What if?....
&
Now what?

Navigating aging & dementia care needs for adults with Down syndrome

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Photo from guidebooks produced by ndss.org

Life expectancy for adults with Down syndrome

Over the past century:

9 years in the 1920's

60 years in the 2000's

Photo from guidebooks produced by ndss.org

Growth in Demographics of Adults with DS since 1950

Population

- **How many people with Down syndrome are living in the U.S. today?** Including people born outside of the U.S., we estimate that the number of people with Down syndrome living in the U.S. has grown from 49,923 in 1950 to 220,186 in 2018 (Figure 5).

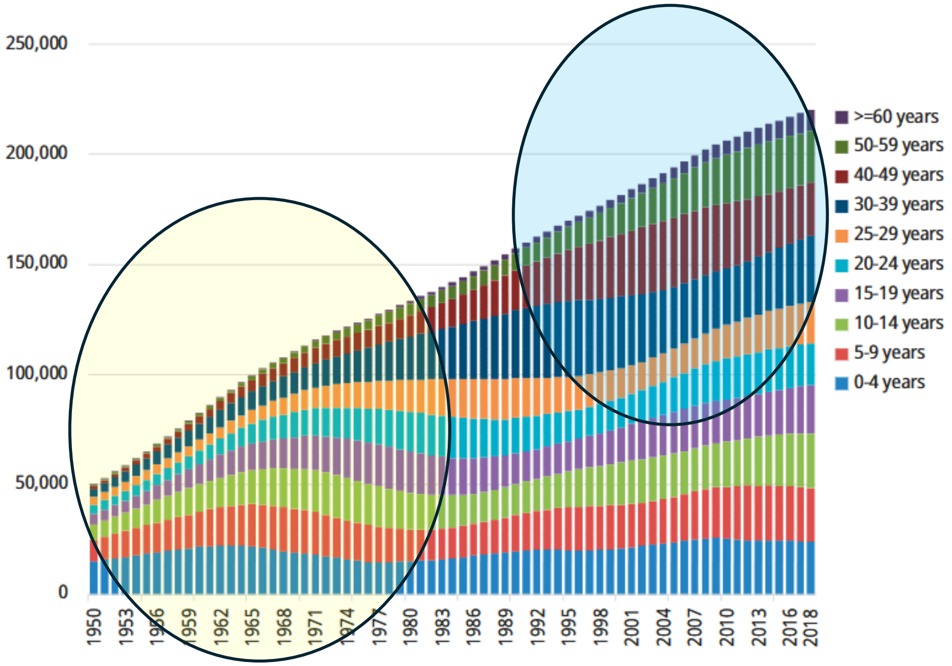
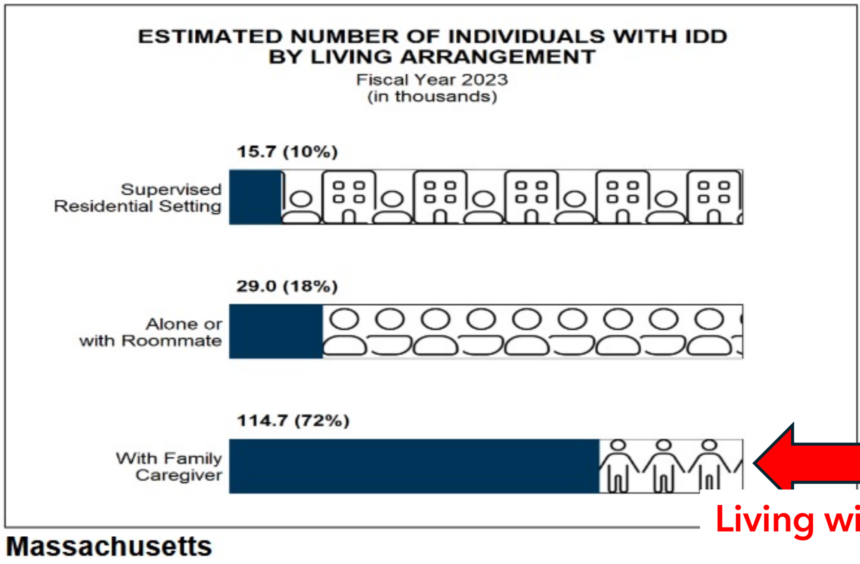


Figure 5. Population of people with Down syndrome in the USA, 1950-2018

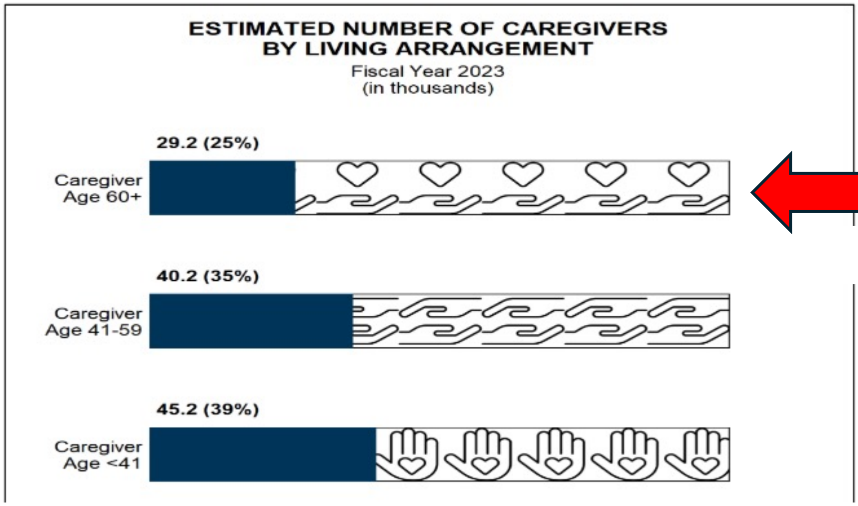
Accessed January 14, 2026
Updated: December 17, 2025 |
https://go.downsyndromepopulation.org/usa-factsheet

Living arrangements and caregiver demographics for people with I/DD in Massachusetts



72%

Living with a family caregiver



25%

Caregiver age 60+

Source: Tanis, E.S., et al. (2025). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Disabilities, The University of Kansas. https://stateofthestates.ku.ed

Growing Older

- Accelerated aging
- Common aging-related conditions are encountered at an earlier age
- Overexpression of multiple genes on chromosome 21 contribute to aging process

Photo from guidebooks produced by ndss.org

Common conditions with aging:

- Vision and hearing loss
- Obstructive sleep apnea
- Celiac disease
- Cervical spine disease
- Thyroid dysfunction
- Osteoarthritis
- Osteoporosis
- Obesity/overweight
- Menopause
- Dental disease
- Functional decline
- Mental health changes

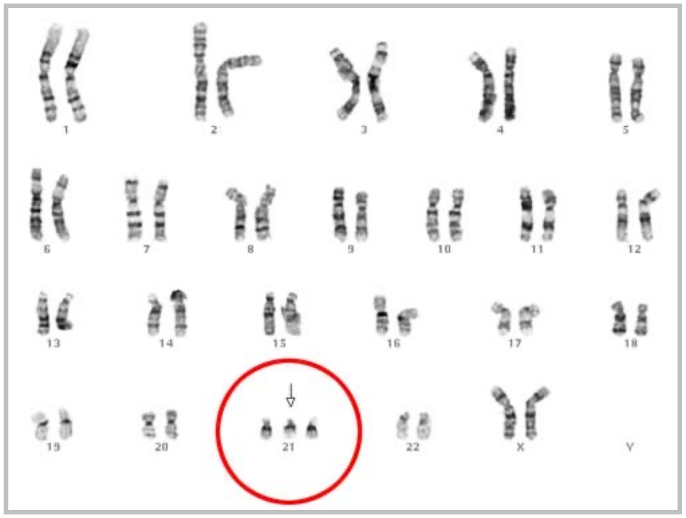
Photo from guidebooks produced by ndss.org

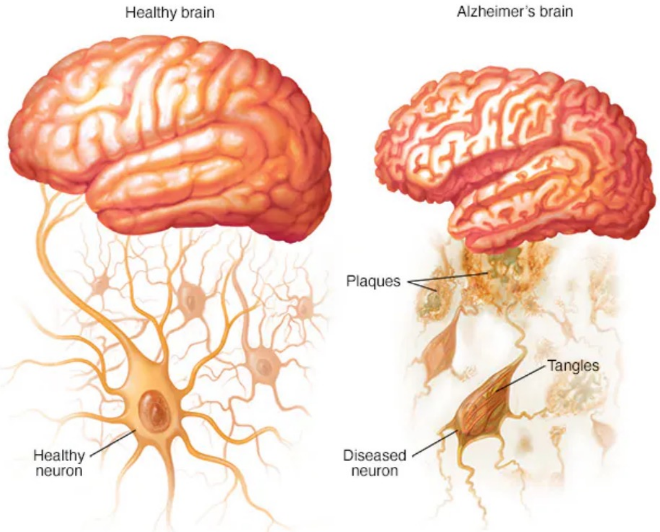
Genetic connection to Alzheimer’s disease

3 copies of chromosome 21 in Down syndrome (trisomy 21)

Gene that codes for amyloid precursor protein (APP) overexpressed due to extra copy of chromosome 21, leading to overproduction/accumulation of beta amyloid

Chromosome 21 also has genes associated with changes related to accelerated aging





Accessed from mayoclinic.org 3/2025

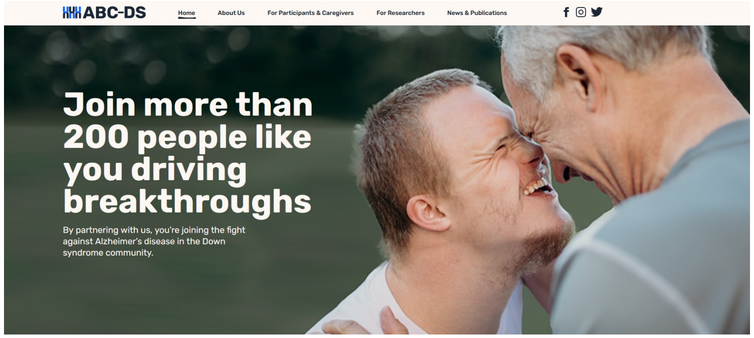
Research output in the past 10+ years has picked up substantially

SAVE THE DATE

Genetically Determined Alzheimer's Disease: ADAD-DSAD Conference

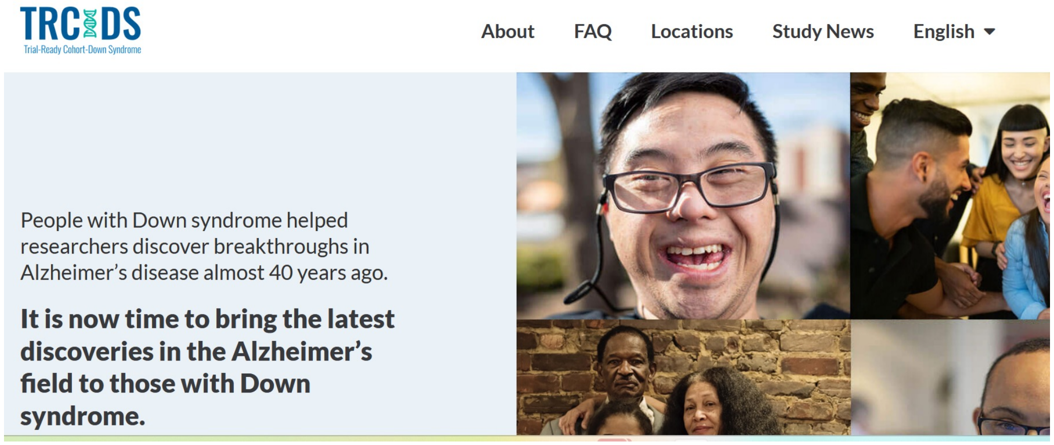
3rd edition

Modernist Hospital of Sant Pau | April 9th and 10th, 2026



Join more than 200 people like you driving breakthroughs

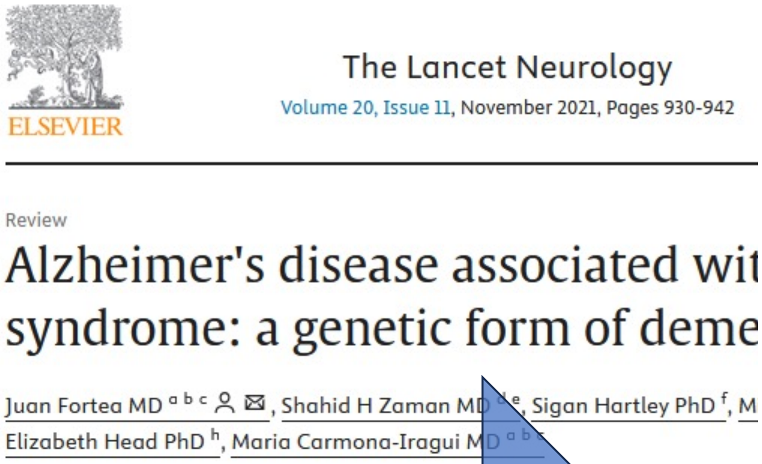
By partnering with us, you're joining the fight against Alzheimer's disease in the Down syndrome community.



People with Down syndrome helped researchers discover breakthroughs in Alzheimer's disease almost 40 years ago.

It is now time to bring the latest discoveries in the Alzheimer's field to those with Down syndrome.

Accessed from websites Feb 2026:
dsad-adad.com; abc-ds.org; trcds.org; actc-ds.org



ELSEVIER

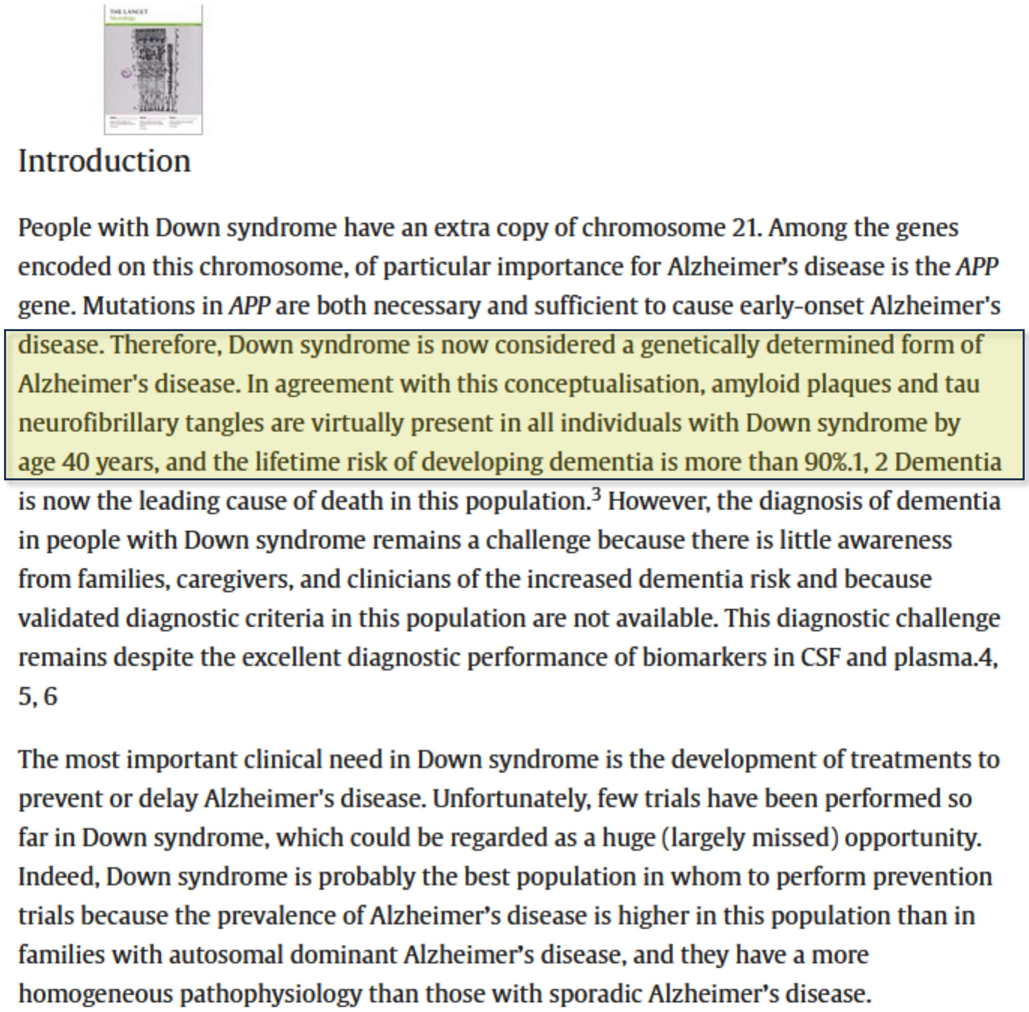
The Lancet Neurology
Volume 20, Issue 11, November 2021, Pages 930-942

Review

Alzheimer's disease associated wit
syndrome: a genetic form of deme

Juan Fortea MD [a b c], Shahid H Zaman MD [d e], Sigan Hartley PhD [f], M
Elizabeth Head PhD [h], Maria Carmona-Iragui MD [a b c]

Current literature now commonly refers to Down syndrome as a 'genetically determined form of Alzheimer's disease and lifetime risk of up to 90%



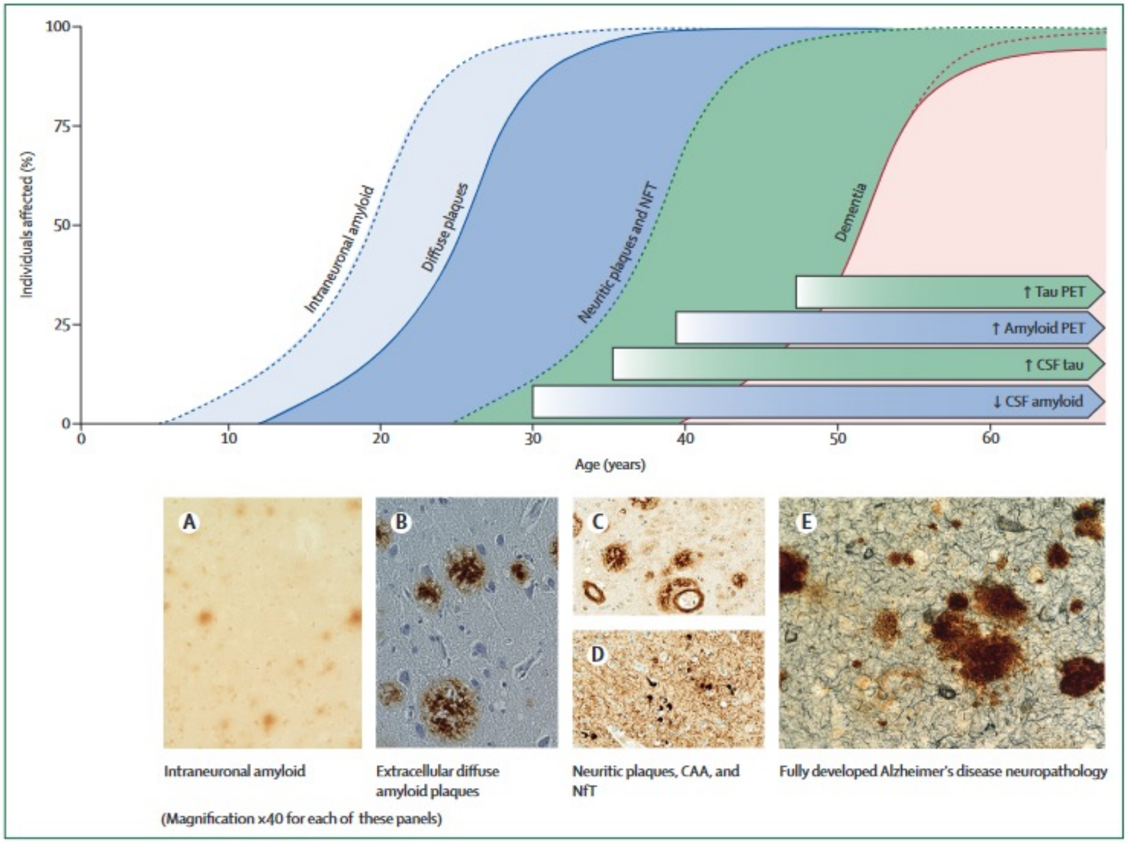
Introduction

People with Down syndrome have an extra copy of chromosome 21. Among the genes encoded on this chromosome, of particular importance for Alzheimer's disease is the *APP* gene. Mutations in *APP* are both necessary and sufficient to cause early-onset Alzheimer's disease. Therefore, Down syndrome is now considered a genetically determined form of Alzheimer's disease. In agreement with this conceptualisation, amyloid plaques and tau neurofibrillary tangles are virtually present in all individuals with Down syndrome by age 40 years, and the lifetime risk of developing dementia is more than 90%.1, 2 Dementia is now the leading cause of death in this population.[3] However, the diagnosis of dementia in people with Down syndrome remains a challenge because there is little awareness from families, caregivers, and clinicians of the increased dementia risk and because validated diagnostic criteria in this population are not available. This diagnostic challenge remains despite the excellent diagnostic performance of biomarkers in CSF and plasma.4, 5, 6

The most important clinical need in Down syndrome is the development of treatments to prevent or delay Alzheimer's disease. Unfortunately, few trials have been performed so far in Down syndrome, which could be regarded as a huge (largely missed) opportunity. Indeed, Down syndrome is probably the best population in whom to perform prevention trials because the prevalence of Alzheimer's disease is higher in this population than in families with autosomal dominant Alzheimer's disease, and they have a more homogeneous pathophysiology than those with sporadic Alzheimer's disease.

Development of pathologic features of Alzheimer's disease over decades

Alzheimer's disease associated with Down syndrome:
a genetic form of dementia
Fortea J et al.
Lancet Neurol 2021; 20: 930–42



Intraneuronal amyloid

Extracellular diffuse amyloid plaques

Neuritic plaques, CAA, and NfT

Fully developed Alzheimer's disease neuropathology

(Magnification x40 for each of these panels)

***Figure 1:* Lifelong accumulation of Alzheimer's disease neuropathology in people with Down syndrome**
Intraneuronal amyloid accumulation starts in the first decade of life (blue dotted line [A]; frontal cortex). The deposition of extracellular diffuse plaques (solid blue line) starts in adolescence and is then observed in nearly all individuals after age 30 years ([B] cingulate gyrus). Amyloid deposition progresses with the accumulation of compact neuritic plaques ([C] superior temporal gyrus) in the fourth decade. Tau pathological changes are observed starting in the third decade, with subsequent appearance of NFT in the fourth decade ([D] superior temporal gyrus). After age 40 years, the pathological diagnostic criteria for Alzheimer's disease are fulfilled (dotted green line; [C, D]) and pathological changes continue to increase in severity in old age ([E] frontal cortex). Amyloid and tau deposition can be detected through in-vivo biomarkers. CSF changes occur almost 10 years before they are detectable with PET. After age 40 years, the prevalence of dementia increases exponentially, affecting more than 90% of adults older than 60 years of age (solid red line); Alzheimer's disease is possibly fully penetrant in individuals with Down syndrome (red dotted line). NFT=neurofibrillary tangles. CAA=cerebral amyloid angiopathy.

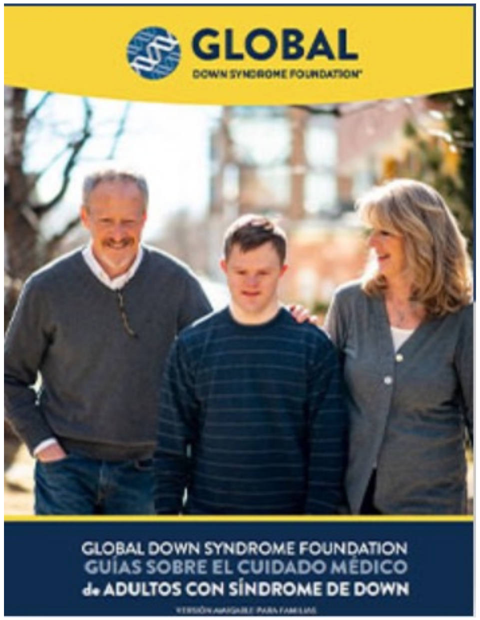
So….what if?

Putting action behind what we know now:

- Various and overlapping aging-related changes are common/expected with advancing age
- PLUS risk of developing dementia is high

- Seek out/advocate for health care attuned to the needs of adults with Down syndrome throughout the lifespan -

Lots of good resources to get started


GLOBAL
DOWN SYNDROME FOUNDATION
GLOBAL DOWN SYNDROME FOUNDATION
GUÍAS SOBRE EL CUIDADO MÉDICO
de ADULTOS CON SÍNDROME DE DOWN

GLOBAL Adult Guideline published in the Special Communication section of the print and online October 2020 issue of JAMA, available at: globaldownsyndrome.org

CARE DOWN SYNDROME
national down syndrome society

DSC2U
Down Syndrome Clinic to You


AGING AND DOWN SYNDROME
A HEALTH AND WELL-BEING GUIDEBOOK
ALZHEIMER'S ASSOCIATION
ndss
ntg

ndss.org/resources; careds.org; dsc2u.org

Get a good assessment

- **depending on geography, resources, services – this can feel much easier said than done…however:*

- Don’t let prevalence poison curiosity

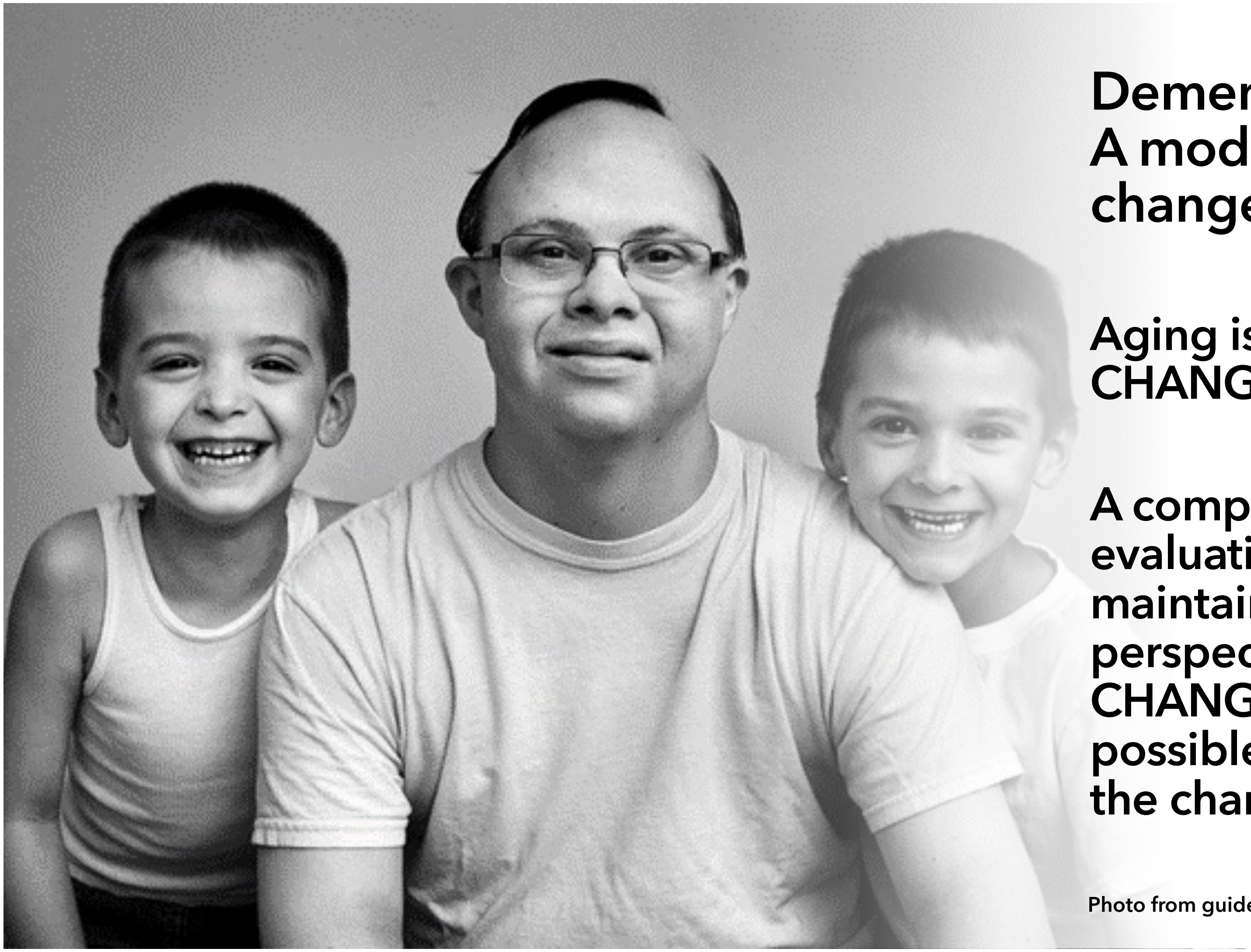
- Dementia remains primarily a clinical diagnosis

- Additional diagnostics are supportive to the clinical framework

- Assessment is largely based in history taken from collateral informants. Conversation/dialogue with family and caregivers is a springboard to many important and person-centered next steps.

A Framework for Assessing Change*

* Of all kinds

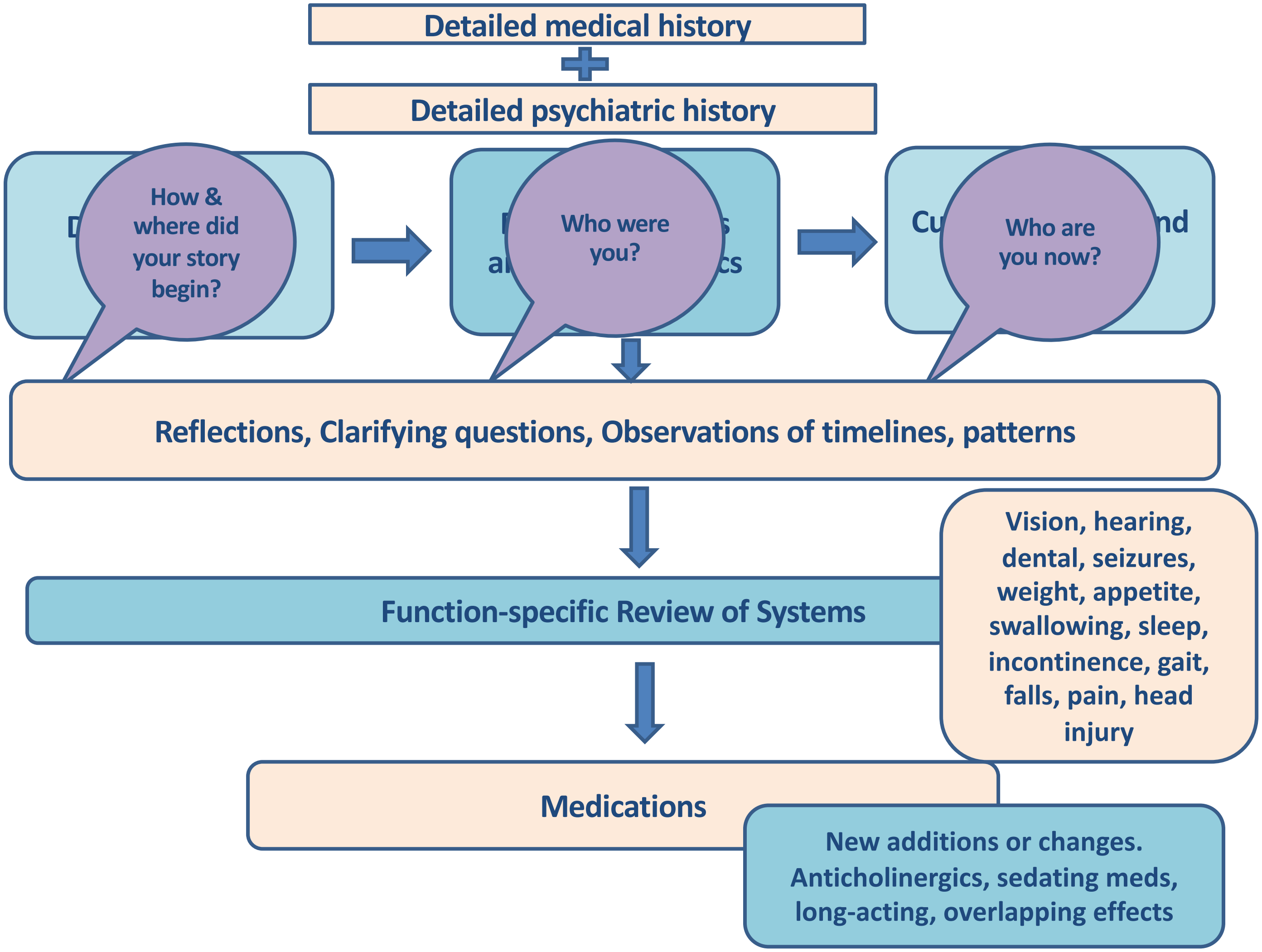


Dementia assessment: A model for assessing change

Aging is a function of CHANGE over time

A comprehensive evaluation should maintain a broad perspective of assessing CHANGE, looking for all possible contributors to the changes that are seen

Photo from guidebooks produced by ndss.org



Detailed medical history

+

Detailed psychiatric history

How & where did your story begin?

Who were you?

Who are you now?

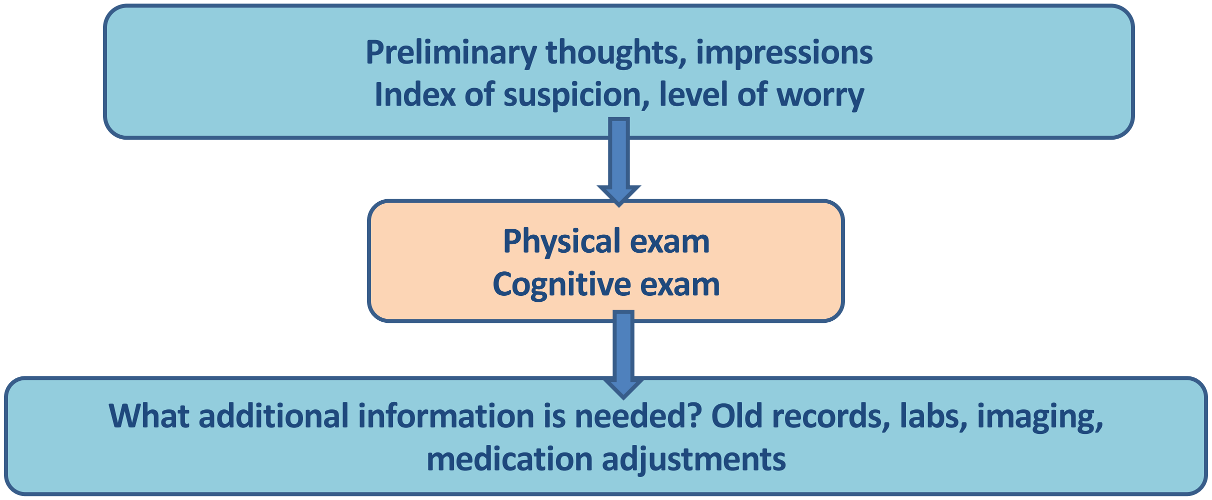
Reflections, Clarifying questions, Observations of timelines, patterns

Function-specific Review of Systems

Vision, hearing, dental, seizures, weight, appetite, swallowing, sleep, incontinence, gait, falls, pain, head injury

Medications

New additions or changes. Anticholinergics, sedating meds, long-acting, overlapping effects



Preliminary thoughts, impressions
Index of suspicion, level of worry

Physical exam
Cognitive exam

What additional information is needed? Old records, labs, imaging, medication adjustments

Diagnostic impressions
AND thoughts about coexisting contributing factors:

What items are:
- -Treatable
- -Improvable
- -Modifiable

What can we do to move the needle?

DSM-IV criteria for dementia	DSM-5 criteria for major neurocognitive disorder (previously dementia)
A1. Memory impairment	**A.** **Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains*:** - Learning and memory - Language - Executive function - Complex attention - Perceptual-motor - Social cognition
A2. At least one of the following: - Aphasia - Apraxia - Agnosia - Disturbance in executive functioning	
B. The cognitive deficits in A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning	**B.** The cognitive deficits interfere with independence in everyday activities. At a minimum, assistance should be required with complex instrumental activities of daily living, such as paying bills or managing medications.
C. d	ognitive deficits do not occur exclusively in ext of a delirium
	ognitive deficits are not better explained by mental disorder (eg, major depressive der, schizophrenia)

Storytelling, history

References:
American Psychiatric Association Diagnostic and Statistical Manual, 4th ed, APA Press, Washington, DC, 1994.
American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), American Psychiatric Association, Arlington, VA 2013.

DIAGNOSIS AND TREATMENT GUIDELINES
Consensus Recommendations

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

Julie A. Moran, DO; Michael S. Rafii, MD, PhD; Seth M. Keller, MD;
Baldev K. Singh, MD; and Matthew P. Janicki, PhD

Mayo Clin Proc. August 2013;88(8):831-840

TABLE 2. Common Contributors to Memory Changes in Adults With I/DD

Condition	Presentation
Sensory deficits	Hearing loss Vision loss, low vision, depth perception changes
Metabolic disturbances	Electrolyte abnormalities Hypoglycemia/hyperglycemia B_{12} or folate deficiencies Undetected thyroid dysfunction Anemia Toxic levels of antiepileptic or psychoactive medications Toxic adverse effects of certain medications (eg, hyperammonemia in chronic valproic acid use)
Coexisting mood disorder	Either newly detected or subacute worsening of baseline mood disorder Note: Depression can cause symptoms that seem similar to dementia and can co-occur with early dementia
Pharmacologic concerns	Polypharmacy, drug-drug interactions, and altered pharmacokinetic properties
Sleep problems	Sleep apnea and other undetected sleep disorders
Seizures	Undetected or worsening seizure disorders
Pain	Undiagnosed pain or undertreated pain
Mobility problems	Mobility disorders and loss of functionality
Psychosocial or environmental stressors	Changes in routines, death or impairment of family members or close acquaintances, new regimen at home or in the workplace, reactions to threatening situations
Others	Conditions that may be associated with cognitive deficit (chronic subdural hematoma, brain tumors, multiple sclerosis, human immunodeficiency virus, and cryptococcal infection)
Additional considerations: prevalent conditions in adults with Down syndrome	Vision impairment due to early development of cataracts and increased risk of keratoconus Hearing loss due to conductive hearing deficits Thyroid dysfunction, particularly hypothyroidism Obstructive sleep apnea Celiac disease Atlantoaxial instability and other cervical spine disorders, including osteoarthritis and spinal stenosis Osteoarthritis and associated pain and mobility limitations

I/DD = intellectual and developmental disabilities.

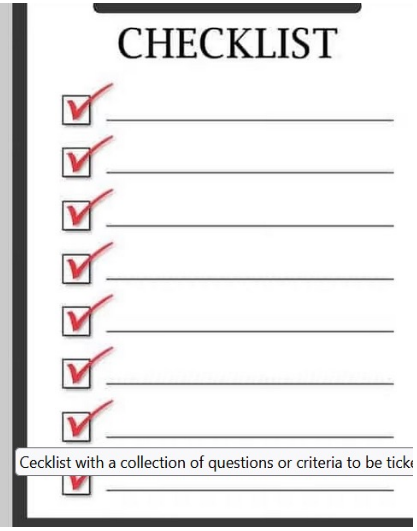
“What If?” Action steps

- ☐ Allow the awareness of risk to help empower good advance planning

- ☐ Plan proactively for AGING, aiming to avoid or minimize any crisis or emergency that could be planned for in advance.

- ☐ Remember that aging comes with CHANGE [for individuals AND caregivers]

- ☐ Please don’t solely rely on a plan that’s contingent on the hope that nothing changes



“What If?” Action steps

- ☐ Think practically beyond wishes and hopes. What would it take to turn those hopes or goals into reality? *(eg: “I want Carl to live at home forever”)*

- ☐ Identify your teammates. Talk to them early and often.

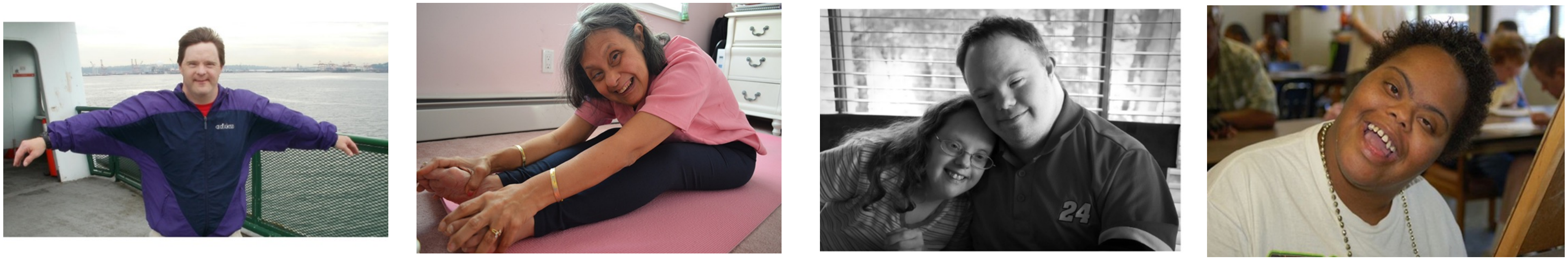
- ☐ Be flexible. “Terms and conditions may apply” for some plans

- ☐ Think about what “matters most”

Cecklist with a collection of questions or criteria to be tick

“What If?” Action steps

- ☐ Document “baseline” as it’s happening!

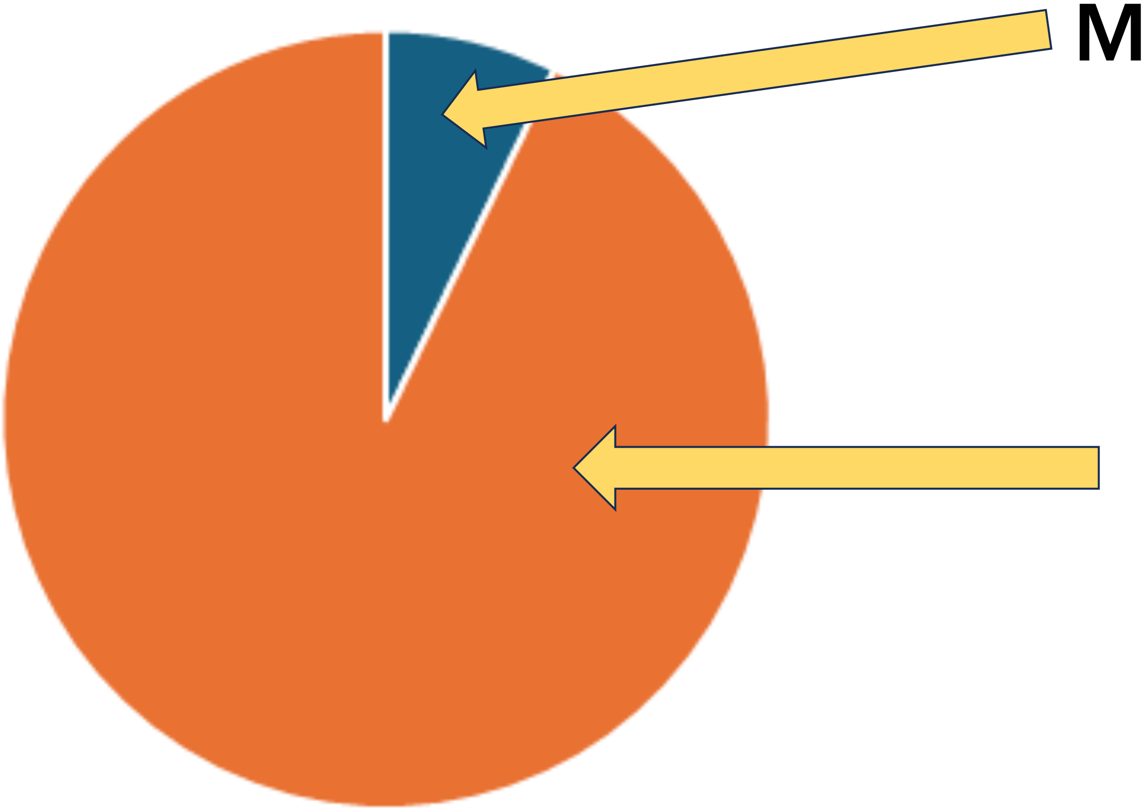


- ☐ Seek out mentally stimulating, enjoyable activities.
- ☐ Nurture social connections with family, peers, community
- ☐ Encourage a healthy diet and regular physical exercise
- ☐ Look at physical environments with a long lens, think about suitability to age in place

Photo from guidebooks produced by ndss.org

Now What?

Treatment



Medications

Everything else

Longstanding medication options:

Cholinesterase inhibitors - (donepezil, rivastigmine, and galantamine)

- increase cholinergic transmission by inhibiting cholinesterase at the synaptic cleft. Modest symptomatic benefit.
- Side effects: GI upset, nausea, dizziness, drowsiness, cardiac effects (bradycardia, syncope, altered cardiac conduction)

NMDA receptor agonists (memantine)

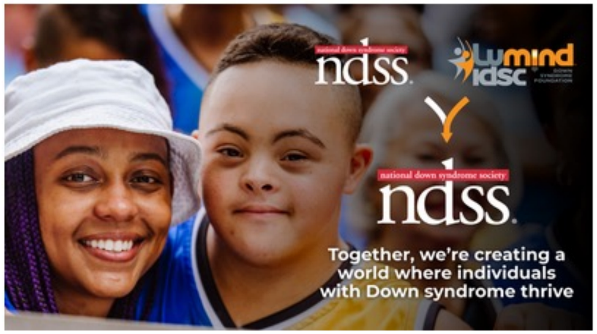
- NMDA receptor is involved in learning and memory. Glutamate is a primary excitatory amino acid in the CNS and overstimulation of receptors leads to excitotoxicity and neuronal cell death.
- Side effects: confusion, dizziness, drowsiness, headache, GI upset

On the horizon

Anti-amyloid therapies, monoclonal antibodies
Expert information here at this conference!

ntg National Task Group on Intellectual Disabilities and Dementia Practices

ABC-DS



Don't miss these medication considerations:

- Treatments to address co-occurring depression or anxiety (common!)
- Optimization of medications to address co-occurring medical conditions
- Options to address pain and discomfort
- The geriatrician's fave: deprescribing

Can you spot the HUGE treatment strategy hidden in all these memory medication ads?

Screenshots from YouTube.com

Caregiving

Alzheimer’s Association. 2025 Alzheimer’s Disease Facts and Figures. Alzheimer's Dementia 2025

WORKFORCE

Nearly 900,000 additional direct care workers will be needed between 2022 and 2032 — more new workers than in any other single occupation in the United States.

CAREGIVING

Nearly 12 million Americans provide unpaid care for a family member or friend with dementia, a contribution to the nation valued at more than $413 billion.

Caring for the Caregiver

Recognizing caregiver/care partner diversity

- Diverse group of individuals who may be family members, caregivers, friends, direct support staff

Prioritizing caregiver well-being

- Finding ways to replenish
- Adequate support for caregivers

Addressing caregiver needs

- Discuss the potential for caregiver stress and burnout
- Seek help when needed: respite
- Grief and bereavement: anticipatory grief, layered losses

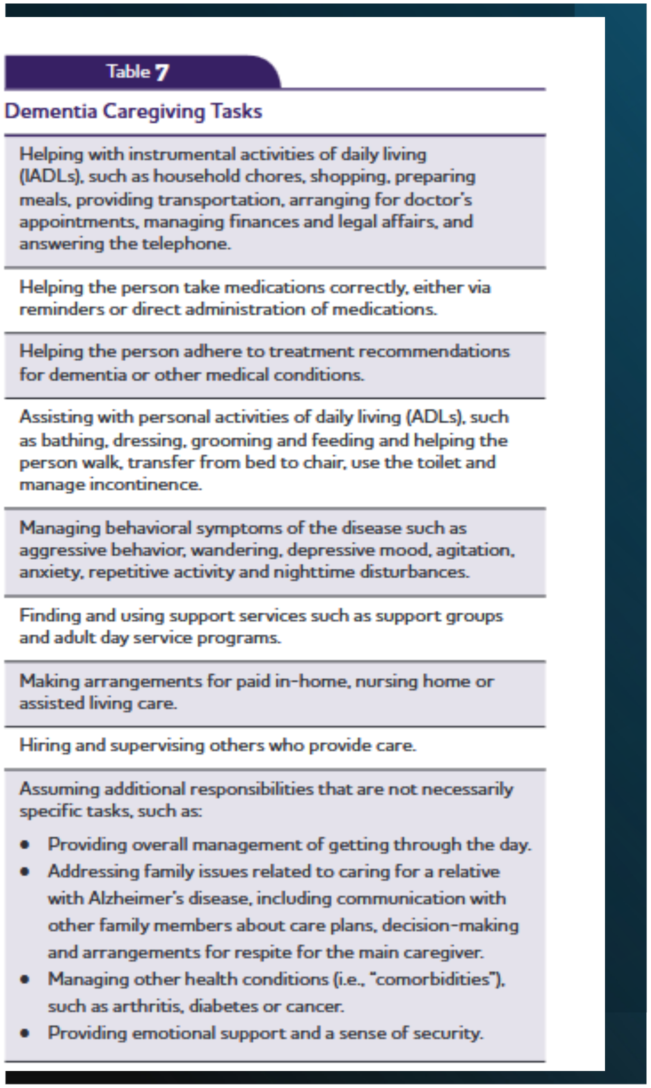


Table 7

Dementia Caregiving Tasks

Helping with instrumental activities of daily living (IADLs), such as household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances and legal affairs, and answering the telephone.
Helping the person take medications correctly, either via reminders or direct administration of medications.
Helping the person adhere to treatment recommendations for dementia or other medical conditions.
Assisting with personal activities of daily living (ADLs), such as bathing, dressing, grooming and feeding and helping the person walk, transfer from bed to chair, use the toilet and manage incontinence.
Managing behavioral symptoms of the disease such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity and nighttime disturbances.
Finding and using support services such as support groups and adult day service programs.
Making arrangements for paid in-home, nursing home or assisted living care.
Hiring and supervising others who provide care.
Assuming additional responsibilities that are not necessarily specific tasks, such as: • Providing overall management of getting through the day. • Addressing family issues related to caring for a relative with Alzheimer's disease, including communication with other family members about care plans, decision-making and arrangements for respite for the main caregiver. • Managing other health conditions (i.e., "comorbidities"), such as arthritis, diabetes or cancer. • Providing emotional support and a sense of security.

Unique Landscape of Down Syndrome & Dementia

- Genetic link = elevated and earlier risk & accelerated aging
- Variable baseline abilities and intellectual disability
- Assessment different from general population
- Differences in communication, emotional and sensory processing
- Diagnostic overshadowing
- Lifelong caregiving
- Dual aging journey
- Sibling caregiving role
- Grief of "hard earned" abilities

Growing Need for Dementia Capable Care

Demographics

- Most adults with Down syndrome live with family or in community settings
- Aging caregivers and housemates create complex and collective care needs
- Siblings may be caregiving while raising families
- Creates high demand for knowledgeable and long-term supports

Systemic Gaps

- Healthcare providers often lack specialized training in I/DD and dementia
- Direct support professionals need specialized education and tools
- Gaps can be barriers to accurate diagnosis and appropriate care
- Solutions include advocacy, specialized education, training, inclusion, research

Progression of Alzheimer's Disease: Early Stage

- **Subtle Mood & Personality Changes:** Misplacing items, forgetting familiar routines, changes in mood

- **Reduced Engagement & Social Withdrawal:** Avoiding social opportunities, losing interest in previously enjoyed activities, confusion, or anxiety.

- **Cognitive Decline:**
  - **Recurrent forgetfulness disrupting daily life:** specifically involving immediate, short-term, or newly learned information
  - **Language & Word Finding:** Vocabulary becomes simpler or more limited; increased difficulty finding the right words
- **Decline in Functional Skills:**
  - **Planning & Problem-Solving:** New difficulties with sequencing multiple steps, such as repeatedly forgetting necessary items
  - **Routine Tasks:** Decreased work productivity and new confusion with familiar household chores or leisure tasks that were previously done well

- **Disorientation & Spatial:**
  - **Time & Place:** Losing track of the day of the week or appearing confused in familiar spaces.
  - **Spatial Relationships:** New difficulty navigating known environments
  - **Misplacing Items:** Putting objects in unusual places (e.g., mayonnaise jar in a cupboard) and losing the ability to retrace steps

Progression of Alzheimer's Disease : Middle Stage

- **Pervasive Memory Loss:** Short-term memory loss becomes more constant, and long-term memories may begin to fade.
- **Language & Communication Decline:** Vocabulary becomes noticeably smaller or simpler; individuals struggle significantly to find the right words or follow instructions.
- **Functional Dependency:** Deterioration of daily skills leads to a need for constant prompts and increased help with personal hygiene (bathing/grooming).
- **Disorientation:** Increased confusion regarding the time of day, routine schedules, or recurring events.
- **Physical & Motor Changes:** Worsened gait, weakness, and unsteadiness; notably, this stage may include the emergence of new onset seizures.
- **Eating & Swallowing (Dysphagia):** Coordination and strength of swallowing muscles deteriorate, increasing the risk of choking or aspiration.
- **Mood & Behavioral Fluctuations:** Agitation, poor frustration tolerance, and difficulty coping with transitions or changes in routine.

Progression of Alzheimer's Disease: Late Stage

- **Profound Memory Loss:** Complete loss of short-term memory and loss of long-term memories.
- **Total Functional Dependency:** Full reliance on others for all personal care, including bathing, dressing, and the ability to eat.
- **Severe Communication Loss:** Meaningful speech is often reduced or limited primarily to sounds and vocalizations.
- **Total Incontinence:** Complete loss of both bowel and bladder control.
- **Mobility Loss:** Individuals often use a wheelchair or bed bound
- **Terminal Medical Complications:** Death in this stage is typically due to failure to thrive, aspiration pneumonia, or other recurrent infections.
- **Care Goals:** Transition of focus toward "Overall Goals of Care," emphasizing comfort, dignity, and quality of life through palliative or hospice services.

Principles of Caregiving for Adults with Down syndrome & Dementia

- Person Centered Care: honoring the individual
- Focus on the individual's unique life story
- Focus on abilities, not limitations
- Maintain dignity and respect
- Encourage self-direction and choice
- Foster meaningful activities
- Adapt care to evolving abilities and limitations
- Sharing diagnosis
- Maintain support to care partners / caregivers

From ndss.org

Principles of Proactive Planning for the Lifespan

- **Promote Lifelong Wellness:** Incorporate healthy habits, routine health care, and regular exercise early to optimize brain health and potentially lower risk factors for dementia.

- **Education as Empowerment:** Sense of control over future planning and navigating a diagnosis by using knowledge to establish a "roadmap" for the journey.

- **Early Meaningful Discussions:** Begin discussions about future care and preferences as early as possible while the individual can still be self-directed in choice and decision-making.

- **Baseline:** Establish a formal record of "objective" and "subjective" baseline abilities-ideally by age 35–40.

- **Maintain Ongoing Dialogue:** Ensure care conversations are periodic and evolving.

- **Involve a Circle of Support:** Engage a multidisciplinary team—including family, siblings, friends, care managers, healthcare providers, Department of Developmental Services, and community staff to ensure consistent, coordinated, and relationship-centered care.

Planning for the Future Considerations

- **Seek Legal Specialists:** Engage Elder Law, Financial Planning, and Special Needs attorneys early to navigate state specific rules, trusts, financial planning, and policies.

- **Designate Decision-Makers:** Formally name a healthcare proxy or guardian early to ensure authorized advocacy.

**MA legal pathway for end-of-life decisions differ for guardians; expanded authority involves family, DDS, and the court for decisions like Massachusetts Order for Life Sustaining Treatment (MOLST).*

- **Collaboration with health care team:** document actionable, portable medical orders for life-sustaining treatment (e.g., CPR, intubation) that communicate the individual's wishes across all care settings.

- **Document Life Preferences:** Record lifelong likes, dislikes, and values to maintain a person-centered approach to overall decision-making throughout the dementia journey.

- **Coordinate Goals of Care:** Discuss legal documents and end-of-life wishes with the medical team to protect the individual’s rights and prioritize quality of life.

- **Long-Term:** Review special needs trusts and explore programs like Medicaid early; initiate planning early with DDS and the care team to sustain evolving care needs.

Proactive Care Planning

- Regular evaluations for routine care and by providers and specialists familiar with Down syndrome and dementia.
- Monitor for co-occurring medical conditions common in Down syndrome that can exacerbate symptoms.
- Plan for changes in physical functioning, mobility, and safety.
- Stay active, get enough rest, eat a healthy diet, and avoids preventable illness.
- Periodic medication review.

Communication as Connection: Moving Beyond Words

Effective communication is vital: use several sensory inputs; plan for changes in communication

- Simplify language and use short, clear sentences or words
- Speak slowly and patiently
- Allow ample time for the individual to process information and respond.
- Use visual aids such as pictures, symbols, or gestures, to support understanding.
- Validate feelings and avoid arguing.
- Use comforting touch, a calm tone of voice, and reassurance

Person-Centered Communication

- Acknowledge and build upon the individual's existing communication skills.
- Include the individual and address by their preferred name.
- Maintain eye contact and use a respectful tone of voice.
- Pay attention to nonverbal cues, such as facial expressions and body language.

Creating a Supportive Environment

- Maintain a familiar environment and routine.
- Tap into emotions to find a connection: warm smile, a hand to hold, or a reassuring hug.
- When speaking or interacting, try to maintain a positive tone.
- Minimize distractions, use visual cues, ensure adequate lighting, create a safe environment to avoid falls.
- Anticipate and plan for certain stressful events and times of day.
- Pair a pleasurable or a distracting activity to a stressful or pleasant activity .
- Plan meaningful activities that bring enjoyment, maintain dignity, and foster existing strengths and capabilities.
- Celebrate the small victories.

Strategies for Health and Well Being

- **Prioritize Comfort and Quality of Life:** Focus on preserving dignity and well-being as the primary goals of care, especially as the disease progresses.

- **Investigate Pain and Discomfort:** Proactively look for non-verbal clues of pain—such as facial expressions, rigid posturing, or sounds—as pain is a major, treatable contributor to agitation and behavior changes.

- **Play "Behavioral Detective":** Treat behaviors like agitation and anxiety as communication; identify patterns by documenting the timing, duration, and specific triggers.

- **Behavioral & Psychological Symptoms:** Examine the behavior for harmfulness or illness, explore solutions like adapting the surroundings or your own approach, and then try different responses to see what helps.

- **Integrated Care:** Employ an "all-of-the-above" approach using medical, environmental, non-pharmacological, and pharmacological strategies to navigate evolving care.

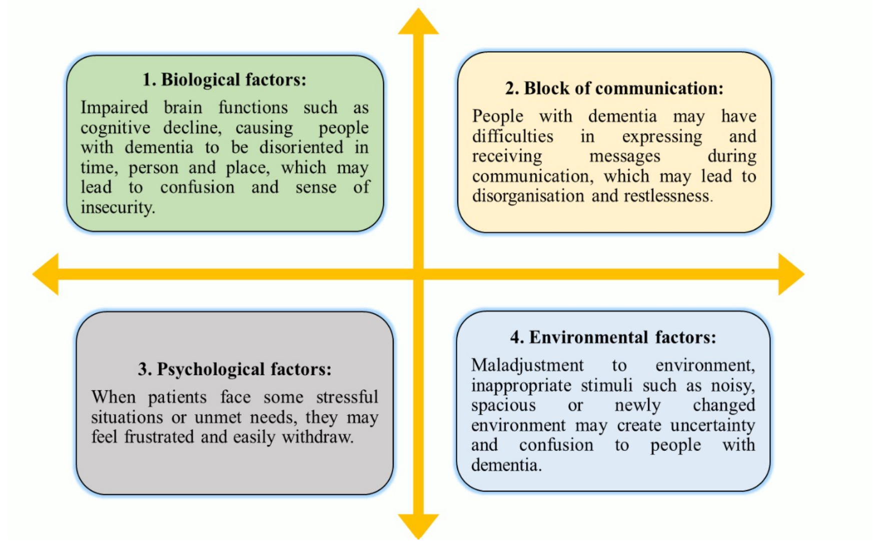
Behavioral and Psychological Symptoms of Dementia (BPSD)

Common Challenges

- Behaviors can ebb and flow
- Take on various form
- Old behaviors may re-emerge
- For others new behaviors may arise
  - Agitation, anxiety, depression
  - Wandering and disorientation
  - Aggressive or repetitive behaviors

Behavior Support

- Problem-solve around behavior often
- Feels like detective work - try to find patterns
- Identify triggers
- Look for other physical or environmental contributors
- Strategy is applied throughout entire course of dementia
- Always changing; response to behaviors will have to adapt and change over time
- Rule out medical contributors



1. Biological factors:

Impaired brain functions such as cognitive decline, causing people with dementia to be disoriented in time, person and place, which may lead to confusion and sense of insecurity.

2. Block of communication:

People with dementia may have difficulties in expressing and receiving messages during communication, which may lead to disorganisation and restlessness.

3. Psychological factors:

When patients face some stressful situations or unmet needs, they may feel frustrated and easily withdraw.

4. Environmental factors:

Maladjustment to environment, inappropriate stimuli such as noisy, spacious or newly changed environment may create uncertainty and confusion to people with dementia.

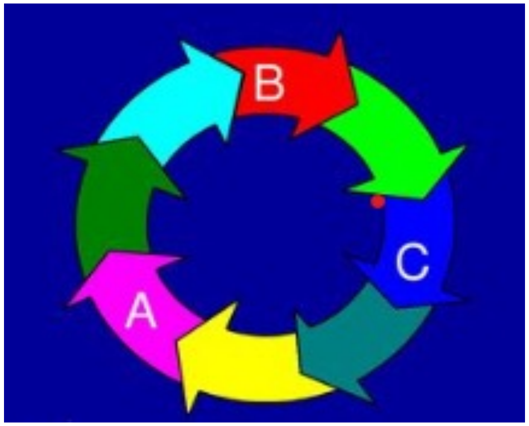
Source: Elderly Health Service, Dept of Health

Behavioral and Psychological Symptoms of Dementia (BPSD)

- Behavior is a form of communication
- Could something be causing the individual pain?
- Could this be related to medical illness or medications?

ABCs of Behavior

- **A**ntecedent: Anything that happens right before behavior occurs; referred to as "triggers"
- **B**ehavior: Is the behavior safe/dangerous, how often/long does it occur? Who is it a problem for?
- **C**onsequences: What is the reaction and what happens next? How do others respond? Do these responses make it worse?



Non-Pharmacological Approaches

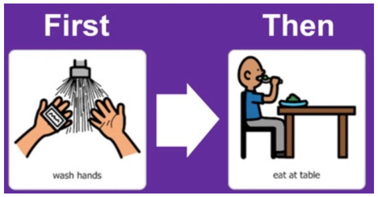
- Are there unmet needs? Cold, hungry?
- Connect, Not Correct / Join reality
- "Fiblets"/Therapeutic Non-Truths
- Redirection, distraction

Avoiding Inappropriate Medication Use

- Antipsychotic medications should be a last resort

Communication Support

- **Simplify Verbal Input:** Use shorter sentences and smaller words
- **Wait for Response:** Allow extra time for the individual to process information
- **The "One-at-a-Time" Rule:** Provide instructions or ask questions one step at a time
- **Closed-Ended Questions:** Shift from open-ended questions to "Yes/No" choices
- **Positive Redirection:** Use the "art" of shifting focus toward a calming or pleasurable activity
- **Validate the Emotion:** Look for the feelings behind the words or sounds
- **Avoid Correction or Arguing:** Do not criticize, correct, or attempt to reason
- **Environmental Cues:** Mark doors with familiar pictures or objects



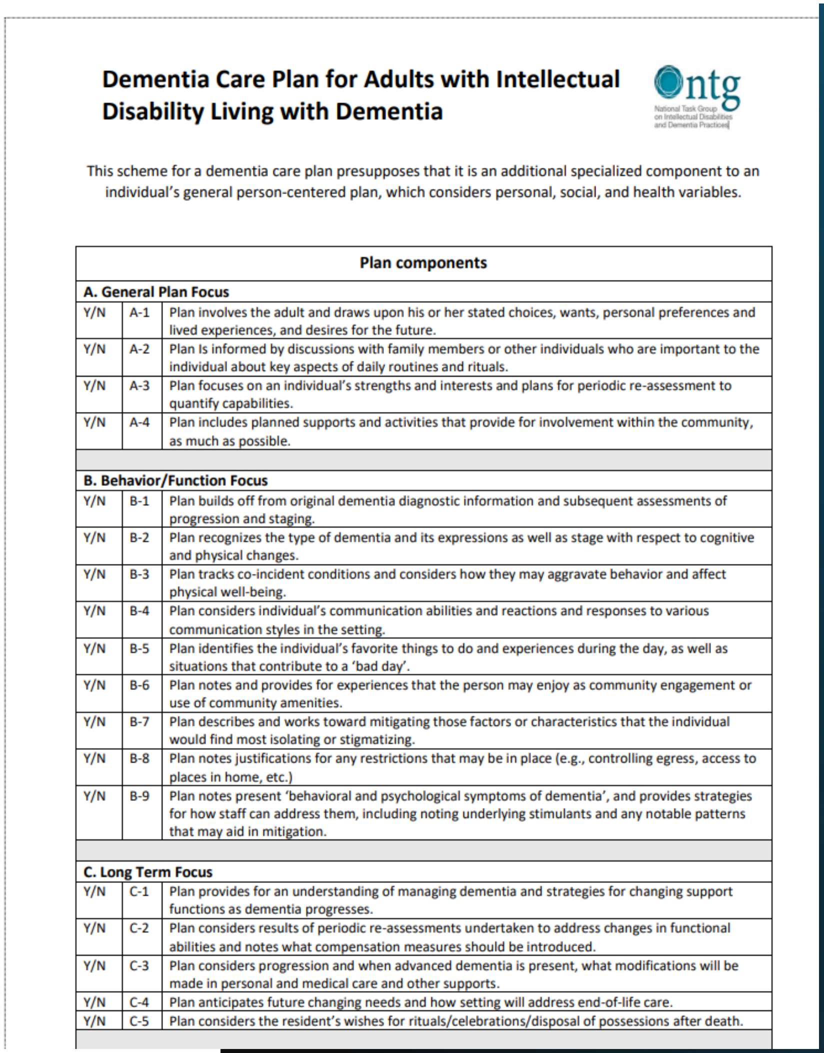
Source: Advocate Medical Group: Adult Down Syndrome Center

Creating a Dementia Care Plan

Key Components

- Plan is a specialized component added to an individual's general person-centered plan.
- Involves the adult, their preferences, and discussions with family and care partners.
- Focuses on individual strengths, interests, and community involvement.
- Addresses dementia type, progression, and related conditions.
- Manages behavioral symptoms
- Anticipates changing needs, including end-of-life care.
- Includes periodic reassessments and adjustments to support.
- Involvement of key people: family, DDS, day program, residential program, care managers, medical care team, extended support network.

Source: National Task Group (NTG) on Intellectual Disabilities and Dementia Practices: ntg.org



Dementia Care Plan for Adults with Intellectual Disability Living with Dementia

This scheme for a dementia care plan presupposes that it is an additional specialized component to an individual's general person-centered plan, which considers personal, social, and health variables.

Plan components		
A. General Plan Focus		
Y/N	A-1	Plan involves the adult and draws upon his or her stated choices, wants, personal preferences and lived experiences, and desires for the future.
Y/N	A-2	Plan Is informed by discussions with family members or other individuals who are important to the individual about key aspects of daily routines and rituals.
Y/N	A-3	Plan focuses on an individual's strengths and interests and plans for periodic re-assessment to quantify capabilities.
Y/N	A-4	Plan includes planned supports and activities that provide for involvement within the community, as much as possible.
B. Behavior/Function Focus		
Y/N	B-1	Plan builds off from original dementia diagnostic information and subsequent assessments of progression and staging.
Y/N	B-2	Plan recognizes the type of dementia and its expressions as well as stage with respect to cognitive and physical changes.
Y/N	B-3	Plan tracks co-incident conditions and considers how they may aggravate behavior and affect physical well-being.
Y/N	B-4	Plan considers individual's communication abilities and reactions and responses to various communication styles in the setting.
Y/N	B-5	Plan identifies the individual's favorite things to do and experiences during the day, as well as situations that contribute to a 'bad day'.
Y/N	B-6	Plan notes and provides for experiences that the person may enjoy as community engagement or use of community amenities.
Y/N	B-7	Plan describes and works toward mitigating those factors or characteristics that the individual would find most isolating or stigmatizing.
Y/N	B-8	Plan notes justifications for any restrictions that may be in place (e.g., controlling egress, access to places in home, etc.)
Y/N	B-9	Plan notes present 'behavioral and psychological symptoms of dementia', and provides strategies for how staff can address them, including noting underlying stimulants and any notable patterns that may aid in mitigation.
C. Long Term Focus		
Y/N	C-1	Plan provides for an understanding of managing dementia and strategies for changing support functions as dementia progresses.
Y/N	C-2	Plan considers results of periodic re-assessments undertaken to address changes in functional abilities and notes what compensation measures should be introduced.
Y/N	C-3	Plan considers progression and when advanced dementia is present, what modifications will be made in personal and medical care and other supports.
Y/N	C-4	Plan anticipates future changing needs and how setting will address end-of-life care.
Y/N	C-5	Plan considers the resident's wishes for rituals/celebrations/disposal of possessions after death.

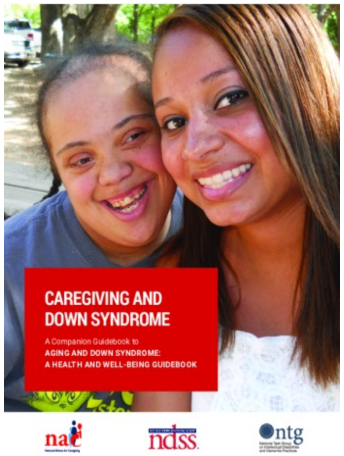
Key Takeaways

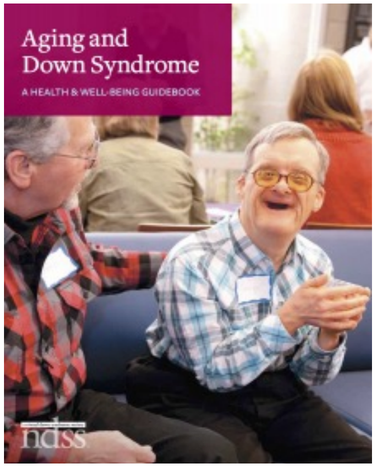
- **Proactive Planning** is essential for individuals with Down syndrome across the lifespan
- **Early & Accurate Diagnosis** helps in better support and quality of life
- **Person-Centered and Relationship-Based Care**
- **Supporting Caregivers** is as important as supporting the individual
- **Importance of a Support System**

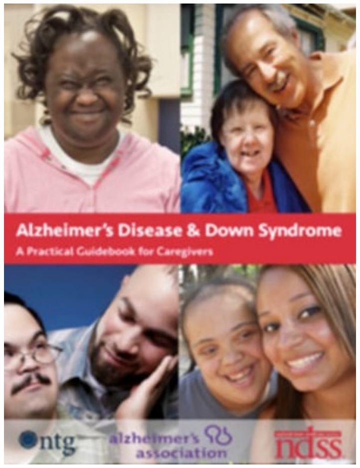
Resources

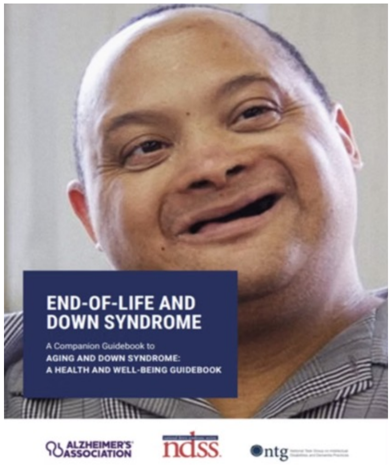
National Down Syndrome Society (NDSS) Publications: https://ndss.org/publications

- Caregiving and Down Syndrome: A Companion Guidebook to Aging and Down Syndrome
- Aging and Down Syndrome: A Health & Well-Being Guidebook
- Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers
- End of Life and Down Syndrome: A Companion Guidebook to Aging and Down Syndrome









Resources

Medical Care

- Global Down Syndrome Foundation Healthcare Guidelines: https://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/
- National Down Syndrome Society Healthcare Guidelines: https://ndss.org/resources/healthcare-guidelines
- Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia-National Task Group on Intellectual Disabilities and Dementia Practices: https://www.the-ntg.org/_files/ugd/c53c74_a682966bef4646ff9dda2edb1f4ff2fb.pdf
- Things to Know about Health and Adults with Dementia-A Guide for Families, Caregivers and Adults with ID- Seven Hills Rhode Island and National Task Group: https://www.the-ntg.org/pl/_files/ugd/40fa53_d40f6a8b0ade48dea8268f01be21a6fe.pdf

Resources

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

- **NTG-Early Detection Screen for Dementia (NTG-EDSD)**-tool to record observations of changes in function: https://www.the-ntg.org/pl/ntg-edsd
- **Publication Library:** https://www.the-ntg.org/pub-ntg-edsd
- **Family & Caregiver Resources:** https://www.the-ntg.org/family-caregiver-resources
- **Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia**: https://www.the-ntg.org/_files/ugd/c53c74_5f50a82f914849c88c6b5372cd38de4c.pdf
- **Guidance on the Use of Antipsychotics:** https://www.the-ntg.org/publications-2/guidance-on-use-of-antipsychotics-with-adults-with-id-and-dementia
- **NTG Dementia Care Plan:** 8c1d0a_d5cd46026d544117b8b8be44982f3817.pdf

Resources

Shriver Center at UMass & Massachusetts Department of Developmental Services (DDS): Aging with Intellectual and Developmental Disability Trainings

- **Understanding and Recognizing Dementia in Intellectual and Developmental Disability (IDD) Training**: https://shriver.umassmed.edu/programs/cdder/

- **Family and Training Modules:** https://shriveronline.org/course/view.php?id=55

- **Staff Training Modules**: https://shriveronline.org/course/view.php?id=54

Additional Resources

- **Jenny's Diary: A Resource to Support Conversations about Dementia with People Who Have an Intellectual Disability:** https://onecaregiverresourcecenter.org/wp-content/uploads/2023/12/jennys_diary_non_uk_ebook.pdf

- **Mass Down Syndrome Congress (MDSC) Resource Library:** https://mdsc.org/resource/

- **Mass Down Syndrome Congress Caregiver Support Group:** Contact MDSC

- **Down Syndrome and Alzheimer's Support Private Facebook Group-** for families of people who have a primary diagnosis of Down syndrome with an additional diagnosis of Alzheimer's disease.

Resources

End of Life/Advance Care Planning

- **Thinking Ahead: My Way, My Choice, My End of Life**: https://mn.gov/mnddc/honoring-choices/Thinking-Ahead-English-web.pdf
- **End of Life Care Planning Toolkit- The Victoria and Stuart Project:** https://www.victoriaandstuart.com/
- **Massachusetts Medical Orders for Life Sustaining Treatment (MOLST):** https://www.mass.gov/info-details/molst-transition-to-polst
- **Honoring Choices**: https://www.honoringchoicesmass.com/molst/
- **UMass Chan Medical School, Eunice Kennedy Shriver Center**- webinar is a collaboration of the Massachusetts Department of Developmental Services (DDS) and CDDER: https://shriver.umassmed.edu/programs/cdder/aging_idd_education/molst/
- **Dept of Developmental Services (DDS)-Information on End-of-Life Planning**: https://shriver.umassmed.edu/siteassets/uploads/2020/12/f.cdder_.2020-endoflifeplanning_tagged.pdf

Thank you!

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