

Care of Patients with Trisomy 21 by the Internal Medicine Physician

Presented By:
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October 28, 2026

The Ohio State University
Wexner Medical Center

Objectives

1. Demonstrate the need for increased education on Trisomy 21 for Internal Medicine Physicians
2. Review the 2020 GLOBAL Down Syndrome Foundation guidelines on care for Adults with Down syndrome
3. Identify resources for clinicians, patients, and families to aid in care for adults with Down syndrome

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Disclosures

No financial COI to disclose

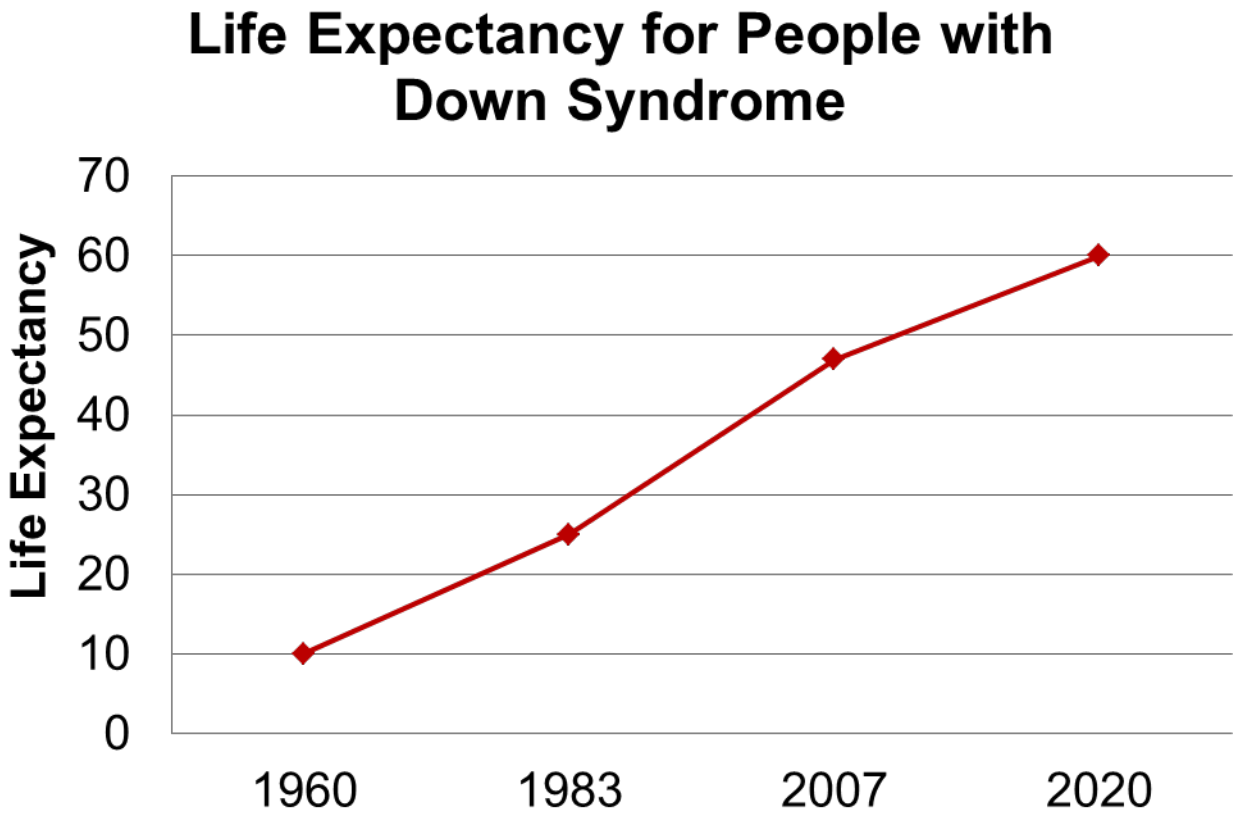
I am a member of the ElevateDD Board of Directors, the parent organization for the Down Syndrome Association of Central Ohio, a volunteer position

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Why Should Internists Care About Down Syndrome?



Likely due to a number of factors, included improvements in care of congenital heart disease and other congenital defects as well as shift the location of care from institutions to the home

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Why Should Internists Care About Down Syndrome?

- Increasing Incidence:
  - Estimated 1 in 1,000 live births in 2002
  - Estimated 1 in 691 live births in 2006
- Exact prevalence unknown, but estimates ~206,000 people with Down Syndrome in the United States, including 125,000 adults > 18 years
  - GLOBAL Down Syndrome Foundation estimates could be as high as 350,000 total individuals
- Estimated that only ~5% of adults have access to a clinic specializing in the care of Down syndrome

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Discrepancies in comfort managing patients with Down syndrome

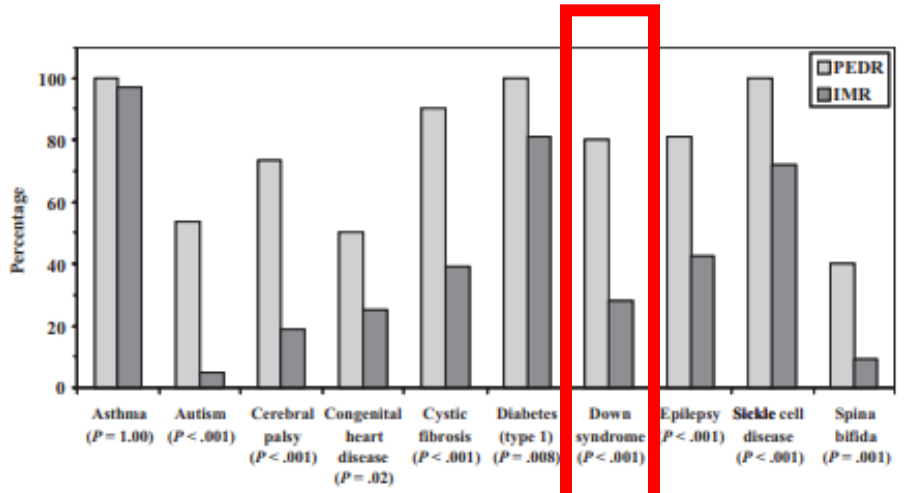


FIGURE 1
Proportion of PEDRs and IMRs who were comfortable with inpatient management of childhood-onset chronic disease.

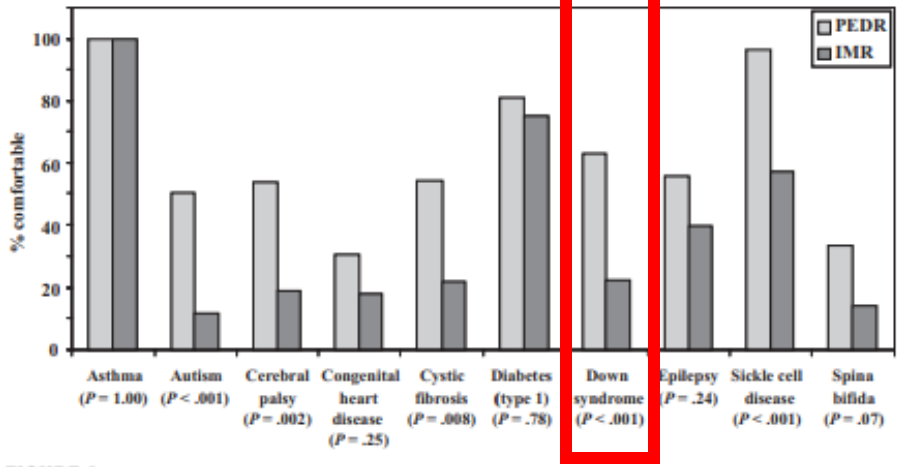


FIGURE 2
Proportion of PEDRs and IMRs who were comfortable with outpatient management of childhood-onset chronic disease.

2010 study in Pediatrics: Internal Medicine residents were significantly less comfortable caring for patients with various childhood-onset diseases compared to their pediatric counterparts (Patel & O'Hare)

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Discrepancies in comfort managing patients with IDD

2013, Journal of Hospital Medicine:

- 40% of IM hospitalists did not feel comfortable caring for adults with childhood onset diseases
- <20% "strongly agreed" they were comfortable caring for this population
- Similar for both community and academic physicians
- Physicians practicing > 7 years reported increased discomfort compared to those with 6 or less years of practice

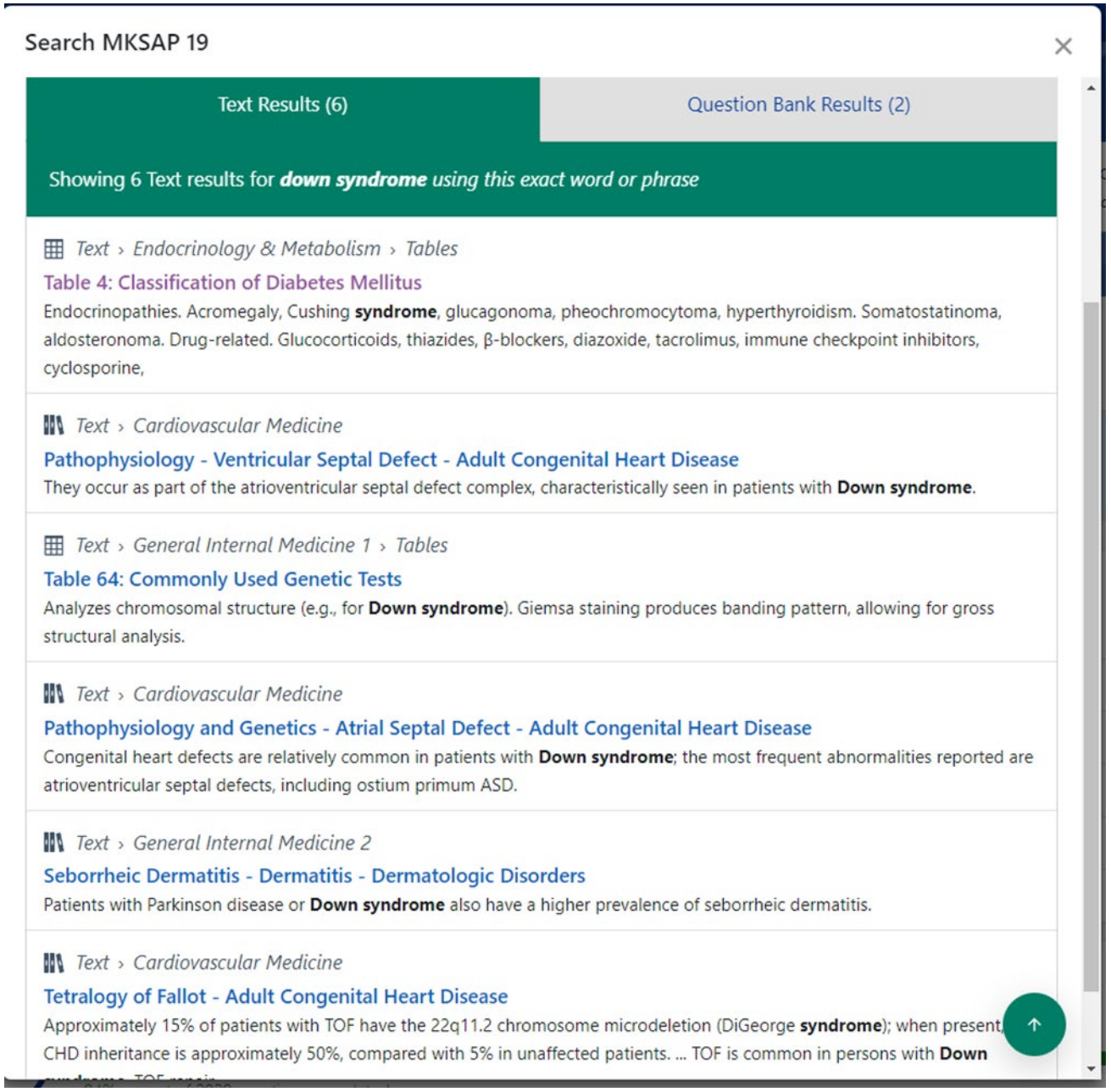
TABLE 2. Mean Likert Ratings for Potential Barriers to Caring for Adults With CDoCO*

Statement	Average Likert(IM Only)	Average Likert (Overall)	Category
Lack of familiarity with the latest literature on specific illnesses	2.82	2.67	MC
Lack of training in CDoCO	2.64	2.45	MC
Difficulty meeting psychosocial needs of young adults with CDoCO	2.53	2.46	PS
Lack of training in adolescent development and behavior	2.53	2.26	MC
Difficulty coordinating with multiple specialists to manage complex problem	2.52	2.47	MC/CC
Difficulty finding outpatient providers to follow up	2.50	2.50	CC
Expectations for significant time/attention needed for proper care	2.41	2.36	PS
Lack of patients'/families' familiarity with adult healthcare systems	2.40	2.37	CC
Lack of physician and patients'/families' familiarity with available outpatient providers to follow up	2.40	2.45	CC
Difficulty assessing patient readiness to assume responsibility for medical plan	2.38	2.20	PS
Difficulty coordinating transitions from pediatric caregivers	2.37	2.40	CC
Difficulty balancing family involvement and patient independence/privacy	2.36	2.27	PS
Difficulty facing severe disability in young patients	2.18	2.02	PS
Reluctance of pediatricians to let go of their patients	1.68	1.73	CC

NOTE: **Abbreviations:** CC, care coordination; CDoCO, chronic diseases of childhood onset; IM, internal medicine respondents; MC, medical competence; PS, psychosocial.

*Likert scale rated 1–4, with 1 = no impact, 4 = great impact.

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Adults with Down syndrome face a health care system that often treats them as kids

The U.S. had about three times as many adults with Down syndrome by 2016 as it did in 1970.

NBC News April 16, 2023

The New York Times

For People With Down Syndrome, Longer Life Has Complications

New York Times: June 1, 2008

The Washington Post
Democracy Dies in Darkness

At last, medical guidelines address care for adults with Down syndrome

By Erin Blakemore
July 4, 2022 at 7:29 a.m. EDT

Diagnostic Overshadowing

- Tendency to attribute new symptoms/new presentations to underlying IDD rather than investigating for new causes
- “It’s just the Down syndrome”
- Important to consider behavioral changes as a means of communication to possible new medical conditions
- We can work to combat this by keeping a broad differential and being aware of common co-morbid conditions

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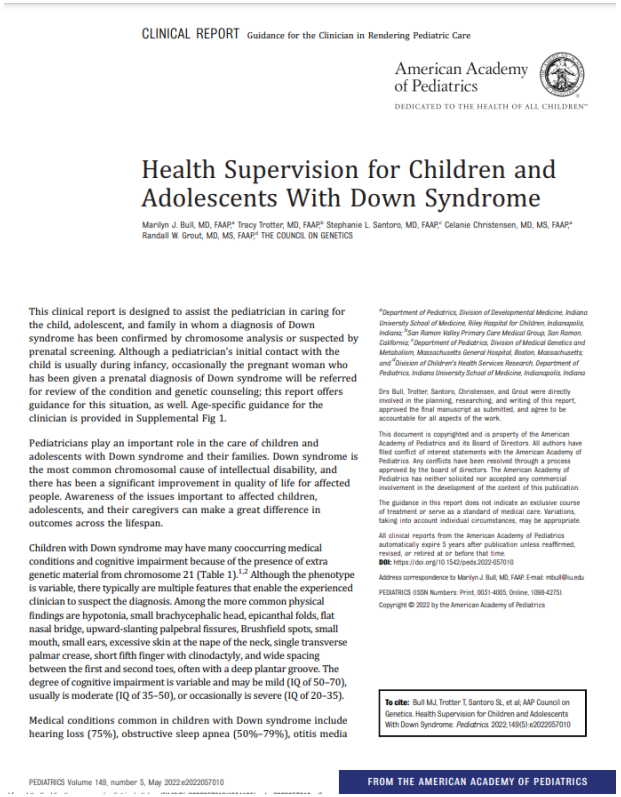
Conditions more common in individuals with Down syndrome

TABLE 1 Medical Problems Common in Down Syndrome

Condition	%
Hearing problems	75
Vision problems	60–80
Nystagmus	3–33
Glaucoma	<1–7
Nasolacrimal duct occlusion	3–36
Cataracts	3
Strabismus	36
Refractive errors	36–80
Keratoconus	1–13
Obstructive sleep apnea	50–79
Otitis media with effusion	50–70
Congenital heart disease	40–50
Feeding difficulty	31–80
Respiratory infection	20–36
Dermatologic problems	56
Hypodontia and delayed dental eruption	23
Congenital hypothyroidism	2–7
Antithyroid antibody positive (Hashimoto thyroiditis; incidence dependent on age)	13–39
Hyperthyroidism	0.65–3
Thyroid disease by adulthood	50
Gastrointestinal atresias	12
Seizures	1–13
Hematologic problems	
Anemia	1.2
Iron deficiency	6.7
Transient abnormal myelopoiesis	10
Leukemia	1
Autoimmune conditions	
Hashimoto thyroiditis	13–39
Graves' disease	1
Celiac disease	1–5
Type 1 diabetes	1
Juvenile idiopathic arthritis	<1
Alopecia	5
Symptomatic atlantoaxial instability	1–2
Autism	7–19
Hirschsprung disease	<1
Moyamoya disease	Down syndrome 26 times greater in patients with Moyamoya than Down syndrome in live births

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Guidelines



CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

Health Supervision for Children and Adolescents With Down Syndrome

Marilyn J. Bull, MD, FAAP,[a] Tracy Trotter, MD, FAAP,[b] Stephanie L. Santoro, MD, FAAP,[c] Celanie Christensen, MD, MS, FAAP,[a] Randall W. Grout, MD, MS, FAAP,[d] THE COUNCIL ON GENETICS

This clinical report is designed to assist the pediatrician in caring for the child, adolescent, and family in whom a diagnosis of Down syndrome has been confirmed by chromosome analysis or suspected by prenatal screening. Although a pediatrician's initial contact with the child is usually during infancy, occasionally the pregnant woman who has been given a prenatal diagnosis of Down syndrome will be referred for review of the condition and genetic counseling; this report offers guidance for this situation, as well. Age-specific guidance for the clinician is provided in Supplemental Fig 1.

Pediatricians play an important role in the care of children and adolescents with Down syndrome and their families. Down syndrome is the most common chromosomal cause of intellectual disability, and there has been a significant improvement in quality of life for affected people. Awareness of the issues important to affected children, adolescents, and their caregivers can make a great difference in outcomes across the lifespan.

Children with Down syndrome may have many cooccurring medical conditions and cognitive impairment because of the presence of extra genetic material from chromosome 21 (Table 1).[1,2] Although the phenotype is variable, there typically are multiple features that enable the experienced clinician to suspect the diagnosis. Among the more common physical findings are hypotonia, small brachycephalic head, epicanthal folds, flat nasal bridge, upward-slanting palpebral fissures, Brushfield spots, small mouth, small ears, excessive skin at the nape of the neck, single transverse palmar crease, short fifth finger with clinodactyly, and wide spacing between the first and second toes, often with a deep plantar groove. The degree of cognitive impairment is variable and may be mild (IQ of 50–70), usually is moderate (IQ of 35–50), or occasionally is severe (IQ of 20–35).

Medical conditions common in children with Down syndrome include hearing loss (75%), obstructive sleep apnea (50%–79%), otitis media

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Drs Bull, Trotter, Santoro, Christensen, and Grout were directly involved in the planning, researching, and writing of this report, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

All clinical reports from the American Academy of Pediatrics automatically expire 5 years after publication unless reaffirmed, revised, or retired at or before that time.

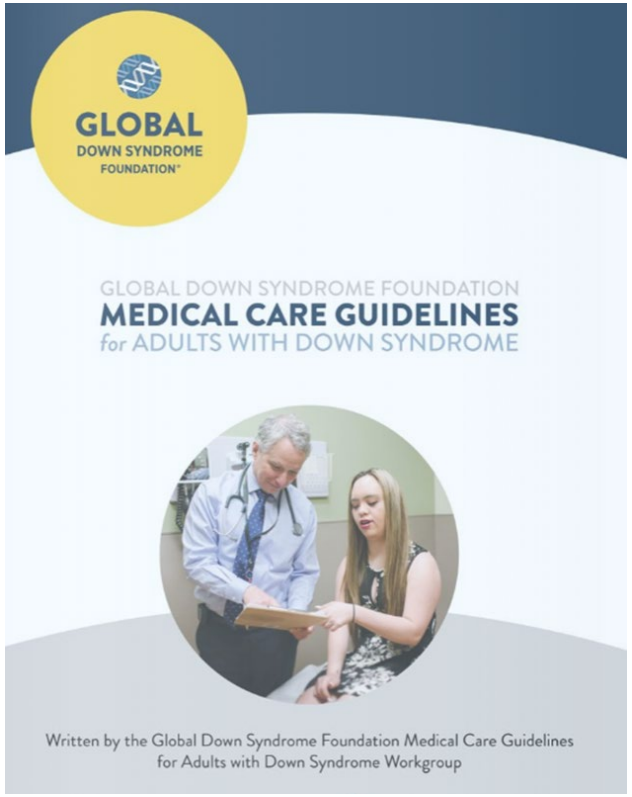
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[AAP Children & Adolescent Guidelines]

[GLOBAL Adult Down Syndrome Guidelines]

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Pediatric Guidelines – Quick Hits

- All individuals should receive an echo regardless of whether a prenatal echo was performed
- TSH at birth and annually thereafter
- Refer to Early Intervention – milestones typically delayed but achievable with supportive care
- Down syndrome specific growth curve
- Annual CBC and ferritin + CRP (or serum iron and TIBC)
- Hearing testing every 6-12 months
- Vision screening every 1-2 years
- Sleep study between age 3-5
  - Assess for sleep disordered breathing annually

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Pediatric Guidelines

Supplemental Information

SUPPLEMENTAL FIGURE 1. Summary of Down syndrome-specific care.

Action	Pre-natal	Birth up to 1 mo	1 mo up to 1 yr	1 yr up to 5 yr	5 yr up to 12 yr	12 yr up to 21 yr
1. Confirm DS diagnosis with either CVS or amniocentesis prenatally or karyotype postnatally	■					
2. Review recurrence risk and offer the family referral to a clinical geneticist or genetic counselor.						
3. Offer parent-to-parent and support group information to the family.						
4. Use CDC DS-specific growth charts to monitor weight, length, weight-for-length, head circumference, or BMI. Use standard charts for BMI after age 10 years.		All healthcare visits				
5. Order an echo, to be read by a pediatric cardiologist.		■				
6. Feeding assessment or video study if any: marked hypotonia, underweight (<5th %ile weight-for-length or BMI), slow feeding or choking with feeds, recurrent or persistent abnormal respiratory symptoms, desaturations with feeds		Any visit				
7. Obtain objective hearing assessment (may be in NBS protocols) and follow EHDI protocols.		■	Up to 6 mo			
8. If TM can't be visualized, refer to otolaryngologist for exam with microscope until reliable TM and tympanometry exams are possible		Every 3-6 mo	‖			
9. Car safety seat evaluation before hospital discharge.		■	‖			
10. CBC with differential		By day 3				
11. If TAM, make caregivers aware of risk/signs of leukemia (e.g., easy bruising/bleeding, recurrent fevers, bone pain)		■				
12. TSH		At birth (if not in NBS)	Every 5-7 mo	Annually, and every 6 mo if antithyroid antibodies ever detected		
13. RSV prophylaxis based on AAP guidelines.		Annually		Through 2 yr		
14. Discuss cervical spine-positioning for procedures and atlantoaxial stability precautions.		All HMV		Biennially		
15. Assess for CAM use, discourage any unsafe CAM practices.		All HMV				
16. Refer children to early intervention for speech, fine motor or gross motor therapy.		Any visit	Up to 3 yr			
17. If middle ear disease occurs, obtain developmentally-appropriate hearing evaluation.			When ear clear	After treatment		
18. Rescreen hearing with developmentally-appropriate methodology (BAER, behavioral, ear-specific).			Start at 6mo, every 6 mo until established normal bilaterally by ear-specific testing, then annually			
19. Refer to ophthalmologist with experience and expertise in children with disabilities.			By 6 mo			
20. CBC with differential if easy bruising or bleeding, recurrent fevers, or bone pain			Any visit			
21. Assess for sleep-disordered breathing; if present, refer to physician with expertise in pediatric sleep disorders.			At least once by 6 mo, then all subsequent HMV thereafter			
22. Ensure child is receiving developmental therapies, and family understands and is following therapy plan at home.		All HMV				
23. CBC with differential and either (1) a combination of ferritin and CRP, or (2) a combination of serum iron and Total Iron Binding Capacity				Annually		
24. If a child has sleep problems and a ferritin less than 50 mcg/L, the pediatrician may prescribe iron supplement.				Any visit		
25. Vision screening			All HMV, use developmentally-appropriate criteria	Photoscreen (all HMV); if unable, refer to ophthalmologist annually	Photoscreen (all HMV); if unable, refer to ophthalmologist biennially	Visual acuity or photoscreening at all HMV, or ophthalmology-determined schedule
26. If a child has myelopathic symptoms, obtain neutral C-spine plain films (see text for details).				Any visit		
27. Obtain polysomnogram.				Between 3-5 yr		
28. Prepare family for transition from early intervention to preschool.				At 30 mo		
29. Discuss sexual exploitation risks.				At least once	At least once	At least once
30. Make developmentally-appropriate plans for menarche, contraception (advocate/offer LARC), and STI prevention.					As developmentally-appropriate, then all subsequent HMV	
31. Discuss risk of DS if patient were to become pregnant.					At least once	At least once
32. Assess for any developmental regression.			All HMV			
33. Discuss and facilitate transitions: education, work, finance, guardianship, medical care, independent living					All HMV starting at 10 yr	

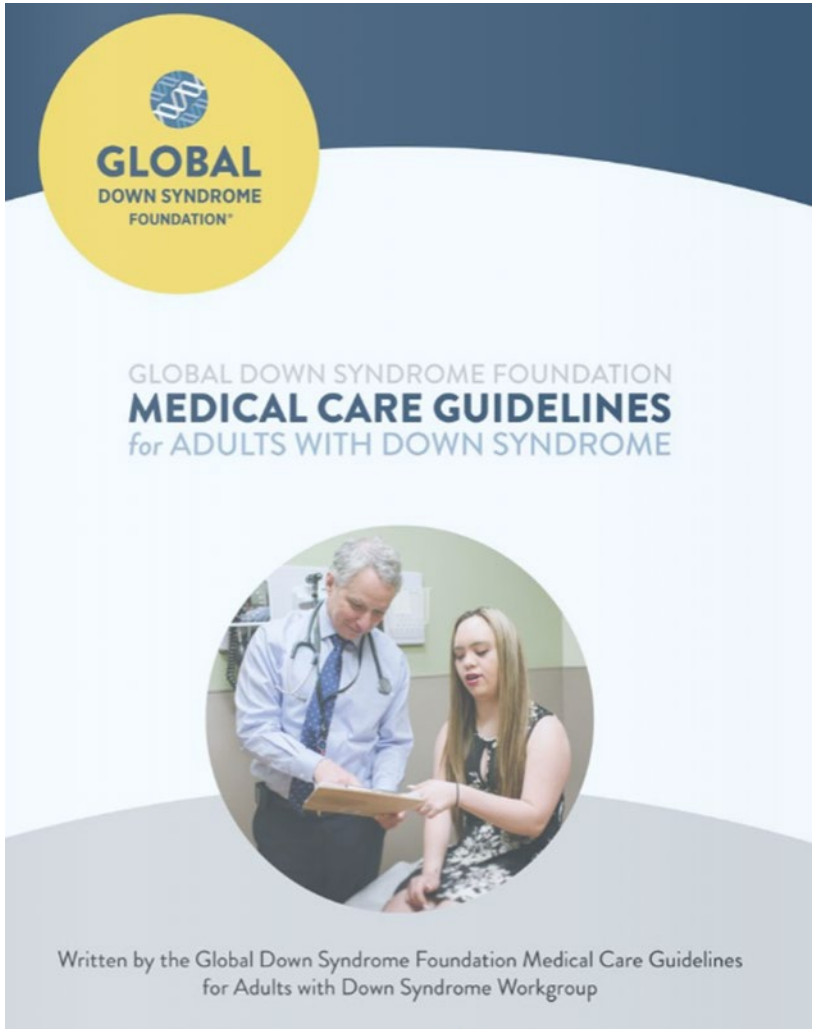
■ Do once at this age
⋯ Do if not done previously
– – – Repeat at indicated intervals
(border) ‖ See report for end point

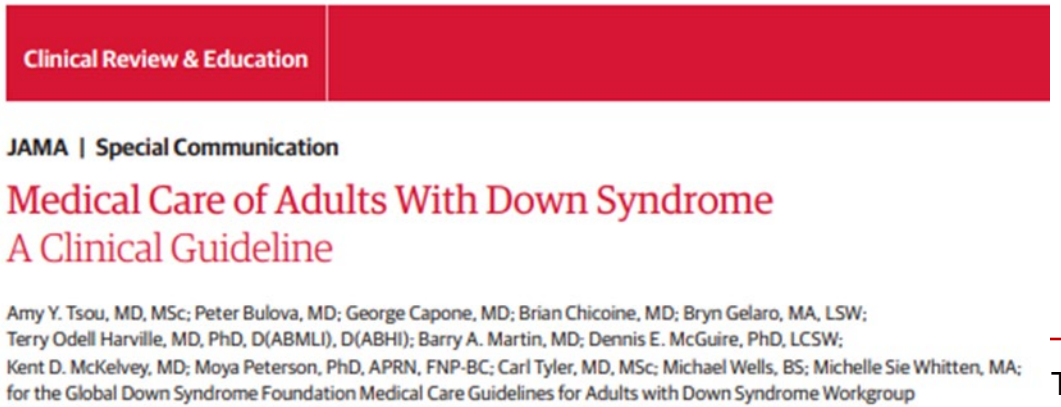
Abbreviations: DS, Down syndrome; CVS, Chorionic villus sampling; HMV, Health Maintenance Visit; BMI, Body mass index; CDC, Centers for Disease Control; EHDI, Early Hearing Detection and Intervention; NBS, Newborn screen; CAM, Complementary and alternative medicine; BAER, Brainstem auditory evoked response; TM, Tympanic membrane; TAM: transient abnormal myelopoiesis

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Guideline for the Care of Adults with Down Syndrome

- First identified evidenced-based guideline for care of adults with Down Syndrome
- Goal to support primary care clinicians caring for adults with Down Syndrome
- 14 recommendations and 4 statements of good practice
- Evaluated domains include: Behavior, dementia, diabetes, ASCVD risk, stroke, obesity, atlantoaxial instability, osteoporosis, thyroid disease, and Celiac Disease




Clinical Review & Education

JAMA | Special Communication

Medical Care of Adults With Down Syndrome
A Clinical Guideline

Amy Y. Tsou, MD, MSc; Peter Bulova, MD; George Capone, MD; Brian Chicoine, MD; Bryn Gelaro, MA, LSW; Terry Odell Harville, MD, PhD, D(ABMLI), D(ABHI); Barry A. Martin, MD; Dennis E. McGuire, PhD, LCSW; Kent D. McKelvey, MD; Moya Peterson, PhD, APRN, FNP-BC; Carl Tyler, MD, MSc; Michael Wells, BS; Michelle Sie Whitten, MA; for the Global Down Syndrome Foundation Medical Care Guidelines for Adults with Down Syndrome Workgroup

Behavior

Recommendation/statement of good practice	Strength of recommendation	Confidence in quality of evidence
Recommendations		
Behavior		
Recommendation 1. When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should refer to a clinician knowledgeable about the medical, mental health disorders, and common behavioral characteristics of adults with Down syndrome	Weak	Very low
Recommendation 2. When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should follow guidelines for diagnosis in the *DSM-5*[37]; the *DM-ID-2*[38] also may be used to adapt diagnostic criteria from the *DSM-5*	Weak	Very low

Recommendation/statement of good practice	Strength of recommendation	Confidence in quality of evidence
Statements of good practice[a]		
Behavior		
Statement 1. A review of behavioral, functional, adaptive, and psychosocial factors should be performed as part of an annual history that clinicians obtain from all adults with Down syndrome, their families, and caregivers		
Statement 2. When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should evaluate for medical conditions that may present with psychiatric and behavioral symptoms		

Diagnosis of mental health conditions can be challenging given wide variety of verbal skills of adults with Down syndrome as well as variable presentation of mental health conditions among patients with intellectual disability

Familiarity with traits common in individuals with Down syndrome and evaluation by experienced clinicians can be helpful, particularly if there is clinical ambiguity

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Considerations for new behavior changes

- **Environmental triggers**
  - Changes to environment, changes to routine, changes to normal caregivers
- **Medical**
  - New sick symptoms, changes in bowel habits, new abnormal movements. Known co-morbidities of chronic conditions
- **Medication-Induced**
  - New medications, changes to doses, missed doses, known side effects of chronic medications, medication interactions
- **Psychiatric**

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Behavior Changes

3 Basic Areas of the Psychosocial Assessment:	Examples of things to notice in behavior, function, and psychosocial areas:	Things to Review with a Medical Professional:
Behavioral Factors	TAKE NOTICE OF CHANGES IN: • Self-talk • "Groove" behaviors (tendency towards sameness or repetition) • Personality • Ability to focus or pay attention • Activity level • Social motivation or engagement • Mood and/or temperament	Type of Changes: • Increase or decrease of the number of times a behavior is displayed in self-talk, groove behaviors, etc • Increase or decrease of levels around focus, activities, social engagement, etc. • Start of new behaviors Behaviors that should be immediately addressed: • Self-harm, Harm to others • Loss of interest in things they previously enjoyed Past psychological history (diagnosis and/or medication)
	TAKE NOTICE OF CHANGES IN:	Types of Changes:

Common medical conditions that may look like psychiatric and behavioral symptoms in adults with Down syndrome and should be checked with a medical professional:	
1. Sleep Apnea 2. Gastrointestinal (Celiac, abdominal pain, GERD) 3. Thyroid Disease 4. Hearing impairment, including ear wax buildup 5. Vison Impairment 6. Urinary tract infection 7. Menstrual pain	8. Sinus and respiratory infections 9. Constipation 10. Dental Pain 11. Seizures 12. Difficulty Swallowing 13. Atlantoaxial Instability or spinal cord injury 14. Other pain (headaches, skin conditions, joint stiffness)

Psychosocial Factors	• Key relationships • Housing arrangement • School/occupation/vocation • Community involvement	• Changes in medication • Divorce, breakups, grief • Changes in routine Immediately report instances of trauma or abuse to police/child services and/or medical professionals, and seek supports

Down Syndrome Regression Disorder

- Newly recognized condition associated with acute to subacute loss of skills and behavioral changes
  - Can involve loss of language, social withdrawal, loss of ADL's, catatonia, new psychiatric symptoms
- Typically affecting individuals with Down Syndrome age 10-30
- No single identified cause. Some cases have followed acute illness/hospitalization or significant life change. Important to pursue broad medical work-up
- Treatments variable, can include antidepressants, benzodiazepines, immunotherapy, ECT

Down Syndrome Regression Disorder Symptoms Checklist **Date:** _____

Symptoms occurring more frequently within the last three months (check all that apply):

1. Behavioral Changes
Date symptom(s) began: _____
- ☐ Eating much more or less than usual
- ☐ Confusion or disorientation
- ☐ Laughing or crying at inappropriate times
- ☐ Frequent changes in mood or rapid fluctuations between happiness, sadness, or anger

2. Changes in Thinking and Processing of Information
Date symptom(s) began: _____
- ☐ Decreased visible emotions and empathy
- ☐ Lack of motivation or lack of engagement
- ☐ Difficulty starting or finishing tasks
- ☐ Worsening memory

3. Loss of Functional and Social Skills
Date symptoms(s) began: _____
- ☐ Loss/worsening of previously learned skills (self-feeding, toileting, dressing, etc.)
- ☐ Decreased social interaction with friends, family, classmates, or coworkers
- ☐ Decreased eye contact
- ☐ Repetitive hand or body movements with no clear purpose

4. New seizures or neurological deficits (weakness, slurring of speech, etc.) determined by a physician
Date symptom(s) began: _____

5. Difficulty sleeping or sleeping at irregular times
Date symptom(s) began: _____

6. Language Difficulties
Date symptom(s) began: _____
- ☐ Difficulty producing speech or trouble reading and understanding speech
- ☐ No longer using speech or speaking only in a whisper

7. Irregular Movements
Date symptom(s) began: _____
- ☐ Lack of movement sometimes with stiff and rigid muscles
- ☐ Moving very slowly or using an unusual walk or run gait pattern

8. Mental Health Symptoms
Date symptom(s) began: _____
- ☐ New or worsened anxiety
- ☐ Delusions (untrue beliefs) or hallucinations (seeing things that are not there)
- ☐ Derealization (feeling detached from surroundings) or depersonalization (feeling of observing oneself from outside of the body)
- ☐ Obsessive compulsive tendencies like lining up items, only talking about specific topics of interest, and difficulty tolerating changes in routine
- ☐ Aggression or agitation toward others

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Dementia

Dementia		
Recommendation 3. Caution is needed when diagnosing age-related, Alzheimer-type dementia in adults with Down syndrome younger than 40 y because of its low prevalence before this age	Weak	Low
Recommendation 4. Medical professionals should assess adults with Down syndrome and interview their primary caregivers about changes from baseline function annually beginning at age 40 y; decline in the following 6 domains as per the NTG-EDSD[39] should be used to identify early-stage age-related Alzheimer-type dementia and/or a potentially reversible medical condition: • Cognition, memory, and executive function • Behavior and personality • Communication • Adaptive functioning • Ambulation and motor skills • General decline in established skills	Strong	Moderate

- Studies demonstrate low prevalence of confirmed dementia in individuals < 40, with significant increases after age 40
  - Estimate 8.9% in 45-49 year olds, 32% in 55-59 year olds
  - One study reported rates of 90-100% in 65-70 year olds
- Screening starting at age 40 recommended to help establish baseline and monitor for subtle changes over time (NTG-EDSD)
- Thorough work-up recommended for any changes in memory/function in patients younger than 40 prior to attributing to Alzheimer's

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Dementia – NTG- EDSD

- Evaluated domains include:
  - ADL's
  - Language & Communication
  - Sleep-Wake Change Patterns
  - Ambulation
  - Memory
  - Behavior & Affect
  - Self reported problems
  - Notable changes observed by others

NTG-EDSD - page 3

[Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
[19]**Activities of Daily Living**				
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)				

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Diabetes

Diabetes		
Recommendation 5. For asymptomatic adults with Down syndrome, screening for type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 y beginning at age 30 y	Weak	Moderate
Recommendation 6. For any adult with Down syndrome and comorbid obesity, screening for type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 2-3 y beginning at age 21 y	Weak	Moderate

- Individuals with Down Syndrome are noted to have increased rates of diabetes compared to population-matched controls
- Given other co-mobidities due to premature aging (e.g. cataracts, neuropathy, renal dysfunction) weak recommendation for earlier, more frequent screening

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Atherosclerotic Cardiovascular Disease

Cardiovascular disease		
Atherosclerotic cardiovascular disease		
Recommendation 7. For adults with Down syndrome without a history of ASCVD, the appropriateness of statin therapy should be assessed every 5 y starting at age 40 y and using a 10-y risk calculator as recommended for adults without Down syndrome by the USPSTF[40]	Weak	Low

- One study showing decreased incidence of ischemic heart disease in adults with Down syndrome age > 50 compared to controls (8.1% vs 13.3%)
- Given overall low quality of evidence, recommended treatment similar to USPSTF guidelines
- Consider shorter life expectancy in the context of lipid management in accordance with *Choosing Wisely* guidelines

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Stroke Prevention

Stroke		
Recommendation 8. For adults with Down syndrome, risk factors for stroke should be managed as specified by the American Heart Association/American Stroke Association guidelines for the primary prevention of stroke[41]	Weak	Very low
Recommendation 9. In adults with Down syndrome with a history of congenital heart disease, given the elevated risk of cardioembolic stroke, a periodic cardiac evaluation and a corresponding monitoring plan should be reviewed by a cardiologist	Weak	Very low

- Some evidence of increased incidence of strokes, with most common source being cardioembolic
- Given higher incidence of congenital heart disease, defer management of stroke risk as associated with these defects to their cardiologists

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Obesity

Obesity		
Recommendation 10. Monitoring for weight change and obesity should be performed annually by calculating BMI in adults with Down syndrome; the USPSTF behavioral weight loss interventions to prevent obesity-related morbidity and mortality in adults should be followed[42]	Weak	Very low
Obesity		
Statement 3. Healthy diet, regular exercise, and calorie management should be followed by all adults with Down syndrome as part of a comprehensive approach to weight management, appetite control, and enhancement of quality of life		

Obesity is common in adults with Down syndrome. No current evidenced based guidelines on best approach in this population, so recommend general lifestyle approach (dietary and physical activity changes) in accordance with general population guidelines and treatment of any predisposing health conditions (e.g. hypothyroidism, sleep apnea)

- Of note – guidelines published prior to more widespread use of GLP-1 medications for weight management

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Atlantoaxial Instability

Atlantoaxial instability		
Recommendation 11. In adults with Down syndrome, routine cervical spine radiographs should not be used to screen for risk of spinal cord injury in asymptomatic individuals; instead, annual screening of adults with Down syndrome should include signs and symptoms of cervical myelopathy using targeted history and physical examination	Weak (against)	Very low

- Although individuals with Down Syndrome have higher risk of atlantoaxial instability, there is poor evidence of the effectiveness of x-rays to identify this and no clear data on correlation between AAI findings on x-ray and resultant spinal cord injury
- Reasonable to screen for new symptoms of spinal cord injury, but concern that routine screening would lead to unnecessary restrictions in physical activity without clear benefit
- Special Olympics over the past 20 years have reported no known spinal cord injuries in > 50,000 individuals

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Osteoporosis

Osteoporosis		
Recommendation 12. For primary prevention of osteoporotic fractures in adults with Down syndrome, there is insufficient evidence to recommend for or against applying established osteoporosis screening guidelines, including fracture risk estimation; thus, good clinical practice would support a shared decision-making approach to this issue	Neither for nor against	NA
Recommendation 13. All adults with Down syndrome who sustain a fragility fracture should be evaluated for secondary causes of osteoporosis, including screening for hyperthyroidism, celiac disease, vitamin D deficiency, hyperparathyroidism, and medications associated with adverse effects on bone health	Weak	Very low

- No clear benefit or harms to screening
- FRAX risk assessment model may not be applicable to this population (common growth characteristics may mean DEXA is less accurate). Also hypothesized to have different mechanism (reduced bone formation rather than excess bone resorption) so standard of care may not be effective

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Thyroid

Thyroid		
Recommendation 14. Screening adults with Down syndrome for hypothyroidism should be performed every 1-2 y using a serum thyrotropin test beginning at age 21 y	Weak	Moderate

- Significant association between Down Syndrome of hypothyroidism, increasing with age. Prevalence estimated 39% in 18 to 29 year olds, 51% in those > 30
- As with mental health, general symptoms can be difficult to identify, therefore recommend routine screening every 1-2 years regardless of symptoms

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Celiac Disease

Celiac disease

Statement 4. Adults with Down syndrome should receive an annual assessment for gastrointestinal and nongastrointestinal signs and symptoms of celiac disease using targeted history, physical examination, and clinical judgment of good practice

- Estimated prevalence of Celiac disease 11% in the Down Syndrome population
- Wide variety of GI and non-GI symptoms
- No routine screening recommendations, but low threshold if any concerning symptoms (see separate handout for patients, families on potential symptoms)

Date of First Symptom(s)	Symptoms
	Constitutional
	Unexpected weight loss or gain
	Difficulty sleeping or restless sleep
	New or worsening of fatigue
	Looking pale ("onset of pallor")
	Gastrointestinal
	Loose stool and/or diarrhea (frequent, watery stools)
	Constipation (infrequent, hard stools)
	Abdominal discomfort (pain/tenderness, bloating/distention)
	Passing gas more than in the past
	Belching/burping to relieve discomfort
	Acid reflux/heartburn
	Mouth sores, ulcers, and/or canker sores
	Psychological
	New or worsening depression or moodiness
	Change in personality/behavior
	Pulmonary
	Increased cough or swallowing food or liquids into the lungs (choking spells)
	Hematological
	Anemia – Iron, Vitamin B12/folic acid deficiency
	Dermatological
	Dry skin or "doughy" skin, or loss of hair in eyebrows
	Very itchy rash (tiny blister-like with some surrounding redness)
	Immune/Autoimmune
	Enlarged thyroid
	Swollen, red, warm, and/or tender joints
	Alopecia (loss of hair on scalp and/or body)
	Other signs of other autoimmune diseases (for example: rheumatoid arthritis, Type 1 diabetes)
	Neurological
	New onset of seizures or change in seizures
	Development of mental "fog" (including forgetfulness or feeling "out of sorts")
	Increased difficulty in remaining on task
	Musculoskeletal
	Muscle cramps/aches

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Summary of new guidelines in comparison to existing guidance for the general population

Table 2. Recommendations Compared With Existing Guidance

Recommendation	Existing guideline
Recommendations in Down syndrome guidelines concur with existing guidance for the general population	
Recommendation 7. Statin therapy for lowering cardiovascular risk for adults with Down syndrome	Agrees with USPSTF guidance for the general population, statin use for the primary prevention of cardiovascular disease in adults: preventive medication[40]
Recommendation 8. Managing risk factors for stroke prevention for adults with Down syndrome	Agrees with AHA/ASA guidelines for primary prevention of stroke[41] for the general population
Recommendation 10. Obesity screening for adults with Down syndrome	Agrees with USPSTF guidance for the general population, Behavioral Weight Loss Interventions to Prevent Obesity-Related Morbidity and Mortality in Adults[42]
Recommendation 13. Evaluating secondary causes of osteoporosis for adults with Down syndrome	Agrees with American Association of Clinical Endocrinologists/ American College of Endocrinology (2016) guideline,[60] Diagnosis and Treatment of Postmenopausal Osteoporosis for the General Population
Recommendations in Down syndrome guidelines differ from existing guidance for the general population	
Recommendation 5. Diabetes screening in asymptomatic individuals with Down syndrome	Recommendation (screen starting at age 30 y [instead of 45] every 3 y[43]) differs from ADA guidance for the general population
Recommendation 6. Diabetes screening in adults with Down syndrome and obesity	Recommendation (screen starting at age 21 y and every 2-3 y [instead of every 3 y] without requiring any additional risk factors[43]) differs from ADA guidance for the general population
Recommendation in Down syndrome guidelines neither for or against existing guidance for the general population	
Recommendation 12. Screening for primary prevention of osteoporosis for adults with Down syndrome	Neither for or against osteoporosis risk prediction tools (FRAX) for the general population
New recommendations in Down syndrome guidelines	
Recommendations 1 and 2. Diagnosis of behavioral health conditions for adults with Down syndrome	
Recommendations 3 and 4. Diagnosis and screening for Alzheimer-type dementia for adults with Down syndrome	
Recommendation 9. Refer adults with Down syndrome and history of congenital heart disease for cardiac evaluation and monitoring plan for adults with Down syndrome	
Recommendation 11. Screening for atlantoaxial instability for adults with Down syndrome	
Recommendation 14. Screening for hypothyroidism for adults with Down syndrome	

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GLOBAL MEDICAL CARE GUIDELINES

for Adults with Down Syndrome Checklist

GLOBAL DOWN SYNDROME FOUNDATION®

This checklist is intended to support the health of adults with Down syndrome directly or through their caregivers. We encourage this checklist to be shared with your medical professionals. Statements in blue represent our recommended, periodic health screenings/assessments that should begin at a specific age. Below each blue screening/assessment recommendation, there are blank boxes. Caregivers or individuals with Down syndrome can check off, date, or initial each blank box when the screening/assessment is completed. For screening/assessment recommendations with a time range (e.g. 1-2 years), the box size represents the longer possible time frame, such as 2 years versus 1. Statements in gray represent advisory recommendations that individuals with Down syndrome and caregivers should follow throughout adulthood.

Screening/Assessment | Advisory | Checkbox | No Recommendations

	21-29 Years	30-39 Years	40-49 Years	50-59 Years	60+ Years
Behavior	A review of behavioral, functional, adaptive, and psychosocial factors should be performed as part of an annual history that clinicians obtain from all adults with Down syndrome, their families, and caregivers. *(Boxes below represent 1 year increments)*				
	When concern for a mental health disorder in adults with Down syndrome is present medical professionals should: a) Evaluate for medical conditions that may present with psychiatric and behavioral symptoms and b) Refer to a clinician knowledgeable about the medical, mental health disorders, and common behavioral characteristics of adults with Down syndrome.				
	When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should follow guidelines for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM 5). The Diagnostic Manual-Intellectual Disability 2 (DM-ID-2) also may be used to adapt diagnostic criteria from the DSM-5.				
Dementia	Caution is needed when diagnosing age-related, Alzheimer's Type Dementia in adults with Down syndrome less than age 40.		Medical professionals should assess adults with Down syndrome and interview their primary caregivers about changes from baseline function annually beginning at age 40. Decline in the six domains as per the National Task Group – Early Detection Screen for Dementia (NTG-EDSD) should be used to identify early-stage age-related Alzheimer's-type dementia and/or a potentially reversible medical condition. *(Boxes below represent 1 year increments)*		
Diabetes		For asymptomatic adults with Down syndrome, screening for type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 30. *(Boxes below represent 3 year increments)*			
	For any adult with Down syndrome and comorbid obesity, screening for type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 2-3 years beginning at age 21. *(Boxes below represent 3 year increments)*				
Cardiac			For adults with Down syndrome without a history of atherosclerotic cardiovascular disease, the appropriateness of statin therapy should be assessed every 5 years starting at age 40 and using a 10-year risk calculator as recommended for adults without Down syndrome by the U.S. Preventive Services Task Force. *(Boxes below represent 5 year increments)*		
	For adults with Down syndrome, risk factors for stroke should be managed as specified by the American Heart Association/American Stroke Association's Guidelines for the Primary Prevention of Stroke.				
	In adults with Down syndrome with a history of congenital heart disease, given the elevated risk of cardioembolic stroke, a periodic cardiac evaluation and a corresponding monitoring plan should be reviewed by a cardiologist.				
Obesity	Healthy diet, regular exercise, and calorie management should be followed by all adults with Down syndrome as part of a comprehensive approach to weight management, appetite control, and enhancement of quality of life .				
	Monitoring for weight change and obesity should be performed annually by calculating Body Mass Index in adults with Down syndrome. The U.S. Preventive Services Task Force Behavioral Weight Loss Interventions to Prevent Obesity-Related Morbidity and Mortality in Adults should be followed. *(Boxes below represent 1 year increments)*				
Atlantoaxial Instability	In adults with Down syndrome, routine cervical spine x-rays should not be used to screen for risk of spinal cord injury in asymptomatic individuals.				
	Annual screening for adults with Down syndrome should be based on a review of signs and symptoms of cervical myelopathy using targeted history and physical exam. *(Boxes below represent 1 year increments)*				
Osteoporosis	For primary prevention of osteoporotic fractures in adults with Down syndrome, there is insufficient evidence to recommend for or against applying established osteoporosis screening guidelines, including fracture risk estimation; thus, good clinical practice would support a shared decision-making approach to this issue would support a shared decision-making approach to this issue.				
	All adults with Down syndrome who sustain a fragility fracture should be evaluated for secondary causes of osteoporosis, including screening for hyperthyroidism, celiac disease, vitamin D deficiency, hyperparathyroidism and medications associated with adverse effects on bone health.				
Thyroid	Screening adults with Down syndrome for hypothyroidism should be performed every 1-2 years using a serum thyroid-stimulating hormone (TSH) test beginning at age 21. *(Boxes below represent 2 year increments)*				
Celiac Disease	Adults with Down syndrome should receive an annual assessment for gastrointestinal and non-gastrointestinal signs and symptoms of celiac disease using targeted history, physical examination and clinical judgement of good practice. *(Boxes below represent 1 year increments)*				

This checklist is not intended to be diagnostic. Presentation of medical and mental health conditions for people with Down syndrome may be atypical. Similar signs and symptoms may be a consequence of multiple reasons, including different disease processes. Thus, the patient evaluation should include considerations of additional causes for any detected sign or symptom. The development of new and/or changes in signs or symptoms should prompt a comprehensive evaluation with your clinician.

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Areas not addressed in 2020 Guidelines

- Sleep Apnea
  - Risk remains high due to anatomic factors, hypotonia
  - No routine screening recommendations, but low threshold to consider
- Anemia/Iron Deficiency
  - No specific screening recommendations. If up to date on their pediatric screenings can use this as a guide. If not can be helpful to check a baseline and low threshold to re-screen
- Cancer Screenings
  - Lower risk of solid tumors including breast (90% less likely), cervical (80%), prostate (91%), skin (50%)
  - Higher rates of leukemia (though absolute risk remains low) and testicular cancer
  - Still recommend following USPSTF guidance, but consider tolerance of more invasive testing and life expectancy

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Women's Health

- Women with Down syndrome receive routine gynecologic care at lower rates than the non-DS population and at lower rates than other forms of health care
- Review of approaches and data to guide common questions/concerns:
  - Hygiene, menorrhagia, dysmenorrhea, birth control, cervical cancer screening, sexual activity, pregnancy, menopause, breast cancer screening
- Resources for providers and patients, families, caregivers



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Patient Evaluation – Communication Strategies

Avoid assumptions – Always address the patient first. Ask for permission to obtain supplemental information from caregivers, guardians, support staff

Ask about preferred communication methods, baseline function

- Some patients will use tablets, picture boards to communicate symptoms, wants, needs

Warn the patient prior to beginning physical exam and try to explain/narrate what will be done prior to completing exam

- Try to describe other tests and procedures prior to completing

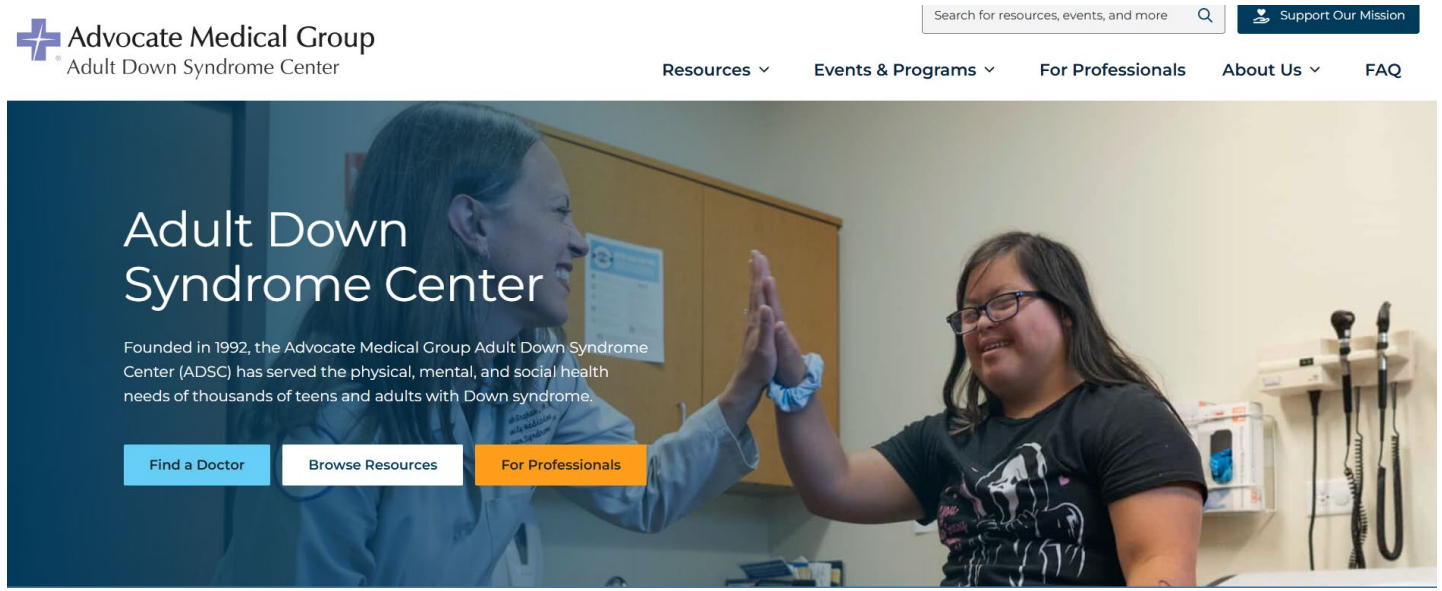
Discuss accommodations that have been successful in the past

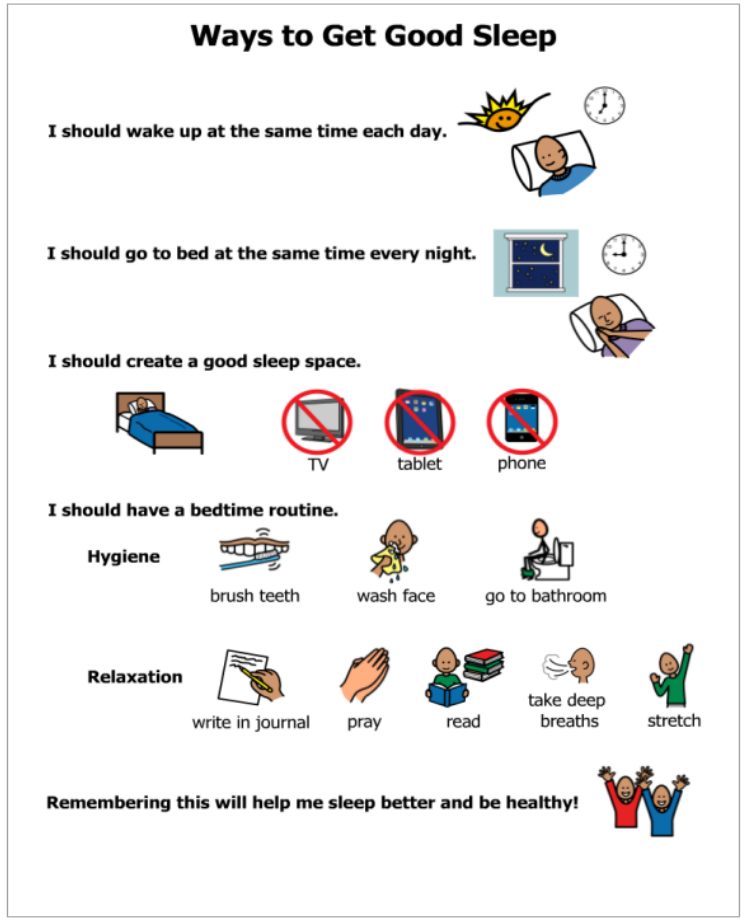
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Encouraging Independence

- Strong visual learners – tend to benefit most from resources with visual supports, videos, modeling/demonstration
- Concrete questions & recommendations
- Work on establishing a routine (“The Groove”)
- Positive Reinforcement

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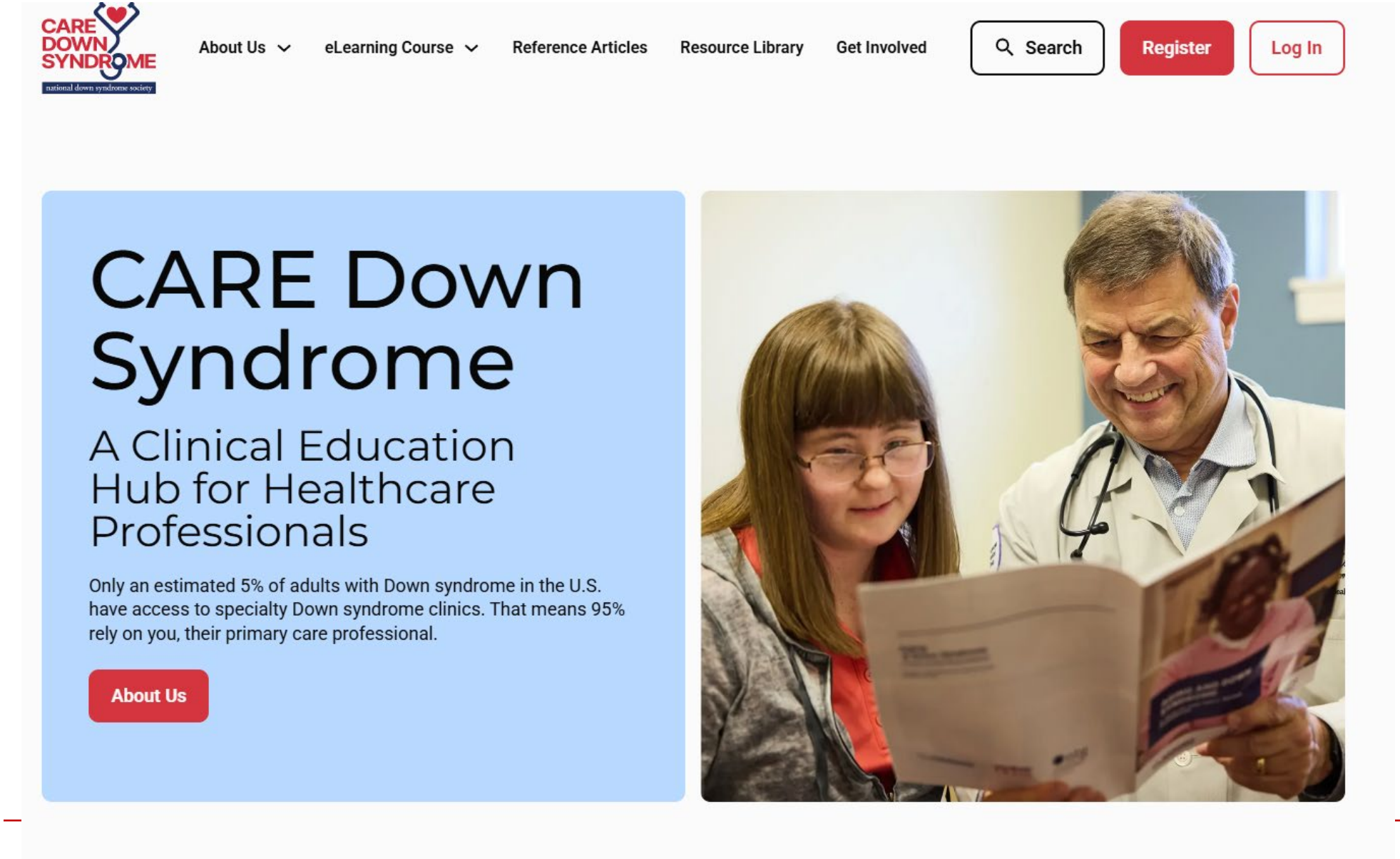


[Advocate Medical Group Adult Down Syndrome Center Resources]

Topics include nutrition, physical activity, hygiene, healthy relationships/boundaries, info on common medical conditions and tests

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Resources for Medical Professionals – Care Down Syndrome



Resources for Medical Professionals – Care Down Syndrome



Explore Our Accredited eLearning Options

Learners can choose from two accredited eLearning options, or complete both to earn even more continuing education credits:

CARE Down Syndrome eLearning Course: Complete the foundational course to earn 2 CE credits and gain a comprehensive overview of caring for adults with Down syndrome.

Topic-Specific Clinical Reference Articles: Explore 17 in-depth articles on clinically relevant subjects like Alzheimer's disease, Down Syndrome Regression Disorder, mental health, and more. Each article is worth 0.25 CE credit.

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Care Down Syndrome



Common Health Conditions in Adults with Down Syndrome

Review of common health conditions in adults with Down syndrome, including variations in vital signs.



Mental Health: Diagn… Treatm… with D… Syndr…

Overview of … Down syndro… contributing … treatment, ar…



Down Syndrome …



Decline in Skills and Behavioral Change in Adults with Down Syndrome

Discover why decline in skills and changes in behavior are common in adults with Down syndrome, including causes, contributing factors, diagnosis, and…



Health Promotion for Adults with Down Syndrome

Approaches for clinicians to integrate physical, mental, and social health promotion into care for adults with Down syndrome.

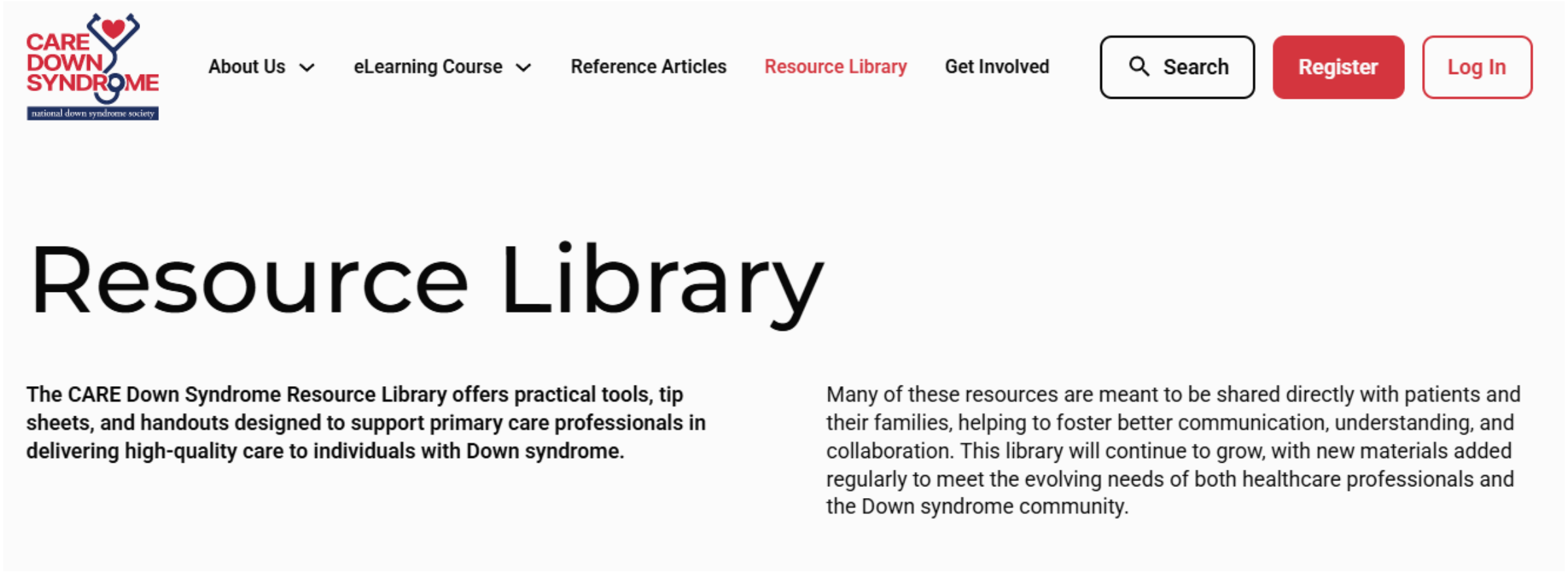


The Importance of Unique Healthcare Guidelines for Adults with Down Syndrome

Guidance on applying Down syndrome-specific care recommendations, including key considerations from the Global Down Syndrome Foundation's Medical Care Guidelines for Adults with…

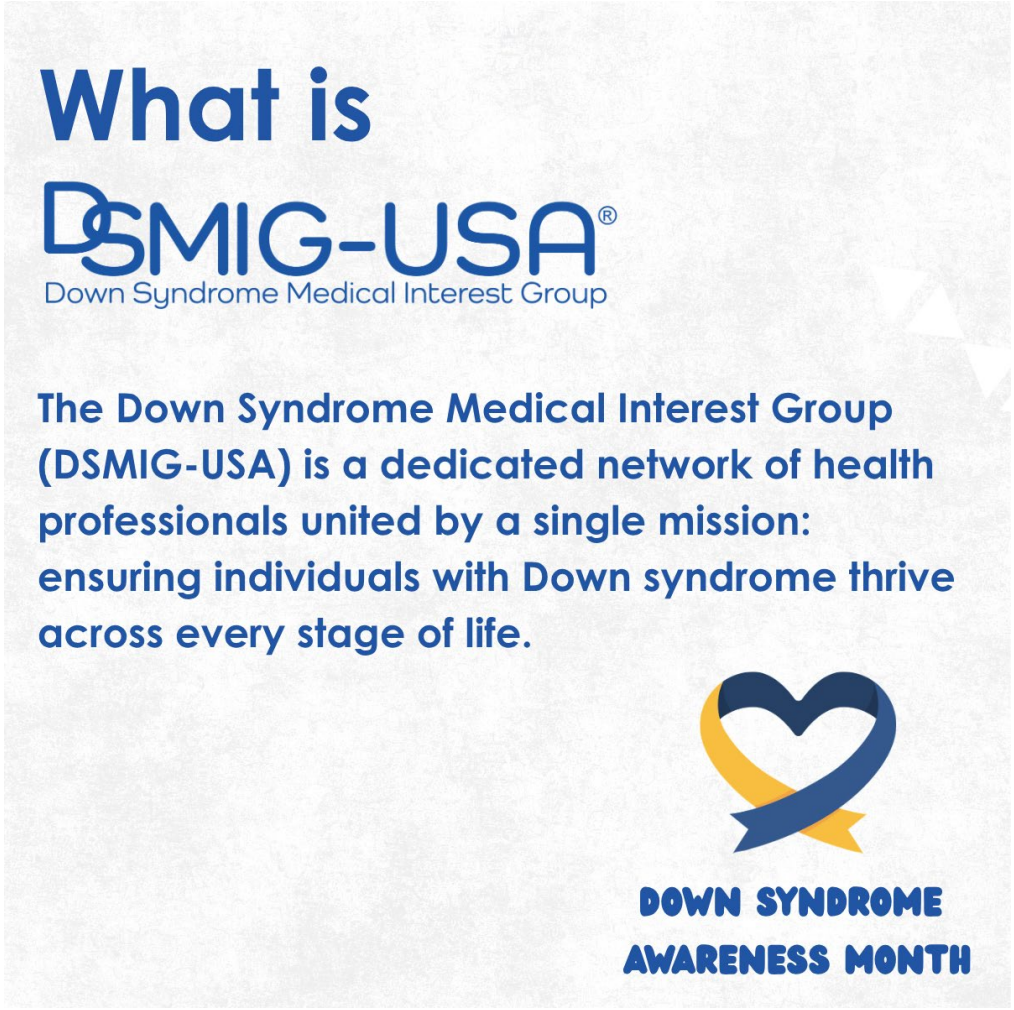
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Resources for Medical Professionals – Care Down Syndrome



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Resources for Medical Professionals - DSMIG



- Speaker Series
- Project Echo
  - Didactic session combined with case based presentation – anyone can submit a challenging case for group discussion
- Annual Symposium

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Resources for Medical Professionals, Patients, Families

national down syndrome society
ndss.

Local Down syndrome organizations

dsaco Down Syndrome Association *of* Central Ohio

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Takeaways

- Individuals with Down syndrome are living longer than ever, but few adults have access to specialty care
- Consider behavior changes as a form of communication – avoid diagnostic overshadowing
- Although Alzheimer's is more common in individuals with Down syndrome, it is incredibly rare prior to age 40. A thorough medical work-up is required prior to attributing changes in mood, memory, behaviors to Alzheimer's particularly at younger ages

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References

- Tsou AY, Bulova P, Capone G, et al. Medical Care of Adults With Down Syndrome: A Clinical Guideline. JAMA. 2020;324(15):1543–1556. doi:10.1001/jama.2020.17024
- Patel MS, O'Hare K. Residency training in transition of youth with childhood-onset chronic disease. Pediatrics. 2010 Dec;126 Suppl 3:S190-3. doi: 10.1542/peds.2010-1466P. PMID: 21123485.
- Bull MJ, Trotter T, Santoro SL, Christensen C, Grout RW; COUNCIL ON GENETICS; Burke LW, Berry SA, Geleske TA, Holm I, Hopkin RJ, Introne WJ, Lyons MJ, Monteil DC, Scheuerle A, Stoler JM, Vergano SA, Chen E, Hamid R, Downs SM, Grout RW, Cunniff C, Parisi MA, Ralston SJ, Scott JA, Shapira SK, Spire P. Health Supervision for Children and Adolescents With Down Syndrome. Pediatrics. 2022 May 1;149(5):e2022057010. doi: 10.1542/peds.2022-057010. PMID: 35490285.
- Santoro SL, Campbell A, Balasubramanian A, Haugen K, Schafer K, Mobley W. Specialty clinics for adults with Down syndrome: A clinic survey. Am J Med Genet A. 2021;185(6)1767-1775. doi:10.1002/ ajmg.a.62169
- Adults with Down syndrome face a health care system that often treats them as kids. NBC News. https://www.nbcnews.com/health/health-news/adults-syndrome-face-health-care-system-often-treats-kids-rcna79766
- Adult Guideline Resources. Global Down Syndrome Foundation. https://www.globaldownsyndrome.org/adult-guideline-resources/
- National Association for Down Syndrome | Facts About Down Syndrome. https://www.nads.org/resources/facts-about-down-syndrome/#:~:text=However%2C%20with%20appropriate%20medical%20care
- CDC. Data and Statistics on Down Syndrome. Centers for Disease Control and Prevention. Published October 23, 2020. https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html
- Manohar H, Subramanian K, Kandasamy P, Penchilaiya V, Arun A. Diagnostic Masking and Overshadowing in Intellectual Disability-How Structured Evaluation Helps. J Child Adolesc Psychiatr Nurs. 2016 Nov;29(4):171-176. doi: 10.1111/jcap.12160. Epub 2016 Nov 30. PMID: 27901303.
- Graham H. Primary Care Provider's Guide to Women's Health and Down Syndrome. National Down Syndrome Society. https://dsmigusa.memberclicks.net/assets/Primary%20Care%20Provider%27s%20Guide%20to%20Women%27s%20Health_FINAL.pdf
- Santoro JD, Patel L, Kammeyer R, Filipink RA, Gombolay GY, Cardinale KM, Real de Asua D, Zaman S, Santoro SL, Marzouk SM, Khoshnood M, Vogel BN, Tanna R, Pagarkar D, Dhanani S, Ortega MDC, Partridge R, Stanley MA, Sanders JS, Christy A, Sannar EM, Brown R, McCormick AA, Van Mater H, Franklin C, Worley G, Quinn EA, Capone GT, Chicoine B, Skotko BG, Rafii MS. Assessment and Diagnosis of Down Syndrome Regression Disorder: International Expert Consensus. Front Neurol. 2022 Jul 15;13:940175. doi: 10.3389/fneur.2022.940175. PMID: 35911905; PMCID: PMC9335003.

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References

- Chicoine B, Rivelli A, Fitzpatrick V, Chicoine L, Jia G, Rzhetsky A. Prevalence of Common Disease Conditions in a Large Cohort of Individuals With Down Syndrome in the United States. J Patient Cent Res Rev. 2021 Apr 19;8(2):86-97. doi: 10.17294/2330-0698.1824. PMID: 33898640; PMCID: PMC8060042
- Fitzpatrick V, Noah A, Rivelli A, Johnson R, Zak M, Espinosa J, Chicoine B. Cancer Prevalence Among Large Cohort of Individuals With Down Syndrome: Implications for Screening Guidelines. Cancer Med. 2026 Jun;15(6):e72007. doi: 10.1002/cam4.72007. PMID: 42252503; PMCID: PMC13243194..
- Smith AJB, Applebaum J, Tanner EJ, Capone GT. Gynecologic Care in Women With Down Syndrome: Findings From a National Registry. Obstet Gynecol. 2020 Sep;136(3):518-523. doi: 10.1097/AOG.0000000000003997. PMID: 32769650.
- Joslyn N, Berger H, Skotko BG. Geospatial Analyses of Accessibility to Down Syndrome Specialty Care. J Pediatr. 2020 Mar;218:146-150.e1. doi: 10.1016/j.jpeds.2019.10.058. Epub 2019 Dec 5. PMID: 31813535.
- Hunt S, Sharma N. Pediatric to adult-care transitions in childhood-onset chronic disease: hospitalist perspectives. J Hosp Med. 2013 Nov;8(11):627-30. doi: 10.1002/jhm.2091. Epub 2013 Oct 12. PMID: 24124077.

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Questions?



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