

Healthcare Guidelines for Individuals with Down Syndrome

About Health Care Guidelines

Health care guidelines help define the standards of quality care for individuals with Down syndrome. In addition to specific recommendations for screening tests, they include information about the kinds of medical conditions that individuals with Down syndrome are at risk for and suggestions for early intervention, diet and exercise and other issues across the lifespan.

Original Interview with William I. Cohen, M.D. on the Significance of Down Syndrome Health Care Guidelines

WHY ARE SPECIALIZED HEALTH CARE RECOMMENDATIONS FOR INDIVIDUALS WITH DOWN SYNDROME SO IMPORTANT?

The importance of the document is to support parents in getting the screening tests done that we believe are important to keep children and adults with Down syndrome healthy. Pediatricians may have between three and five children with Down syndrome in their practice, and although they may be knowledgeable about the current recommendations, I don't expect them to be able to keep up in the same way as parents, who really become experts about the needs of their children. And even though we write about and present these issues in a variety of forums – at scientific meetings and continuing medical-education conferences – the issue may not be as compelling for physicians as it is for parents.

Specialized guidelines help define for parents what is needed, so they can communicate with their primary-care physician and say, "This is what is recommended. This is what we need to do." It is a helpful tool for physicians, too, because it defines the medical vulnerabilities and the necessary screenings.

In 2011 the American Academy of Pediatrics issued the newest version of the Down Syndrome Health Care Guidelines, which replaces all previous versions.

WHAT ADVICE CAN YOU GIVE TO PARENTS ABOUT SELECTING A PEDIATRICIAN AND OTHER HEALTH CARE PROFESSIONALS TO WORK WITH THEIR CHILD WHO HAS DOWN SYNDROME?

That's a very interesting question, and it comes up very often when we see patients in the Down Syndrome Center. The notion that many folks would have is that they need to find someone who's very knowledgeable; that it really is going to help them to have somebody who is an expert on Down syndrome. In my experience, some of the people who believe

they may be experts on Down syndrome may not be current. They may be enamored of their expertise and fail to listen to parents about what may be different with their child.

A mother once came to me with a new baby and said, "My doctor is a family physician, and he said that he doesn't know anything about Down syndrome." I anticipated that she had reacted to this as if it was a problem, but she went on to say, "And so he told me that any information I could bring him would be so appreciated." He, indeed, is the kind of physician you want-one who is open to partnering with a family. The knowledge that someone has is necessary, but not sufficient. In fact, not having the knowledge is less of a problem than believing you have it.

What we need when we have a child with special health care needs is someone who will collaborate-who is open to listening to parents and seeing them as partners. We need to know how to identify someone with that style. One of the best ways to find a pediatrician is to ask families of other children with Down syndrome in the area. Going to parent support groups can be very helpful.

But I will tell you that the most effective thing is for parents to be the educator of the physician.

AAP Guide for Families of Children with Down Syndrome

The American Academy of Pediatrics (AAP) has developed a special guide to help parents and families of children with Down syndrome. This document focuses on medical topics that affect physical health. The medical issues for a child with Down syndrome change with age. For this reason, the document focuses on medical topics that affect physical health and includes checklists by age. View the complete [Health Care Information for Families of Children with Down Syndrome](https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Documents/Health_Care_Information_for_Families_of_Children_with_Down_Syndrome.pdf) by the American Academy of Pediatrics.

An electronic version can be accessed here:

https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Documents/Health_Care_Information_for_Families_of_Children_with_Down_Syndrome.pdf

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. 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. Some tests or pediatric 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.

The family guide referenced above is based on the specialized health care guidelines for children with Down Syndrome published by the American Academy of Pediatrics (AAP).

The guidelines span the prenatal period through age 21. The direct link to the AAP clinical guidelines is included below and may be helpful to share with your child's physician.

These guidelines are based on "Health Supervision for Children with Down Syndrome" published in Pediatrics (Vol. 128, No. 2, August 1, 2011. pp. 393 -406.)

An electronic version of the AAP Clinical Guidelines can be accessed here: pediatrics.aappublications.org/content/128/2/393

Growth Charts for Children with Down Syndrome

Children with Down syndrome (DS) have lower birth weights and grow more slowly than children without DS. For this reason, the use of typical growth charts used by physicians may not accurately reflect the growth of a child with DS. The clinical growth charts specific for children with DS can be used as screening tools to assess growth and nutritional status and to provide indications of how growth of an individual child compares with peers of the same age and sex with DS. Be sure to ask your child's physician which growth charts they are using and make sure they are aware of the charts which include growth information specific to children with DS.

An electronic version of the Growth charts for Children with DS can be accessed here: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

Adapted from the following sources:

National Down Syndrome Society, Healthcare Guidelines,
<https://www.ndss.org/resources/healthcare-guidelines/>

HealthyChildren.org, Children with Down Syndrome: Health Care Information for Families,
<https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx>

NCBI, Growth Charts for Children with Down Syndrome in the United States,
<https://www.ncbi.nlm.nih.gov/pubmed/26504127>