

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

## Child's Age: 5 to 12 Years

### **Regular well-care visits (check-ups)**

It is important to have yearly well-care check-ups. These visits will assist in checking your child's health, giving shots, and answering your questions about your child's health.

### **Monitor growth**

It is important to check growth at every visit. Measurements include height, weight, and body mass index (BMI). 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 testing is needed every 6 months, until each ear can be tested alone. When a child can respond to testing in each ear alone, testing may be done every year. Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT).

### **Vision**

Vision should be checked at each well-care visit. It is also important to have an exam at least every 2 years by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Visits may be needed more often if your child has known eye or vision issues.

### **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 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 use of arms or legs
- Head tilt
- Change in walking
- Numbness (loss of feeling) or tingling in arms or legs

## **Sleep issues**

Obstructive sleep apnea is a common problem for people with Down syndrome. This is a sleep problem that can affect a child's behavior and ability to pay attention. It can also affect the heart. Some symptoms are obvious (snoring, restless sleep, 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 by the age of 4 years. (That testing may be hard to find in some parts of the country.) Let your child's doctor know if your child is having:

- Loud breathing
- Snoring
- Waking up often at night
- Daytime sleepiness
- Restless sleep (moving around a lot)
- Uncommon sleep positions (like sitting up to sleep or sleeping with neck arched back)
- Pauses in breathing during sleep
- Behavior problems

## **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.

## **Behavior and mental health**

Some children with Down syndrome can have behavior or mental health issues that affect how they play and work at home, at school, or in the community. Let your child's doctor know if your child is having problems that make it hard for them to function in the home, community, or school, including:

- Anxiety
- High activity level
- Wandering off
- Not listening
- Obsessive compulsive behaviors (behaviors that are repeated frequently)
- Attention problems
- Sad mood or lack of interest in activities
- Loss of skills (not being able to do the things they used to do)
- Other behavior concerns

## **Development**

As for all children, your child's well child visit is a chance to discuss his/her development, including:

- **School progress and development:** Discuss your child's development, school placement, and service needs with the school.
- **Transition:** Children can need extra support at times of transition: discuss transition from elementary to middle school.
- **Social/independence skills:** Discuss developing social skills, self-help skills, and a sense of responsibility. Discuss working toward independence (doing things by him- or herself) with bathing, grooming, and self-care.

## **Sexuality and puberty**

Children need help to learn the right kind of touch in social situations and correct names for body parts. Puberty brings many changes. As your child approaches and enters puberty, it may help to talk with your child's doctor about several things. Discussions may include:

- Changes in puberty.
- Managing sexual behaviors (such as masturbation).
- Gynecologic (women's health) care for girls with Down syndrome, including periods and mood changes related to (menstrual) periods.
- Fertility, birth control, prevention of sexually transmitted infections.
- Chance for a person with Down syndrome to have a child with Down syndrome.