



Down Syndrome Practice Tool Series 4 of 5

Medical Care for the Child with Down Syndrome from 5 to 13 Years of Age



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When your child needs a hospital, everything matters.

Brief Overview of Down Syndrome

Down syndrome is the most common chromosomal condition in the United States. About 1 in every 700 babies born will be diagnosed with Down syndrome, totaling to approximately 6,000 babies each year.¹ Down syndrome is caused by the presence of the genetic material from a third copy of chromosome 21 (trisomy 21) or an unbalanced translocation between chromosome 21 and another chromosome. Approximately 95% of cases of Down syndrome are sporadic, with no familial history.²

In addition to common physical features (e.g. hypotonia, small brachycephalic head, epicanthal folds, and flat nasal bridge), a number of life-time associated health conditions may affect babies with Down syndrome. Some are age specific but can occur at a variety of ages.

More Common Conditions	%	Less Common Conditions	%
Hearing problems	75	Gastrointestinal atresias	11
Vision problems	60	Thyroid disease	4–18
Refractive errors	50	Seizures	1–13
Obstructive sleep apnea	50–75	Iron deficiency	10
Otitis media	50–70	Transient myeloproliferative disorder	10
Congenital heart disease	40–50	Celiac disease	5
Hypodontia/ delayed dental eruption	23	Anemia	3
Cataracts	15	Other (atlantoaxial instability, autism, Hirschsprung disease, leukemia)	1–2

Here, we summarize guidelines designed by the American Academy of Pediatrics to assist the pediatrician with medical care for a child or young adolescent with Down syndrome between 5 and 13 years of age.²

Periodic Care and Follow Up Specific for Children 5 to 13 Years of Age

Several aspects of care require ongoing assessment throughout childhood and should be reviewed at every physician visit, while others may be conducted at different time intervals depending on the patient's age and health care needs.

• Check hemoglobin (Hb); if child has possible risk of iron deficiency or Hb <11 g/dL, check C-reactive protein and ferritin or reticulocyte hemoglobin	Annually
• Assess TSH to screen for hypothyroidism	Annually
• Instruct to contact physician for change in gait, change in use of arms or hands, change in bowel or bladder function, neck pain, head tilt, torticollis, or new-onset weakness	Biennially
• If child has normal ear-specific hearing, assess behavioral audiogram	Annually
• Refer to pediatric ophthalmologist or ophthalmologist with experience with Down syndrome	Every two years
• Discuss dermatologic issues with parents/guardians	Do once at this age
• Discuss physical and psychosocial changes though puberty, need for gynecologic care and the possibility of pregnancy in the pubescent female	Do once at this age
• Provide influenza vaccine	Annually

Care and Follow Up Needs at All Visits or All Health Maintenance Visits (HMs)

• Assess the emotional status of parents/guardians and intrafamilial relationships	All HMs
• Review signs and symptoms of hypotonia and myopathy — refer for therapies	All HMs
• Discuss cervical spine positioning, especially for anesthesia or surgical or radiologic procedures	All HMs
• Discuss complementary & alternative therapies	All HMs
• Advise risk of some contact sports and trampolines	All HMs
• Check for symptoms of celiac disease; if symptoms present, obtain tissue transglutaminase immunoglobulin (Ig) A & quantitative IgA	All HMs
• Assess for obstructive sleep apnea symptoms — a sleep study (regardless of symptoms) should have been completed at least once by age 4 (do if not done previously)	All HMs
• Discuss attention-deficit/hyperactivity disorder, obsessive compulsive disorder, and wandering off as well as referral to community treatment programs, psychological services, and behavioral specialists	All HMs
• Discuss the use of medication for behavioral management (as needed)	HMs
• Facilitate early intervention for physical, occupational, and speech therapy	All HMs
• Discuss behavioral and social progress; encourage independence with hygiene and self-care	All HMs
• Discuss appropriate management of sexual behaviors, such as masturbation	All HMs
• Counsel families on the transition to middle school (change from 1 class/1 teacher to many classes/many teachers), developing self-help skills and sense of responsibility	All HMs
• If child presents myelopathic signs or symptoms, obtain neutral position spine films	All visits
• If child has congenital heart disease, monitor for signs and symptoms of congestive heart failure	All visits
• Regularly remind parents about increased risk of sexual exploitation (perpetrators are likely people the child knows and trusts, not strangers)	HMs

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References: 1) Centers for Disease Control and Prevention. Data and Statistics on Down Syndrome. Accessed 3/21/2021 at: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>. 2) Bull MJ; Committee on Genetics. Health supervision for children with Down syndrome. *Pediatrics*. 2011 Aug;128(2):393-406. doi: 10.1542/peds.2011-1605. Epub 2011 Jul 25. Erratum in: *Pediatrics*. 2011 Dec;128(6):1212. PMID: 21788214 (<https://pubmed.ncbi.nlm.nih.gov/21788214/>).

Specialty Services at Nationwide Children's and When to Refer

Down Syndrome Clinic

The Down Syndrome Clinic at Nationwide Children's Hospital is a family-centered clinic providing diagnostic and treatment services to children and adolescents with Down syndrome and their families.

Families are linked with medical, educational, social and financial supports in their communities as indicated and resources identified to assist them in meeting the unique needs of their child.

Our team of developmental pediatricians, psychologists, geneticists and advanced practice nurses maintain a close working relationship with the child's primary care physician throughout their care.

Services We Offer

Services are covered by most insurance providers. To expedite insurance coverage we recommend a referral be sent to the clinic by the patient's primary care physician.

- Comprehensive evaluation — Monitoring for feeding issues, atlantoaxial instability and signs of celiac disease
- Assessments for Attention Deficit Hyperactivity Disorder or Autism Spectrum Disorders in individuals with Down syndrome
- Lab and radiology assessments, including recommended health supervision screening and focusing on individual concerns
- Behavior management counseling for families whose children are experiencing behavioral difficulties

Reasons to Call

Parents/caregivers should notify the patient's pediatrician or the Down Syndrome Clinic for the following symptoms:

- Changes in gait
- Changes in use of arms or legs
- Changes in bowel or bladder habits
- New onset of snoring
- New onset of apnea when sleeping or new onset of sleepiness during the day
- New behavior or learning concerns

Additional Resources

Parents and caregivers can find a full list of resources and support groups on the Nationwide Children's Downs Syndrome Clinic webpage. [NationwideChildrens.org/specialties/down-syndrome-clinic](https://www.nationwidechildrens.org/specialties/down-syndrome-clinic)

This tool is part of a 5-part series of practice tools. Please reference the other tools for information relevant to other age groups.

Referrals and Consultations

Online: [NationwideChildrens.org/Request-An-Appointment](https://www.nationwidechildrens.org/Request-An-Appointment)

Phone: (614) 722-6200 or (877) 722-6220 | Fax: (614) 722-4000

Physician Direct Connect Line for 24-hour urgent physician consultations:

(614) 355-0221 or (877) 355-0221.

