

Health Care Information for Families of Children with Down Syndrome

American Academy of Pediatrics

Introduction

Down syndrome is a common condition caused by having “extra” copies of genes on the 21st chromosome. Those extra genes change development during pregnancy, and they continue to have effects after birth and throughout a person’s life. Each person with Down syndrome is unique, having some of the many possible health, learning, and related differences that can occur with this condition.

Some of the differences in people with Down syndrome are common and visible, like the facial appearance. Other changes are less common or less visible but can still cause problems or may need special treatments. The “special treatments” may include medicines, surgeries, or changes in what you should expect. There are no medicines or therapies that are needed by all people with Down syndrome. There are also no medicines or therapies that can “cure” Down syndrome.

Your child’s doctor should be your starting point. Your child needs regular doctor visits and a few special tests. Medical specialists may also need to be involved.

The medical issues for a child with Down syndrome change with age. For this reason, this document is divided into several age groups. Each age group includes a list of issues that may be important to your child at that age. Your doctor can check the full AAP guideline for more details (the web address is given below).

The information within each age group is sorted by the parts of the body that are affected (heart, ears, etc). Many tests only need to be done once. Some areas might need to be looked at again, or even many times, as the child grows to an adult.

This document focuses on medical topics that affect physical health. Other issues can affect social and school success, which may not need doctors or other medical resources but are still important issues for children with Down syndrome. Many people with Down syndrome understand more than they can say. They may need help to communicate in other ways. Most have good social skills, especially if they have friends with typical behavior as models. Respect for and attention to their abilities are often important missing pieces and may be enough to make a big difference in performance and behavior.

The information in these guidelines has grown with the help of families, Down syndrome clinics, and doctors around the world. Most of the information is easy to follow. However, some tests or specialists might be needed that are not available in your area. Your doctor can help to sort out the best next-steps when something can’t be done quickly or nearby.

When you visit the doctor, you might want to bring a notebook to write down information from each visit. A notebook will help you keep all of your child’s medical information in one place. This will be valuable when you meet with new doctors or with others involved in your child’s care.

Local parent support groups can be a very good place to learn about doctors, therapists, and other providers in your community. They may also be able to help with questions about daycare, preschools and schools, other local developmental programs, problems with behavior, help with child care, etc. Your doctor’s office should have names and contact information for groups in your area.

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“Health Care Information for Families of Children with Down Syndrome” was created in July 2013 by the American Academy of Pediatrics (AAP) to give parents and families information about the special health care needs for children with Down syndrome. This document should be used together with the care given by a child’s doctor.

This information is based on the “Health Supervision for Children with Down Syndrome” clinical report from the American Academy of Pediatrics, available here: <http://pediatrics.aappublications.org/content/128/2/393.full>

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