

Idaho Falls Pediatrics

Down Syndrome

What is Down syndrome?

Down syndrome is a genetic disorder which means that there is a problem with a person's chromosomes. Most people have a total of 46 chromosomes. Most children with Down syndrome have a total of 47 chromosomes. Down syndrome results from this extra genetic material. Scientists are still learning about what causes this extra genetic material and exactly how it causes the problems of Down syndrome.

Down syndrome is the most common disorder of human chromosomes. It may be diagnosed before birth, or shortly after birth during a baby's first physical exam.

How is it diagnosed?

The diagnosis before birth is based on lab test results and ultrasound measurements of the fetus. The diagnosis after birth is usually based on how the child looks. Eyes often have a slant to the openings and extra skin at the middle corner. The mouth tends to stay open with the tongue sticking out. Muscle tone is usually low, making the arms and legs more relaxed. The diagnosis is always confirmed by a chromosome test.

How will my child grow and develop?

Growth and development is unique to every child. Children learn to walk, run, use their hands and eyes, understand language, speak, think, and solve problems at different rates. Children with Down syndrome do all of these things too.

However, children with Down syndrome generally grow more slowly, learn more slowly, and have more trouble with reasoning and judgment than other children. They often have a short attention span. Many are very impatient and get easily frustrated and angry.

Growth and developmental milestones unique to children with Down syndrome have been developed and are available.

As your child reaches adolescence, he or she will become more aware of his or her limitations. Emotional problems sometimes occur at this age. Your child may need extra help learning how to control sexual impulses. Doctors believe that a child's emotional health is best supported by staying involved in mainstream home, school, and community activities.

How do I care for my child?

Children with Down syndrome can have many health problems. Some have a heart problem at birth or later in life. As your child grows older, he may have vision, hearing, bone, joint, hormone, or dental problems. Because of these problems, a child with Down syndrome needs more medical and dental care and educational help to reach his or her full potential.

1. Feeding

Breast-feeding a baby with Down syndrome is usually successful and helps the baby's ability to fight infection.

Children with Down syndrome tend to have a small mouth and smooth, flat tongue. This may cause spilling of liquids out of the side of the mouth. This problem usually goes away during infancy as tongue control improves.

Make sure your baby is fully awake before feeding. Place pillows underneath the baby during the feeding. Using a hand to support your child's chin and throat can sometimes help feeding. Talk to your doctor if you have additional questions.

2. Heart evaluation

Because many children with Down syndrome are born with heart defects, your child should be checked by a pediatric cardiologist soon after birth. A test called an echocardiogram, which uses sound waves to create a picture of the heart, is used.

3. Thyroid screening

Babies in nearly all states are tested in the hospital shortly after birth for low thyroid hormone levels. This is usually one of several tests known as the "newborn screen." Children with Down syndrome sometimes have low thyroid hormone levels.

Thyroid screening tests should be repeated for children with Down syndrome at 6 months, 12 months, and then each year thereafter.

4. Hearing

Many children with Down syndrome have hearing problems. Often this is due to frequent ear infections or fluid in the middle ear. There may be other reasons for poor hearing. Hearing problems may come and go or be always present. Any cause of hearing loss should be treated by your doctor. Good hearing helps with language development.

5. Vision

7 of every 10 children with Down syndrome will need glasses. Around 20% of children with Down syndrome have eyes that point in slightly different directions. This needs to be treated. Most children with Down syndrome need to see an eye doctor at about one year of age.

6. Dental and oral concerns

The teeth of a child with Down syndrome usually come in later than the teeth of most children. The first tooth usually appears between 12 and 48 months. Fifty percent of children with Down syndrome are missing one or more teeth. Teeth often will not be in the best position for chewing. For example, a child may have an overbite (the upper teeth coming out forward) or a crossbite (the lower teeth set to one side of the upper teeth).

For an unknown reason, cavities are less common. Careful brushing and flossing is nevertheless needed to prevent cavities and gum disease. Gum disease is more common in children with Down syndrome.

Children with congenital heart defects who are going to have a dental procedure performed often need antibiotic medicine before the procedure.

7. Breathing and sleep apnea concerns

Air passages in the nose, mouth, and chest are smaller than in children without Down syndrome. As a result of the narrowing, a number of problems can occur. Mouth breathing may develop and this can lead to teeth problems. Snoring may be a sign of a narrowed airway. Narrowing may become so severe that the airway becomes blocked, causing air flow to stop. This problem is known as sleep apnea.

Check with your doctor if your child snores a lot, especially if they have loud snoring, followed by silence, a snort, partial awakening, and then snore again.

8. Cervical (neck) spine x-ray

Between the ages of 3 and 5 years, all children with Down syndrome should have x-rays of the upper spine. The x-rays are taken to look for too much movement of the bones in the upper spine when the neck is held in different positions.

Dislocation, or slippage, of the bones in the upper spine is not common but can result in serious injury. Usually, before an injury, the child would have several weeks of symptoms such as: neck pain, head tilt, breathing changes, weakness, or changes in walking ability. If your child has these symptoms, tell your doctor so the spine can be checked. A careful neck exam is important before your child plays in sports.

9. Behavior

Ignore outbursts unless your child becomes destructive. Then use time outs or mild physical restraint until he is calm. Reward your child for times when outbursts don't occur. Ask about local Down syndrome support organizations where parents can share ideas and experiences.

10. Sexuality

Teach your child to not stare at others, make sexual comments, or touch their private parts in public.

11. Emotional Health

Help your child deal with his frustration with his limitations. Suggest other activities which he can do. Behavioral training programs may help your child learn how to respond calmly and appropriately.

12. Social Development

Children with Down syndrome tend to become dependent on others and need experiences that encourage independence.

13. **Unproved therapies**

You will probably hear of many treatments for children with Down syndrome. They may range from megavitamin therapy to facial surgery. The good effects of many of these treatments are unproved and some may be harmful. Check with your child's doctor before trying any treatment.

What kind of treatment and therapy will my child need?

Getting therapy and other services started when your child is young help your child reach his or her greatest potential. The therapies, along with improved medical care, parent education, and increased social acceptance, may explain why people with Down syndrome generally have better skills and higher levels of functioning than in past decades.

The professionals who can provide services include:

- Developmental pediatrician: evaluates and treats medical factors affecting development.
- Infant educator: helps with thinking and problem solving skills.
- Pediatric physical therapist: helps with body movement skills.
- Pediatric occupational therapist: helps with feeding and hand skills.
- Speech and language therapist: helps with communication skills.
- Mental health professional: provides counseling and emotional support.

Often mental health specialists can help design behavioral training programs. For emotional and behavioral problems, medicines may help control moods and inappropriate behavior.

What is the outlook?

The health care needs of children with Down syndrome are better understood than ever before. Scientists are improving their understanding of the genetic basis of the syndrome. Much can be done to prevent and treat medical problems associated with the syndrome.

Although children with Down syndrome may be slow in their achievements and must cope with their limitations, most lead productive, fulfilling lives. You can help your child reach his or her potential by making sure your child has regular checkups and receives proper medical treatment.

Additional information about Down syndrome is available from many books, on-line services, and parent and professional organizations.

*NOTE: This information is provided as a public educational service. The information does not replace any of the instructions your physician gives you. If you have a medical emergency please call 911 or call the Hospital at (208) 529-6111. If you have questions about your child's care, please call Idaho Falls Pediatrics at (208) 522-4600.