

# Health Care Information for Families of Children with Down Syndrome

## Child's Age: 13 to 21 Years or Older

### **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 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). These measurements are very important to assessing the overall health of the child. Discuss diet, activity level, and growth. Your child's doctor can help with question 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 a child's health history and exam. Let your child's doctor know if your child is having increasing fatigue (low energy) or shortness of breath at rest or during activity. If new symptoms appear, an echocardiogram (an ultrasound picture of the heart) may be needed.

### **Hearing**

Hearing testing is recommended at least every year. This may be needed more often if your child has hearing or ear problems.

### **Vision**

Ophthalmology examination by an eye doctor is recommended at least every 3 years or more often if there are 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 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 or anemia (hemoglobin and other tests if needed) should be done every year.

### **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 stooling or urination
- Change in use of arms or legs
- Head tilt
- Change in walking
- Numbness (loss of normal 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 guidelines recommend 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 youth 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 him or her to function in the home, community, or school, including:

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

**Sexuality**

Young people need help to learn the right kind of touch in social situations and the correct names for body parts. Puberty brings many changes and 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
- Risk for a person with Down syndrome having a child with Down syndrome

**Transitions**

Discussion topics may include:

- School placement and goals for education. These should plan for transition and vocational (job skills) training.
- Guardianship and long-term financial planning.
- Adult work and places to live: family relationships, group homes and independent living opportunities, workshop settings, and other community-supported employment
- Working toward independence with bathing, grooming, self-care, and skills of community living
- Places for health care as an adult

**Aging**

Discussion of special health problems for adults with Down syndrome. This includes a tendency to early-aging and higher risk for Alzheimer disease in some people.