

# **Dementia 101 & Down Syndrome**

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# Mission, Vision & Values

- **Department of Health & Human Services**  
Consists of Aging & Disabilities Services, Behavioral Health Services, Housing Services, Children, Youth & Family Services, Management Services, and Veterans Services
- **Mission**  
Empowering safe, healthy and meaningful lives
- **Vision**  
Together, creating healthy communities
- **Values**  
Partnership, Respect, Integrity, Diversity, and Excellence  
(PRIDE)



# Aging & Disability Resource Center



- The Aging & Disability Resource Center (ADRC) is the first place to go to get **accurate, unbiased information on all aspects of life related to aging or living with a disability.**
- The Aging & Disability Resource Center offers information, referral, consultation and assistance regarding access to short- and long-term care services for elders and people with disabilities in Milwaukee County.
- Learn more about ADRC's around the state at the [State of Wisconsin's website.](#)



# Brief Background on DCS

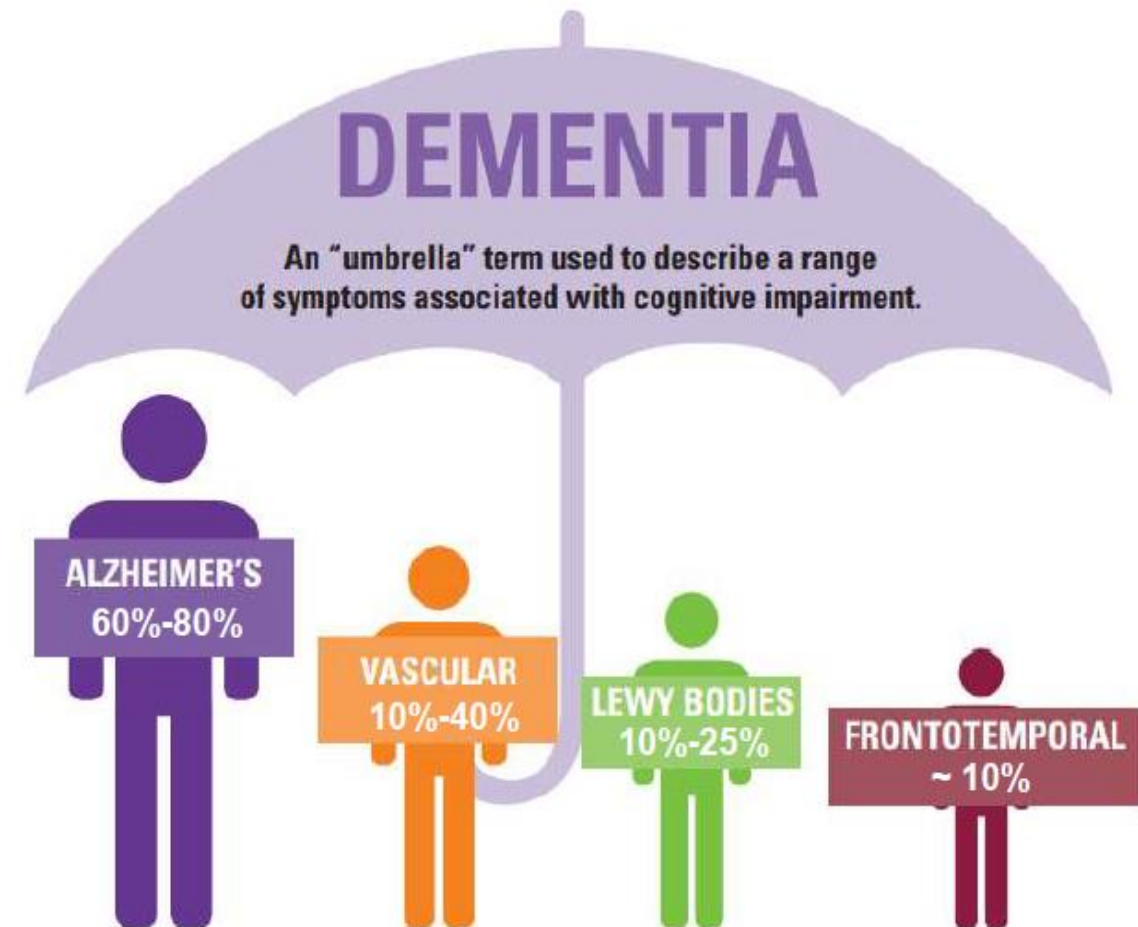


- Dementia capable ADRC
- Dementia friendly communities
- Support people with dementia and their caregivers



# What is Dementia?

- A syndrome that describes a group of symptoms associated with a decline in memory and other thinking skills
- For a person to be considered to have “dementia”, the following criteria must be met:
  - Two or more core cognitive functions must be impaired
  - Change from baseline
  - Affecting day to day life
  - Not explained by something else (depression, UTI, medications, etc.)



# Reversible/ Treatable Dementia

- Medications
- Depression
- Medical problems
- Hearing and Vision impairments
- Vitamin deficiently B-12
- Infections, UTI, fever, sepsis, pneumonia
- Delirium



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# Depression

- Depression is a common cause of “reversible” dementia in the geriatric population
- Unlike younger individuals, elderly depressed patients may present with cognitive impairment, i.e., confusion, memory disturbance, attention deficits, all of which can be mistaken for dementia



# Metabolic/ Endocrine/ Nutritional/ Systemic Disorders

- Metabolic/endocrine/nutritional/systemic disorders (e.g., hypothyroidism, B12 deficiency and systemic infections) are additional causes of “reversible” dementias and can be diagnosed with routine laboratory tests
- **Urinary Tract Infection, Dehydration, and Malnutrition** are very common reversible dementias and need to be assessed first to rule them out before diagnosing dementia





# Medication Induced Dementia

- Most frequent cause of “reversible” dementia
- The incidence of adverse drug reactions increases with age
- To rule out a medication-induced dementia, a thorough drug history and a review of all current medications should be undertaken



# Types Irreversible Dementias

- **Alzheimer's Disease**
- *Vascular Dementia*
- *Lewy Body Dementia*
- Mixed Dementia
- Parkinson's Disease Dementia
- *Frontotemporal Dementia*
- Creutzfeldt-Jakob Disease
- Huntington's Disease
- Wernicke-Korsakoff Syndrome



# Alzheimer's Disease

- A type of dementia caused by plaques and tangles that damages brain cells and nerves
- Most common type, accounting for 60-80% of cases
- A type of dementia that causes problems with memory, thinking and behavior.

# Vascular Dementia

- A type of dementia caused by conditions that block or reduce blood flow to the brain, depriving brain cells of vital oxygen and nutrients
- Causes include brain injuries such as microscopic bleeding and blood vessel blockage
- Previously known as post-stroke dementia, accounts for about 10% of cases
- The location, number and size of the brain injury determines how the individual's thinking and physical functioning are affected

# Lewy Body Dementia

- A type of dementia caused by abnormal microscopic deposits that damage brain cells over time
- Most experts estimate that Lewy Body Dementia is the third most common cause of dementia, accounting for 10 to 25% of cases

# Frontotemporal Dementia

- Type of dementia caused by progressive cell degeneration in the brain's **frontal lobes** or **temporal lobes**
- Includes dementias such as behavioral variant FTD (BV-FTD), primary progressive aphasia, Pick's disease and progressive supranuclear palsy
- FTD was once considered rare, but is now thought to account for up to 10 to 15% of all dementia cases
- People usually develop FTD in their 50s or early 60s, making the disorder relatively more common in this younger age group

Source: <http://www.alz.org/dementia/types-of-dementia.asp> and  
<http://www.alz.org/dementia/fronto-temporal-dementia-ftd-symptoms.asp>



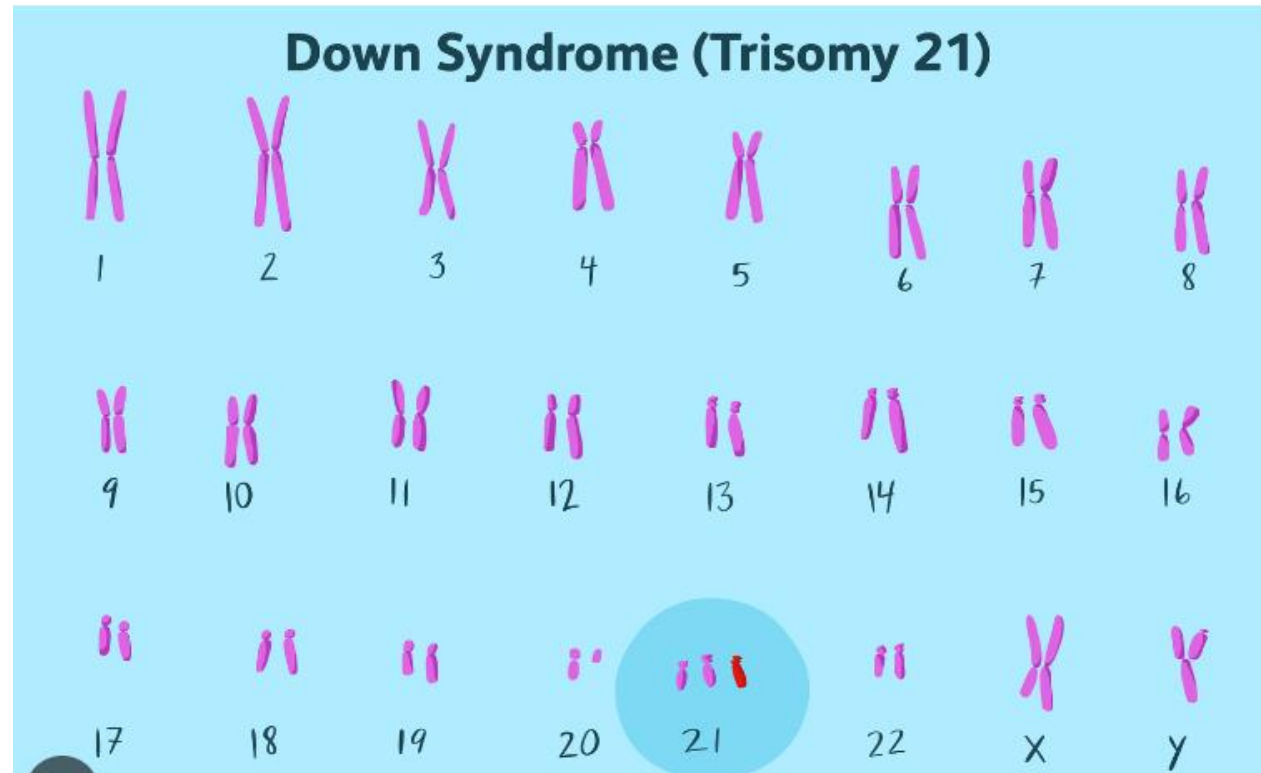
# Alzheimer's Rates Specific to People with Down Syndrome

- Advancing age also increases the chances a person with Down syndrome will develop dementia
- About 30% of people with Down syndrome who are in their 50's have Alzheimer's dementia
- About 50% of people with Down syndrome in their 60's have Alzheimer's dementia



# Pathology

- Elevated risk is genetic and associated with chromosome 21





# Early Symptoms

- Reduced interest in being sociable, conversing or expressing thoughts.
- Decreased enthusiasm for usual activities.
- Decline in ability to pay attention.
- Sadness, fearfulness or anxiety.
- Irritability, uncooperativeness or aggression.
- Restlessness or sleep disturbances.
- Seizures that begin in adulthood.
- Changes in coordination and walking.
- Increased noisiness or excitability.

# Diagnosing Alzheimer's in those living with Down Syndrome

- **Most adult with Down syndrome will not self-report concerns about memory.**
- Diagnosing Alzheimer's requires careful medical evaluation but the following principles should to be provided:
  - Documented baseline of adult function by age
  - Watch for changes in day-to-day function.
  - Rule out other causes of symptoms.
  - Consider the tool called the National Task Group-Early Detection Screen for Dementia (NTG-EDSD)



# What is the NTG-EDSD?

- A tool completed by any person familiar with the person living with Down syndrome and their abilities
- To be used annually beginning at age 40 to compare abilities from year to year and track changes



<sup>(11)</sup> Compared to one year ago, current physical health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

<sup>(12)</sup> Compared to one year ago, current mental health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

<sup>(13)</sup> Conditions present (*check all that apply*)

	Vision impairment
	Blind (very limited or no vision)
	Vision corrected by glasses
	Hearing impairment
	Deaf (very limited or no hearing)
	Hearing corrected by hearing aids
	Mobility impairment
	Not mobile – uses wheelchair
	Not mobile – is moved about in wheelchair

<sup>(14)</sup> Significant recent [in past year] life event (*check all that apply*)

	Death of someone close
	Changes in living arrangement, work, or day program
	Changes in staff close to the person
	New roommate/housemates
	Illness or impairment due to accident
	Adverse reaction to medication or over-medication
	Interpersonal conflicts
	Victimization / abuse
	Other:

If MCI or dementia is documented complete 16, 17, & 18

<sup>(16)</sup> **Diagnostic History**

Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?:

No

Yes, MCI

Date of Dx:

Yes, dementia

Date of Dx:

Type of dementia:

Diagnosed by:

Geriatrician

Neurologist

Physician

Psychiatrist

Psychologist

Other:

<sup>(17)</sup> Reported date of onset of MCI/dementia

[When suspicion of dementia first arose]

Note approximate year and month:

<sup>(18)</sup> Comments / explanations about dementia suspicions:



	Always been the case	Always but worse	New symptom in past year	Does not apply
<b><sup>(19)</sup> Activities of Daily Living</b>				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
<b><sup>(20)</sup> Language &amp; Communication</b>				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
<b><sup>(21)</sup> Sleep-Wake Change Patterns</b>				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
<b><sup>(22)</sup> Ambulation</b>				
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				



# Importance of Early Diagnosis

- More time to plan for the future
- Lessens anxiety about unknown problems
- Increases chances of participating in research
- An opportunity to coordinate care, transportation, living options, financial and legal matters earlier
- Time to develop a relationship with doctors and care partners
- Benefit from care and support services, making it easier for them and their family to manage the disease



# Treatment

- FDA has not approved any drugs specifically to treat dementia associated with Down syndrome
- An international randomized trial has shown **no** benefit for the Alzheimer's drug memantine in adults with Down syndrome



# Where to start after a Diagnosis?

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- **Knowledge**
  - Understand the disease process, symptoms and behaviors, caregiver classes
- **Plan for the future**
  - Support, caregiving, safety
- **Get connected with local supports**
  - ADRC's, Alzheimer's Association, community supports
- **Continuum of care options**
  - Home care options, LTCP, Assisted living, CBRF's, SNF's, memory care



# Who to connect with after diagnosis?

- Neurologist
- Geriatrician
- Occupational therapist (OT)
- Neuropsychologist
- Speech language pathologist (SLP)

# Suggestions for Day-to-Day Care

- Assess if these needs are being met in living situation:
  - Medical
  - Physical
  - Social
  - Emotional
  - Personal Safety

# Community Resources

- Aging and Disabilities Resource Center of Milwaukee County
  - Call Center: 414-289-6874
  - Email: [adrc@milwaukeecountywi.gov](mailto:adrc@milwaukeecountywi.gov)
- Alzheimer's Association
  - 24/7 Help Line: 1-800-272-3900
- Dementia Friendly Communities
- Wisconsin Alzheimer's Institute Affiliated Dementia Diagnostic Clinic Network
  - 6 memory clinic locations in Milwaukee County
- Memory Cafes & SPARK Programs



# Community Resources

- The Down Syndrome Association of Wisconsin

<https://www.dsaw.org/programs-services>

- The National Down Syndrome Society

[Aging and Down Syndrome: A Health & Well-Being Guidebook | National Down Syndrome Society \(NDSS\)](#)

- Global Down Syndrome Foundation

[Our Story | Global Down Syndrome Foundation](#)

- Dementia Care Specialists

[ADRC: Support for People with Dementia and their Caregivers | Wisconsin Department of Health Services](#)



# Questions?



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