National Task Group on Intellectual Disabilities and Dementia Practices

When Memory Changes: Guidance for Families of Adults with Down Syndrome

Kathryn Pears, MPPM

November 19, 2025

Kathryn G. Pears, MPPM
Chief Operating Officer, NTG

Kathryn Pears has over 40 years personal and professional experience in the field of dementia. As a former caregiver for her father, diagnosed with Alzheimer's in 1981 at the age of 56, she learned how difficult this journey is for caregivers and how important quality of life and access to qualified health professionals is for the well being of the person living with dementia.

Ms. Pears was Director of Programs and Policy for the Alzheimer's Association, Maine Chapter, for nearly 20 years before forming her own consulting and training company, Dementia Care Strategies.

An active member of the NTG since 2011 and former board member she accepted the position of Chief Operating Officer in 2022. As co-lead trainer for the NTG's national model training curriculum on aging, intellectual disabilities, and dementia she continues to travel the country educating professionals and family caregivers on the best practices in care for aging adults with ID at risk of or who have developed Alzheimer's disease or a related dementia.

Objectives

- Introduce the NTG
- Talk a bit about aging
- “Know enough to be dangerous”
- Caregiving resources

Who We Are

The NTG is the only national nonprofit organization that is specifically addressing the needs of aging adults with intellectual disabilities who are at risk of or who have developed Alzheimer's disease or a related form of dementia.

The NTG:

- Advocates for inclusive federal policies
- Publishes guides, white papers, and consensus documents on a variety of issues related to intellectual disabilities and dementia
- Provides in-person and online training and education for professional staff and family caregivers
- Collaborates with other national organizations to advance research and policy change
- Supports families through its monthly online family support group

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National Task Group on Intellectual Disabilities and Dementia Practices

www.the-ntg.org

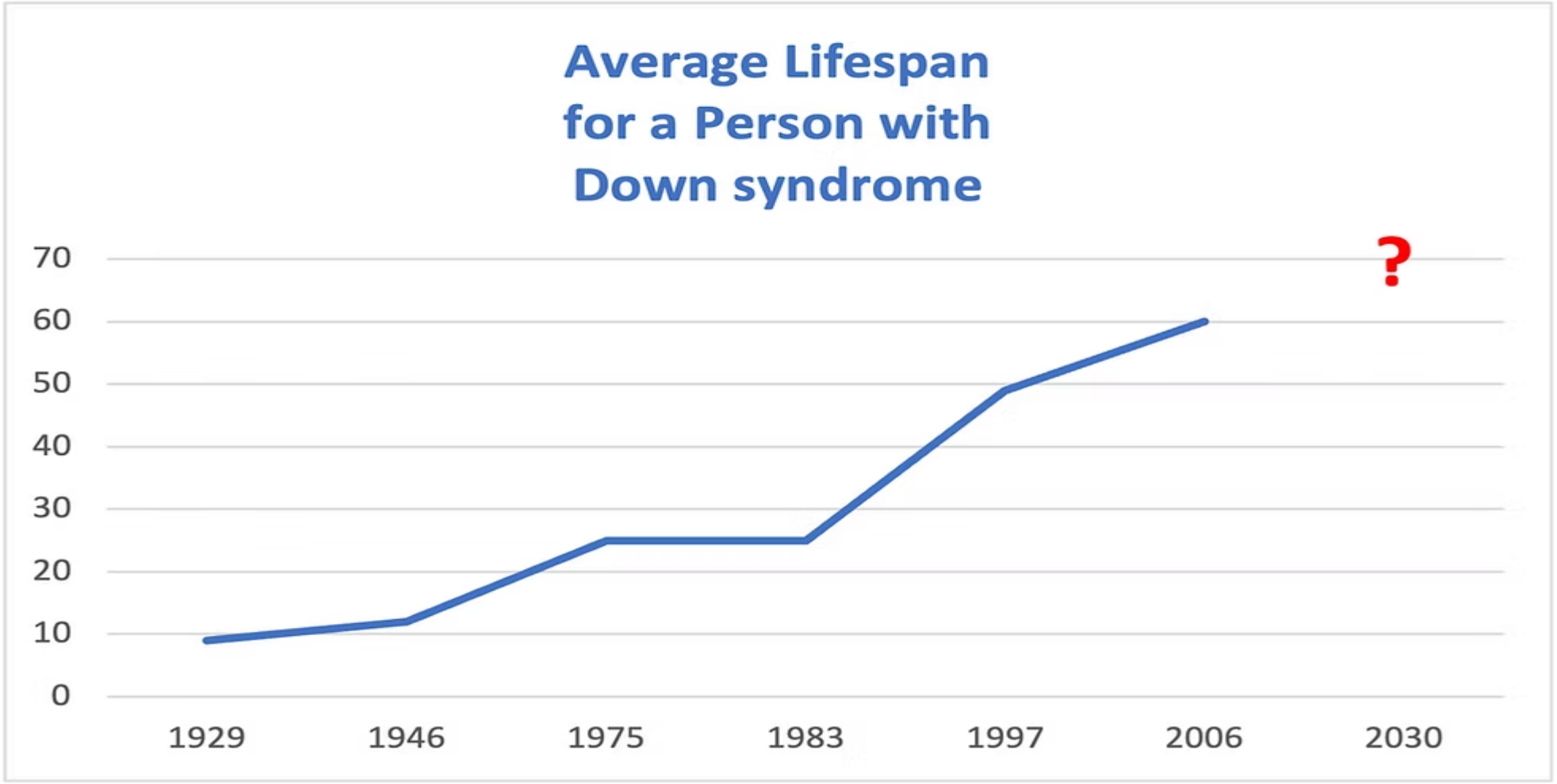
The Good News: Lifespan is Increasing

Older Adults with Intellectual Disabilities

- Of those aging with a lifelong disability, individuals with ID are the largest group.
- People with IDD are living longer than ever
  - 641,000 people with ID over age 60
  - Numbers will double, or even triple, by 2030 (Heller, 2013.)
- Increased risk of dementia in some groups (e.g., Down syndrome)
- Agencies are supporting older adults in larger numbers
- Early recognition → better outcomes and fewer crises

Especially True for Individuals with Down Syndrome

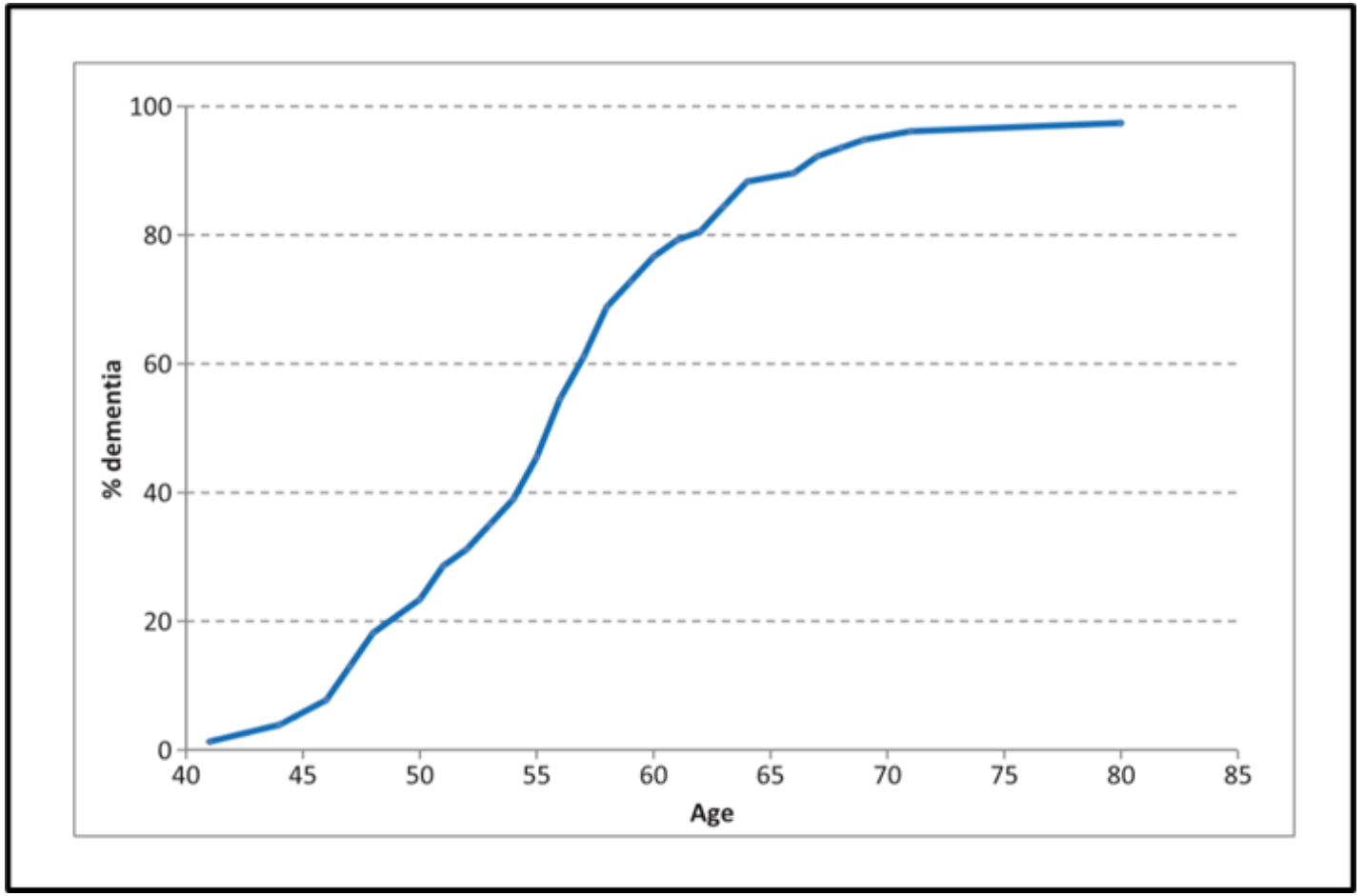
More people with DS living with aging-related disorders… including AD pathology



Source: beyonddownsyndrome.net

Increased Risk of Alzheimer's in Down syndrome

- Chromosome 21
- Accelerated aging
- Atypical presentation of Alzheimer's
- Assessment challenges
- Not enough experts in health care who can identify and treat aging symptoms in those with DS



Source: McCarron et al., (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. Journal of Intellectual Disability Research Sep;61(9):843-852

Typical Aging vs. Aging in IDD

- Typical Aging: predictable gradual decline
- Aging in IDD: earlier onset, accelerated changes, overlapping conditions
    - Down syndrome – Accelerated aging (15-20 years)

While aging follows a typical pattern for most people, adults with DS experience earlier and more pronounced changes—especially those with lifelong health disparities or sensory impairments.

Down Syndrome: Unique Aging Profile

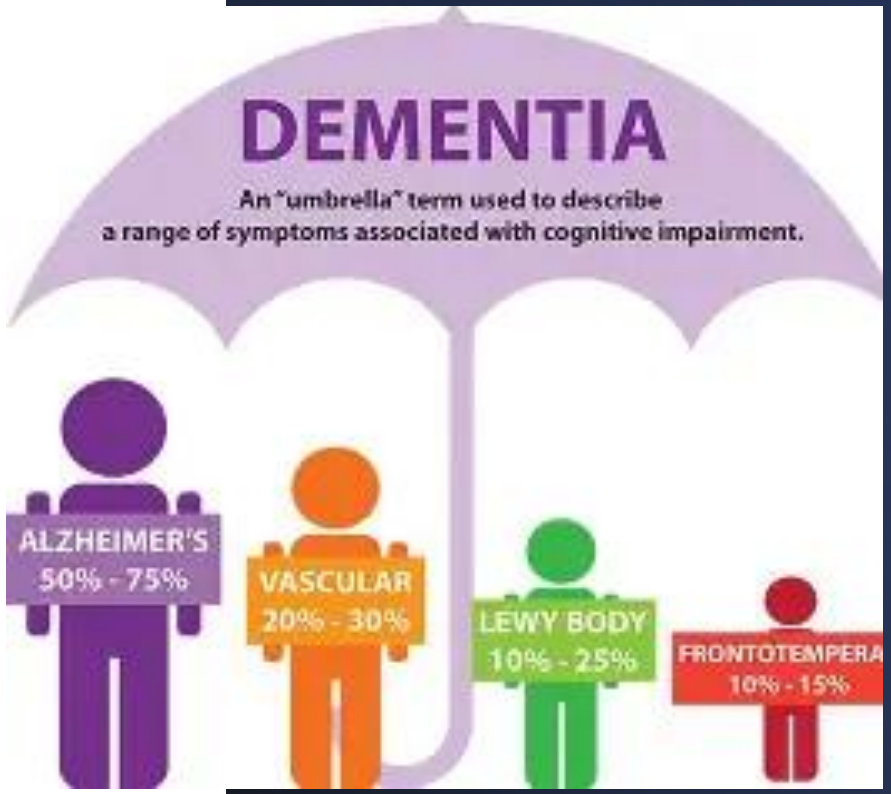
- Earlier onset of Alzheimer's
- Biological factors (chromosome 21 → APP gene)
- Average onset often in the 40s–50s

Early monitoring is essential.

“Know Enough to be Dangerous”

First…what is dementia?

- Dementia is an “umbrella term”
- Dementia is NOT a disease
- NOT ALL CHANGE IS DUE TO DEMENTIA
- **Many changes can be due to** medications, depression, delirium, sensory loss, sleep apnea, hypothyroidism, B12 deficiency, celiac disease, pain (especially if unaddressed), NPH, extreme psychosocial stressors…even Lyme disease
- A proper “differential diagnosis” is critical (more on this shortly)
- A diagnosis of any kind of dementia should **NEVER** be made on the basis of one office visit (or a phone call) or on symptoms alone!



Regression (DSRD) vs. Alzheimer's

- Under age 40 Alzheimer's disease is very uncommon.
- Sudden change in younger adults, adolescents, and children is likely Down Syndrome Regression Disorder (DSRD)
- Symptoms mimic the symptoms of Alzheimer's – behavioral changes, loss of previously acquired skills
- This is a potentially treatable condition
- Diagnosis of exclusion – All potentially treatable conditions must be excluded…and it's a long list.
- Cause unknown, likely a number of factors – autoimmune disorders, stress/emotional trauma
- Jonathan Santoro, MD

It’s More Than Memory

What changes might you see?

What changes might you observe in daily activities?

ADLs

- Incontinence
- Balance and gait problems
- Apraxia- dressing, feeding, speaking
- Increased need for assistance with bathing and grooming

IADLs

- Difficulty handling money (if this was previously a skill)
- Difficulty maintaining one's own living space
- Difficulty using the phone or other devices

Source: Lucille Esralew, Ph.D.

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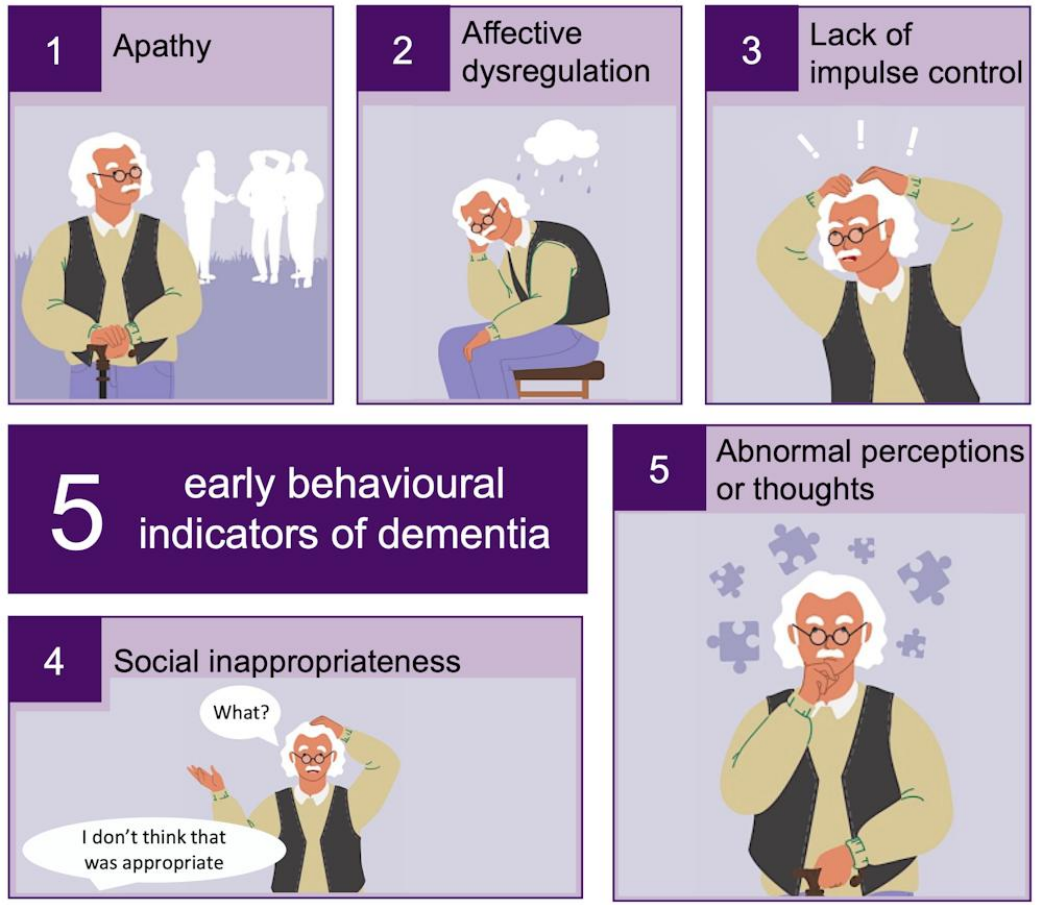
What Changes Might You Observe in Behavior?

- Increased impulsivity: hoarding, verbal and physical aggression
- Increased reactivity to others
- Social behavior not matched to social situations
- Increased restlessness and agitation



Source: Lucille Esralew, Ph.D.

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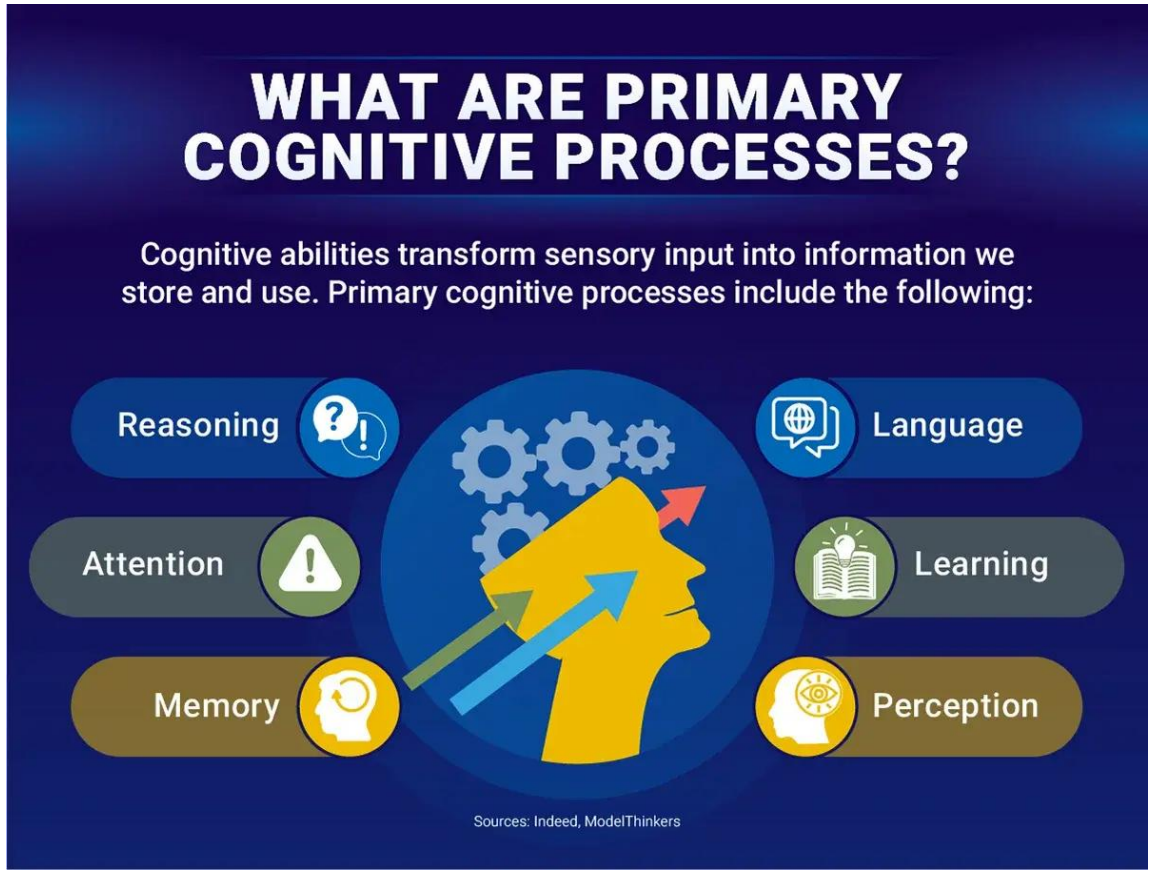
What Changes Might You Observe in Cognition (Thinking)?

- Memory changes that interfere with productivity at work or chores at home
- Problems maintaining focused attention; the person becomes highly distractible
- Difficulty adapting to change
- Language skills may become impoverished

Source: Lucille Esralew, Ph.D.



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Determining the cause of these changes is challenging for health care professionals

- No training in medical or nursing school
- Underlying disability and medical conditions create diagnostic challenges for health care professionals and can lead to potentially treatable conditions being misdiagnosed as dementia.
- Service providers and caregivers (professional and families) need to “know enough to be dangerous” to advocate for the individual with ID.
- Tool: NTG-EDSD

Diagnostic Overshadowing

Attribution of symptoms to a pre-existing condition rather than a potential co-morbid condition

- Can be detrimental to quality of care and can **contribute to delays in diagnosis and treatment, unnecessary or unsafe care** and inequities of care.
- **Contributes to health disparities** and is of particular concern in groups experiencing health disparities, such as individuals with disabilities.
- Speed, stress and lack of training contribute to diagnostic overshadowing.
- **Most clinicians do not have training**, experience and skills grounded in treating individuals with disabilities – again putting these individuals at increased risk for diagnostic overshadowing.

Examples:

- Withdrawal → assumed "non-social"
- New confusion → assumed "low functioning"
- Sleep changes → assumed "routine issue"

Sentinel Event Alert

A complimentary publication of The Joint Commission — Issue 65, June 22, 2022

Diagnostic overshadowing among groups experiencing health disparities

A 42-year-old woman with a diagnosis of mental illness visited a gastroenterologist after experiencing frequent nausea and stomach pain. The doctor diagnosed functional abdominal pain syndrome (FAPS) and told the patient she would have to "learn to live with it." Later, the patient discovered FAPS was a "somatization disorder," meaning that her pain was attributed to her mental and emotional state. The patient lived with the pain and nausea for months and began unintentionally losing weight, which triggered anorexia. Eventually the patient sought out a new gastroenterologist at a women's medical center. This time, the physician took her symptoms seriously, put her through a series of tests, and after administering a breath test, determined that the patient suffered from small intestinal bacterial overgrowth.[1]

The initial misdiagnosis had a significant impact on the quality of life of this patient, who spent over a year recovering her lost weight and getting her eating disorder under control. This patient still takes medication for her mental illness diagnosis but is tempted to leave these off the medication list she provides to future healthcare practitioners. This was the second misdiagnosis she received in two years, so she worries about disclosing her medication regimen since it may influence how the doctor sees her.[1]

This situation – given from the patient's point of view – is an example of the risk of diagnostic overshadowing, defined as the attribution of symptoms to an existing diagnosis rather than a potential co-morbid condition.[2,3] The medical literature includes extensive evidence that diagnostic overshadowing exists within the interactions of clinicians with patients of all ages who have physical disabilities or previous diagnoses such as, but not limited to, au
neurological deficits, as well as patients with cond
but not limited to, LGBTQ identifications, history o
literacy and obesity.[2,4-23]

Why it is important to address diagnostic oversha

- ***Diagnostic overshadowing is a harm that***
  Correlated to clinician bias (i.e., cognitive
  can be detrimental to quality of care and
  diagnosis and treatment, unnecessary or
  care.[25] Once an initial diagnosis has beer
  takes hold and reduces a clinician's abilit
  This bias can affect future patient workup
  providers are framed. See the sidebar, "C
  bias/diagnostic overshadowing."
- ***Diagnostic overshadowing contributes to***
  particular concern in groups experiencin
  individuals with disabilities.
- ***Many people have a pre-existing diagnos***
  overshadowing can occur with virtually ar
  diagnosis or condition. Over 1 billion peo
  disability. This corresponds to about 15%
  to 190 million (3.8%) people aged 15 yea
  difficulties in functioning, often requiring
  of people experiencing disability is increa
  conditions and population aging. People

Published for Joint Commission accredited organizations and interested health care professionals, *Sentinel Event Alert* identifies specific types of sentinel and adverse events and high-risk conditions, describes their common underlying causes, and recommends steps to reduce risk and prevent future occurrences.

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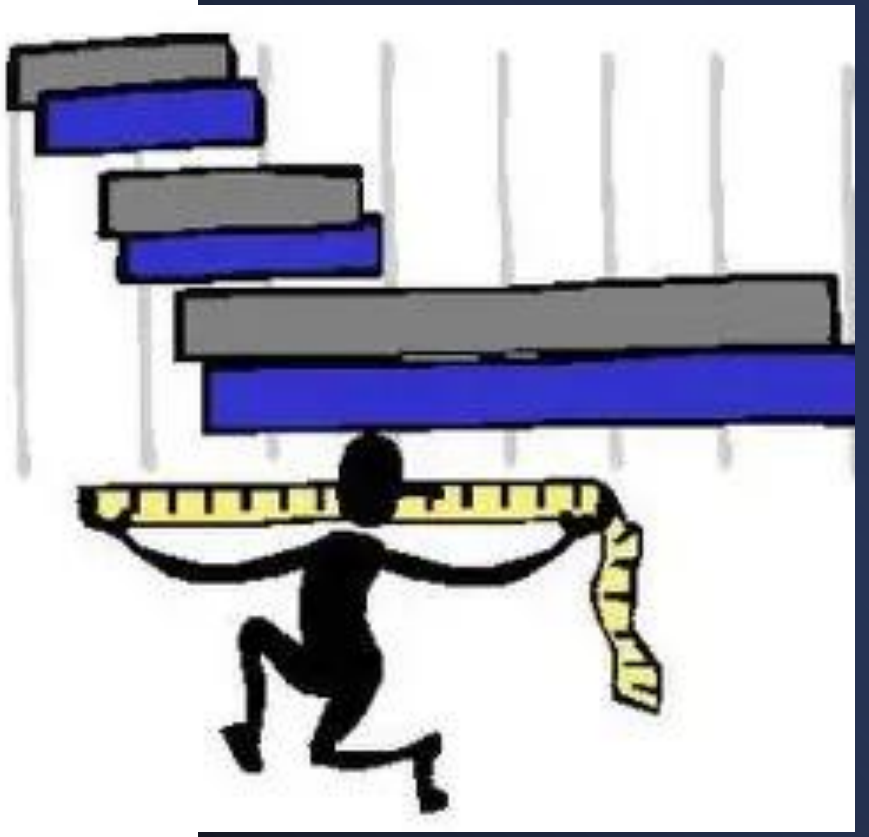
Noticing change?

NTG-Early Detection Screen for Dementia “EDSD”

A useful **tool and resource** for caregivers.

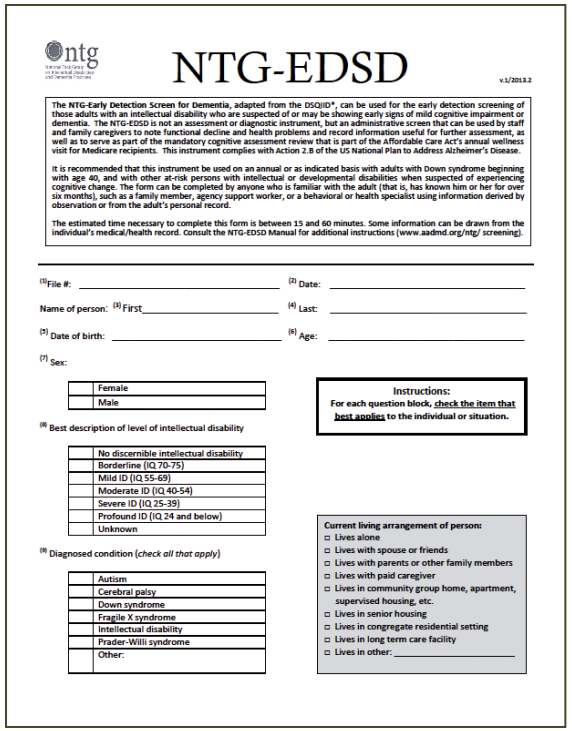
Caregivers play a critical role in noticing changes early.

- Early signs are subtle
- Behavior often changes before memory
- Compare *current* behavior to *baseline* functioning



NTG-Early Detection Screen for Dementia (NTG-EDSD)

- Completed by support staff, family, and other stakeholders to note the presence of key behaviors associated with dementia
- Picks up on health status, ADLs, behavior and function, memory, and self-reported problems
- Available in multiple languages ***www.the-ntg.org***



NTG-EDSD

v.1/2013.2

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.

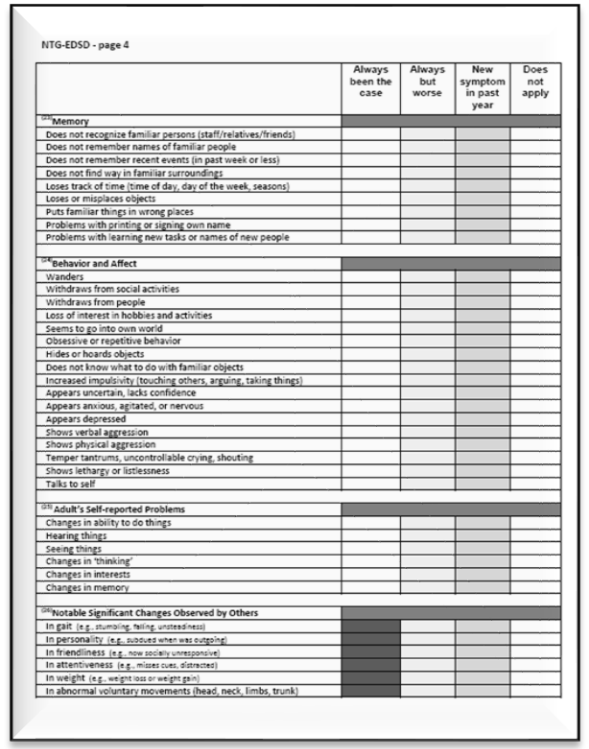
(8) Best description of level of intellectual disability

	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

(9) Diagnosed condition (*check all that apply*)

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

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: _____



NTG-EDSD - page 4

	Always been the case	Always but worse	New symptom in past year	Does not apply
(10) Memory				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
(11) Behavior and Affect				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
(12) Adult's Self-reported Problems				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
(13) Notable Significant Changes Observed by Others				
In gait (e.g., stumbling, failing, unsteadiness)				
In personality (e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

Who Can Be Screened Using This Rating Tool?

- Any individual with IDD, regardless of the cause of their IDD
- A person with Down syndrome beginning at ages 35-40 (Note: this suggestion is a change from recommendations printed on the form)
- A person with non-Down syndrome IDD (intellectual disability, ASD, Fetal Alcohol Syndrome, Epilepsy, CP, et al.) beginning at age 50 or when changes have been noted
- Anyone can complete the EDSD!

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The Importance of Baseline Information

- When we measure “baseline,” we are identifying someone’s usual or typical behaviors or functioning.
- This helps us recognize when a person may be changing in their usual, typical behaviors and skill sets.
- By identifying what is changing and what remains the same, we have a better idea of how to tailor services, care, and support.

An advocacy tool!

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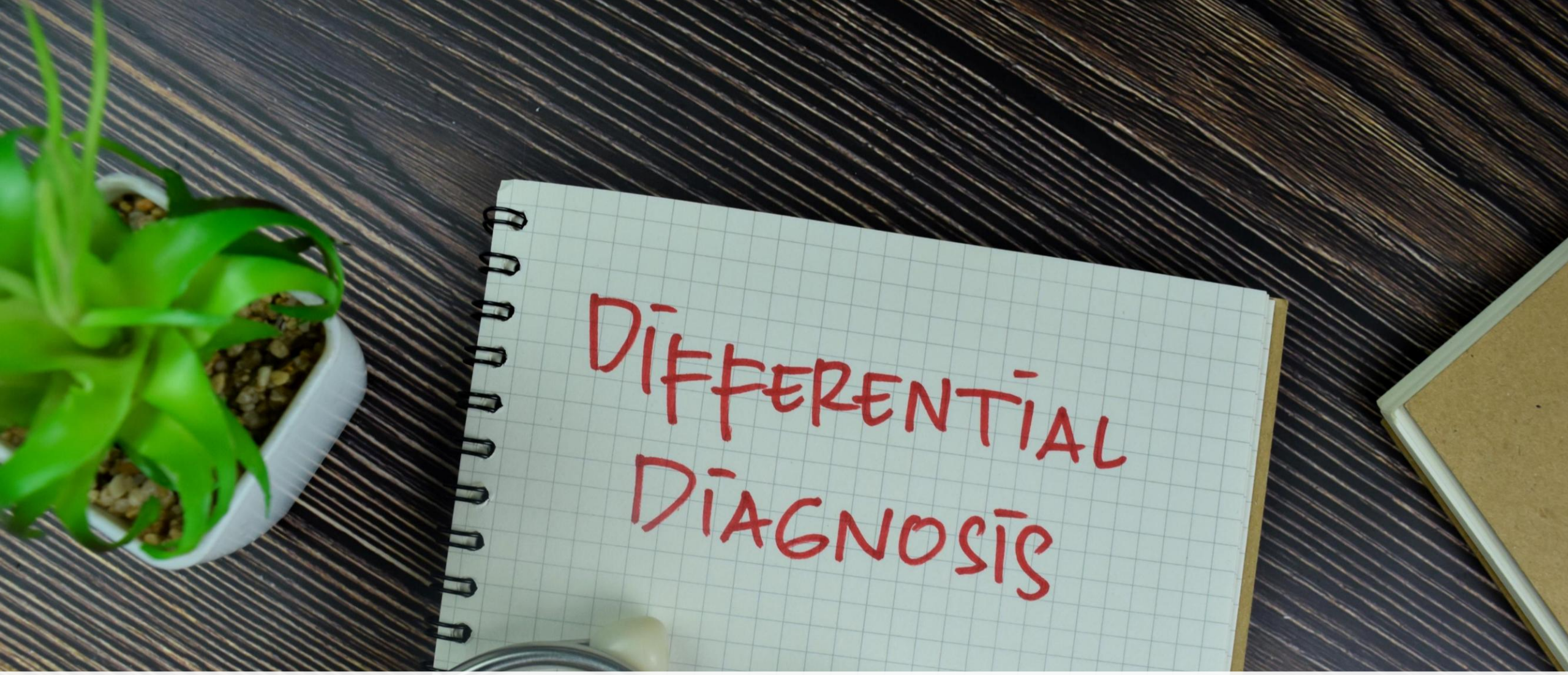
After you have completed the EDSD

Next Steps



Differential Diagnosis…when symptoms could be caused by a number of different causes

Delirium – Medical Emergency

- Sudden change?
- Most common causes: Urinary tract infection, fecal impaction, pneumonia…but that's the short list
- Medical evaluation ASAP!

Recent stressors?

Major Life Changes or Loss

- Death or illness of a parent, sibling, caregiver, or long-term staff
- Moving to a new home or losing familiar routines
- Retirement from a day program or job
- Losing friends or peers in their living environment
- Reduced independence due to health change

Health Stressors:

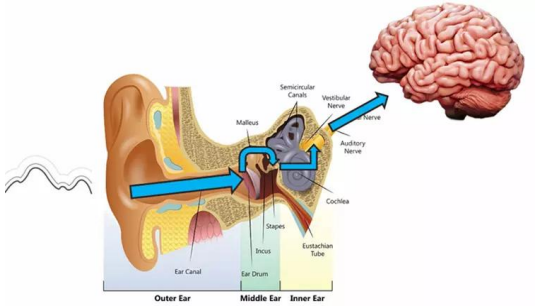
- Untreated pain (tooth pain, arthritis, constipation, infections)
- Sleep disorders, including sleep apnea
- Hearing or vision loss
- Thyroid disorders (common in DS)
- Onset of dementia, especially Alzheimer's disease
- Medication side effects or interactions

Changes in Caregivers or Staff Turnover

- New staff members who don't know their routines
- Multiple changes in caregivers or support team
- Lack of consistent communication or expectations

Hearing or Vision Impairments?

- 50-80% of people with Down syndrome have hearing issues that range from mild to profound (Yahia et al.)



- Eye disease is reported in 60-80% of patients with Down syndrome including less severe problems like tear duct abnormalities to vision-threatening diagnoses such as early age cataracts (Bull et al., 2022).

Medications?

- Metabolism is decreased as we age (remember accelerated aging of people with Down syndrome)
- Prescribing cascade
- Polypharmacy? 10 or more
- Types of medications
    - Beers List 2023*
    - Anticholinergics* – antipsychotics, Benadryl, overactive bladder
        - Anticholinergic Burden Scale, benzodiazepines (better - Trazadone)
    - Seizure medications – Depakote (agitation, confusion…check ammonia level)

*** Will be included in resources**

Recommended Lab Tests

- Complete blood count {(CBC)
- Metabolic function tests - Electrolytes (particularly sodium), Glucose, kidney function B12 levels
- Thyroid levels
- Folate level
- In patients with rapidly progressive symptoms, CSF analysis should be considered for prion disease or other infectious processes.

Other:

- CT, MRI
- Lumbar puncture
- Neuropsychological testing
- PET Scan

What if it is Alzheimer’s?

Medications and management

Medications for Alzheimer's

Standard medications

- Acetylcholinesterase inhibitors: Aricept (donepezil), Exelon (rivastigmine), Razadyne/Reminyl (Galantamine)
- NMDA (N-methyl-D-aspartate) inhibitor: Namenda (memantine)

New therapeutics

- Leqembi, Donanemab

Behaviors & Nonpharmacologic Management

- Identify triggers
- Control pain, overstimulation
- Communication strategies – Don’t argue, “therapeutic fiblets”
- Medication may be warranted for anxiety, depression
- Environmental modifications – Color contrast, eliminate glare and reflections, remove dark rugs
- Delirium – sudden change is a medical emergency
- Antipsychotics – start low and go slow only after attempting nonpharmacologic management strategies

General Strategies

- Caregiver education! Knowledge is power
  - Behaviors are generally a reaction to something in the environment, pain, confusion, caregiver interaction.
- Advance planning
  - Aging in place?
  - Have a plan…and a back-up plan
- Assemble your “team”
- Know your limits (a strength, not a weakness)
- Self-care
- Palliative care, hospice

Lifespan Approach

A lifespan approach

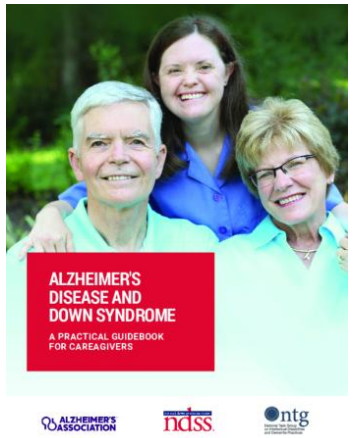
- Life story to share with providers and caregivers
- Healthcare and Lifestyle: Regular healthcare, healthy lifestyle choices, and mental stimulation are essential for maintaining brain health and preventing cognitive decline

This approach highlights the importance of a holistic view of brain health, considering both biological and environmental factors throughout the lifespan.

Tools and Resources

NTG-EDSD

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia In Adults With Intellectual Disabilities



The National Down Syndrome Society, in partnership with The National Task Group on Intellectual Disabilities and Dementia Practices and the Alzheimer's Association, is releasing a guidebook specifically for those caring for an individual with Down syndrome diagnosed with Alzheimer's disease.

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Do you want to talk about dementia with someone who has a learning disability?

Scroll down to learn more about Jenny's Diary

Download Jenny's Diary 2025

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Advocate Medical Group
Adult Down Syndrome Center

I'm looking for...

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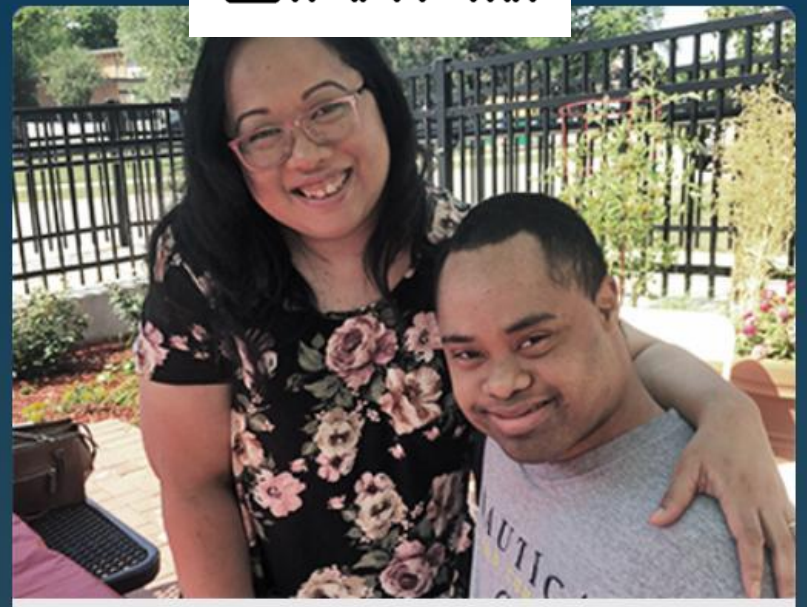
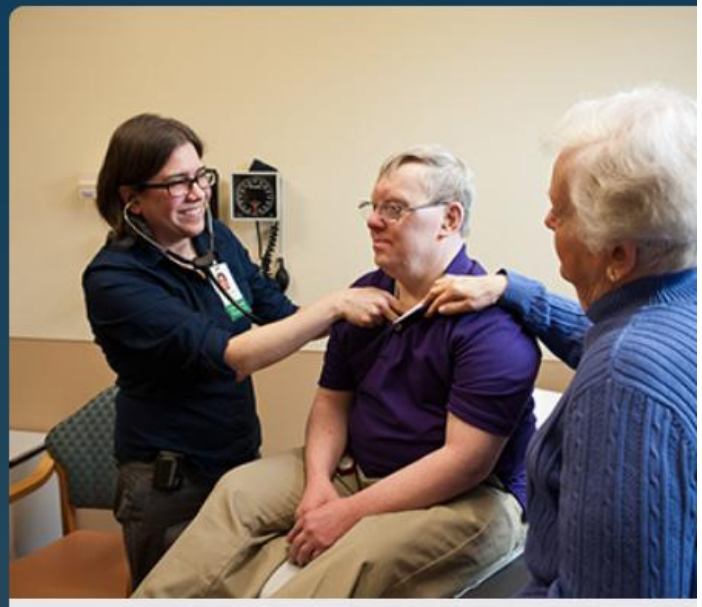
Resource Library | All Resources

People with Down Syndrome



Families & Caregivers



Health Care Professionals

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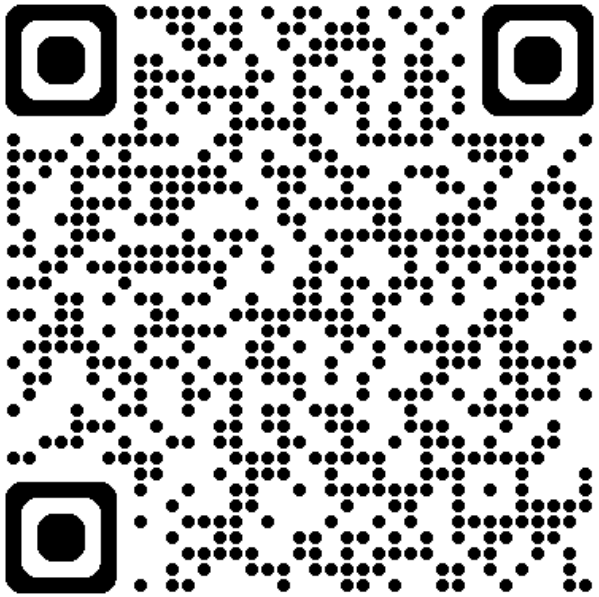

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Home | Family Support | Professionals | NTG-EDSD | Training | Resources | Projects

Family Support

QUICK LINKS

- Family Caregiver Resources
- Family Webinars & Recordings
- Frequently Asked Questions
- Family Support Groups
- Screening (NTG-EDSD)
- Resources on Family Caregiving
- Resources on Dementia & AD
- DS-MIG ECHO for Families
- NTG Caregiver Newsletters

Helen Journal

Dear Families,

As the mother of three adult children with Down syndrome (two of whom have mild dementia), it is my honor to welcome you to The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) Family Support website. As family caregivers, we are always looking for information, resources and support to enable us to be the best caregivers we can be. We recognize that many family members provide hands-on, day-to-day care, others provide financial or legal assistance, while others are involved from a distance, but still in important ways. And, the NTG recognizes the care given by Direct Support Professionals (DSPs) and strives to provide them with the information and support they need. No matter how you provide care, the work NTG does supports all caregivers, especially family caregivers.

The NTG is committed to providing the most current information and resources on disability and dementia topics and to offer support. As researchers and physicians learn more about treating dementia, we will bring that information to you along with information on topics that many families are searching for. I also invite you to join our new webinars and podcasts and our virtual family support group. The NTG's Family Support's email is familysupport@the-ntg.org should you ever have a question or concern. Remember, you are not alone on your caregiving journey even though some days you may feel that you are. The NTG is here for you.

Nancy Murray

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Questions and Discussion

What are you hearing?
How can the NTG support you in your work?

Contact me anytime...

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