

Health Care Information for Families of Children and Adolescents with Down Syndrome

Child's Age: 1 Year to 5 Years

Regular well-care visits (check-ups)

At the one-year check-up, you should look at the checklists for newborns and infants to be sure everything has been done as recommended. Follow-up on known problems with specialists and be sure that reports are sent to your child's primary doctor.

Monitor growth

It is important to check growth at every visit. Measurements include height, weight, body mass index (BMI), and head circumference. Your child's growth can be put on the Down Syndrome Growth Charts and on the charts for typical children. Discuss your child's diet, activity level, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

Heart

The need to see a cardiologist (heart doctor) during this age is based on the child's health history and examination. Children with cardiac problems may need to be monitored even after repair for remaining issues and development of pulmonary hypertension (high pressure in blood vessels of the lungs).

Hearing

Hearing should be checked every 6 months, with audiogram and tympanometry tests until normal hearing is documented by testing of both ears separately (usually by 4-6 years of age). Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT). Higher risks of hearing problems can go with middle ear fluid and ear infections. Treatment of middle ear fluid often includes the use of ear tubes.

Vision

Vision should be checked at each visit to the doctor and with yearly checkups by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Crossing eyes or blocked tear ducts might be reasons for quicker action. Early use of eye patches, glasses, or both may help to fix eye crossing while lowering the need for surgery and the risk of vision loss.

Thyroid

The thyroid gland is usually normal in babies with Down syndrome. It can stop working normally for half of people with Down syndrome by adulthood. The symptoms of low thyroid can be hard to notice in people with Down syndrome, so a blood test (TSH) is needed every year, or sooner if symptoms change. When there is a problem, treatment is safe and can often be started by your primary doctor.

Blood tests

Tests for low iron (ferritin, serum iron, and other tests) and anemia (CBC and other tests if needed) should be done every year. Low ferritin can be associated with sleep problems, and your doctor may prescribe iron.

Stomach or bowel problems (diarrhea, constipation)

Discuss toilet patterns at each visit, especially any ongoing problems with loose stools or constipation. These are common in children with Down syndrome. Some children with Down syndrome have celiac disease, which is a problem with tolerating some grains, including wheat. Testing can help to identify that condition and may lead to changes in diet. Celiac disease can affect growth, stooling patterns, and behavior. Let your child's doctor know if your child is having:

- Very loose stools
- Hard to treat constipation (hard or painful stools)
- Slow growth/weight loss
- Belly pain or stomach swelling
- New or challenging behavior problems

Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done, and the results are abnormal, your child may be referred to a spine or neck specialist. Special neck positioning may be needed for some medical procedures. Let your child's doctor know if your child is having:

- Stiff or sore neck
- Change in stool or urination pattern
- Change in walking
- Change in use of arms or legs
- Numbness (loss of normal feeling) or tingling in arms or legs
- Head tilt

Sleep issues

Obstructive sleep apnea is a common problem for people with Down syndrome, especially those with low muscle tone. Some symptoms are obvious (snoring, restless waking at night, daytime sleepiness), but it can be hard to tell just by watching. AAP recommends that every child with Down syndrome have a sleep study between the ages of 3 and 4 years. (That testing may be hard to find in some parts of the country.) Treatment can include special breathing equipment, surgery, or medications.

Skin

Discuss with your child's doctor if your child has very dry skin or other skin problems.

Brain and nervous system

Discuss with your child's doctor concerns about neurologic problems, such as seizures and loss of skills (not being able to do the things that they used to do).

Dental

Delayed and missing teeth are common. Teeth often come in unusual order.

Testes

Cancer of the testicles is slightly more common in boys with Down syndrome. Your child's doctor will examine for any changes, including lumps or swelling.

New treatments

Talk to your doctor about any new treatments or medications you may consider.

Counseling for chance of recurrence

Talk to your doctor about future pregnancy planning and chances of having another child with Down syndrome and where prenatal diagnosis is available.

Developmental services (early intervention)

Review your child's development with your doctor. Your child should be referred to local early intervention services. Additional options for therapy may be needed. Speech progress can be slow in Down syndrome, but after some delays many will learn to talk. Until speech is easier for your child, he or she might need help finding other ways to communicate, such as using sign language, pictures, reading, or using electronic communication tools. Behavior problems are often linked to problems with communication, but may reflect other issues, including ADHD or autism. Ask your doctor to screen for autism because it occurs more commonly in children with Down syndrome.

Social safety

Hidden abuse occurs and may be misdiagnosed. Talk with your doctor about how to explain social safety and "good and bad touch" as your child grows older.