

Alternatives:


- Dementia Questionnaire for Persons with Mental Retardation (Evenhuis, 1996)
- Dementia Scale for Down syndrome

NTG Early Detection Screen for Dementia

Adapted from:

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb et al., 2007), and
- Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group from the DSQIID, 2010)

- Down Syndrome begin EDS at age 40, then annually
- Non-DS begin at age 50



NTG-EDSD

v1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

*The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

(1) File #: _____ (2) Date: _____

Name of person: (3) First _____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

Female
Male

Instructions:

For each question block, **check the item that best applies** to the individual or situation.

(8) Best description of level of intellectual disability

No discernible intellectual disability
Borderline (IQ 70-75)
Mild ID (IQ 55-69)
Moderate ID (IQ 40-54)
Severe ID (IQ 25-39)
Profound ID (IQ 24 and below)
Unknown

Current living arrangement of person:

Lives alone

Lives with spouse or friends

Lives with parents or other family members

Lives with paid caregiver

Lives in community group home, apartment, supervised housing, etc.

Lives in senior housing

Lives in congregate residential setting

Lives in long term care facility

Lives in other: _____

(9) Diagnosed condition (check all that apply)

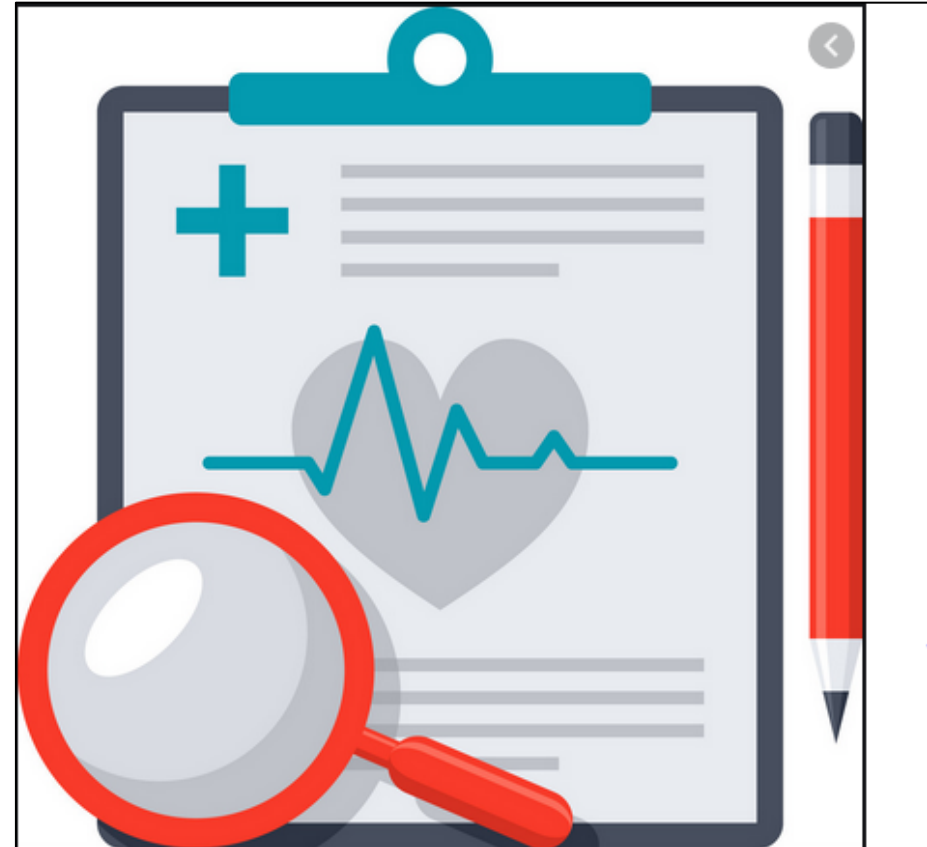
Autism
Cerebral palsy
Down Syndrome
Fragile X Syndrome
Intellectual disability
Prader-Willi syndrome
Other: _____

www.aadmd.org/ntg/screening

Differential Diagnosis

- Functional ability
- Physical health
- Cognition
- Mental health

(Elsawy & Higgins, 2011)



Importance of Differential Diagnosis

1. Rule out treatable conditions
2. Receive appropriate treatment and support services
3. Maintain the highest possible quality of life and functioning
4. Avoid medications that could make symptoms worse



Essentials of a Diagnostic Workup

- Physical
- Histories:
 - psychiatric
 - personal/family
 - past medical
 - mental state assessment
- MRI, CT and/or PET scans to detect brain changes or lesions
- Lab tests:
 - Complete blood cell count
 - Serum electrolytes
 - Glucose
 - Creatinine
 - Serum B12 levels
 - Thyroid function tests
 - Liver function tests
 - Celiac screening if DS

FLDDSO Geriatric Assessment Clinic

- Started in the 1990s
- Clinical team: physician, clinical psychologist, OT, PT, SLP
- Individual is accompanied by family, DSP, agency nurse, etc.
- Max. 8 appointments per month; currently 4 month wait
- In-person: Rochester, Newark, Geneseo
- Each visit takes 2-3 hours

Warning Signs of Dementia

These symptoms must be notable and usually occur in a cluster

Unexpected memory loss

Difficulty doing usual tasks

Getting lost or misdirected

Confusion in familiar situations

Personality changes

Problems with gait or walking

Onset of new seizures

Loss of interest in favorite activities

Yes, it's "dementia" –
now what?

Treatments

Medications

- Treatment to slow AD
 - Aducanumab - *discontinued*
 - Lecanemab
- Treatments for symptoms
 - Donepezil, rivastigmine, galantamine, memantine and memantine combined with donepezil: treat cognitive symptoms
 - Brexpiprazole – treats agitation
 - Suvorexant – treats insomnia

Non-drug Treatments

Often used to maintain or improve thinking, behavior, and the ability to perform activities of daily living:

- physical activity and exercise
- memory and orientation activities
- music therapy
- art therapies
- pet therapy

Person-Centered Care (PCC)

- PCC is the philosophy that the person should always be the first consideration in the delivery of dementia care (Kitwood, 1997)
- The American Geriatrics Society (2016) stated that individuals' values and preferences are elicited and, once expressed, guide all aspects of their healthcare
- PCC is a philosophical framework that guides delivery of healthcare and is based on individuals' values and preferences (Fazio et al., 2018)

(Van Haitsma et al., 2020)

Tips for Activities

- Be welcoming
- Meet basic physiological needs
- Orient to date, time, place, and season
- Provide clear expectations/cues - verbally and non-verbally
- Emphasis on maintenance of current function
- Allow down time
- Create opportunities for personal space/time to process
- Be with the person and join the person in their world
- Honor culture
- Use imagination (e.g., [TimeSlips](#))

Goals Change

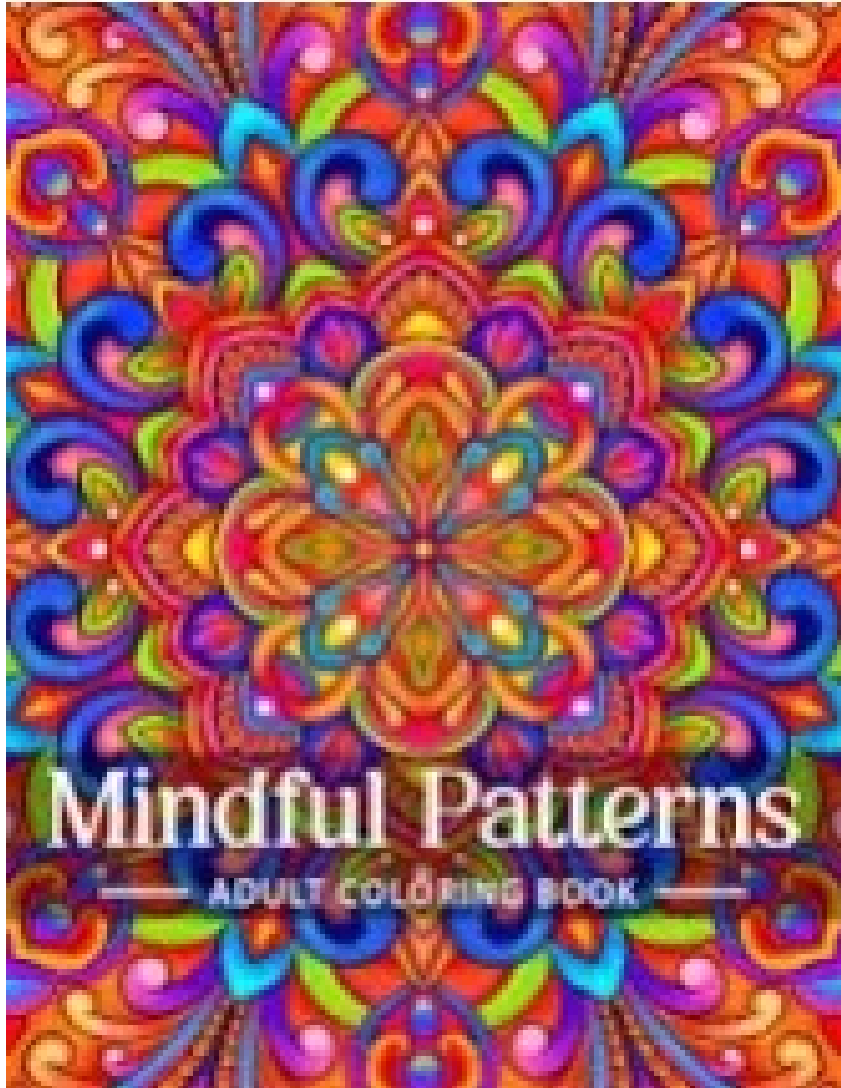
LIFESPAN GOALS

- Sensory stimulation & challenge
- Novelty & exposure to new information
- Skill building
- Increase independence
- Choices and opportunities

GOALS WITH DEMENTIA

- Balance of ease of use with limited sensory stimulation
- Predictable, consistent routine
- Maintain function and social interaction as much as possible
- Limited choices – maybe only one option at a time
- Support and failure free activities

Failure Free Activities



- Adapt activities to suit the needs and capacity of the person
- Focus on simple activities which reinforce self-esteem while relieving boredom and frustration
- Emphasis is on remaining abilities

Tips for Failure Free Activities

- Limiting choices to one-at-a-time based on previous known preferences.
- Provide gentle guidance and hand over hand assistance if the person is struggling with previous learned skills.
- Break tasks down into single step directions waiting for completion of each step before proceeding to the next step.
- Positive body language and calm, gentle tone of voice.
- Distract when upset with positive comments or diversional activities.
- Add music
- Use “therapeutic fiblets” as needed

Creation of “Palliative Environments”

- Palliative care is specialized medical care for people with serious illness. It focuses on providing patients with relief from the symptoms, pain and stress of a serious illness—whatever the diagnosis. (Center to Advance Palliative Care [CAPC], 2014)
- We must create “palliative environments that are age-friendly and hospitable to the engagement of older adults and their caregivers with health professionals in processes of mutual recognition and vulnerability, open communication, and healing.” (Morrissey et al., 2015)



Accompaniment and Mutual Solidarity

(Watkins, 2019)

To accompany someone is to go somewhere with him or her, to break bread together, to be present on a journey with a beginning and an end. There's an element of mystery, of openness, of trust, in accompaniment. The companion says: "I'll go with you and support you on your journey wherever it leads. I'll share your fate for a while—and by "a while," I don't mean a little while."

Accompaniment is about sticking with a task until it's deemed completed—not by the companion, but by the person being accompanied.

(Farmer, 2013, p. 234)

Mutual Accompaniment and the Creation of the Commons

MARY WATKINS

With a Foreword by George Lipsitz and
a Contribution by G. A. Bradshaw





Your Challenge

- I challenge you to:
- be present and notice a change in behavior, function or cognition
- be creative and engage people with dementia in a person-centered, palliative environment
- be brave enough to accompany people with dementia through this disease, especially at the end of their journey

Questions?

Email: LauraM_Robinson@urmc.rochester.edu