



Welcome

“Down Syndrome: A Parent’s Guide to Medical Care” is a series of booklets designed to help you learn more about the general medical needs of infants, children and adolescents with Down syndrome. Each brochure in this series will guide you through the age-based medical recommendations for children with Down syndrome, so that you can better work with your child’s healthcare provider.

Always...

- Bring up any concerns you may have about your child with your child’s doctor.
- Tell your child’s doctor about any medications or home remedies your child is taking.
- Tell your child’s doctor right away if you notice any of the following: changes in the way your child walks or uses their arms or hands; a change in urination; any weakness; neck pain or head tilt.
- Tell your child’s doctor about any heavy breathing, snoring, uncommon sleep positions, frequent night awakening, daytime sleepiness, pauses in breathing and behavior problems. These could be signs of additional healthcare concerns.

COMMUNITY RESOURCES

Break the Barriers
www.breakthebarriers.org
(559) 432-6292

Central Valley Regional Center (CVRC)
www.cvrc.org
4615 N. Marty Ave.
Fresno, CA 93722
Fresno: (559) 276-4300
Merced: (209) 723-4245

CITI Kids
965 N. Sunnyside Ave., #24
Clovis, CA 93611
(559) 327-8450

Down Syndrome Association of Central California (DSACC)
www.dsacc.org
1491 W. Shaw Ave.
Fresno, CA 93711
(559) 228-0411

Exceptional Parents Unlimited Children’s Center
www.epuchildren.org
4440 N. First St.
Fresno, CA 93726
(559) 229-2000

National Down Syndrome Congress
www.ndsccenter.org
(800) 232-6372
Healthcare Website:
www.ds-health.com

National Down Syndrome Society
www.ndss.org
(800) 221-4602

Parenting Network – Visalia Family Resource Center
1900 N. Dinuba Blvd., Suite C
Visalia, CA 93291
(559) 625-0384

Valley Children’s Healthcare – Family Resource Center
downsyndrome
@valleychildrens.org
(559) 353-8880

These guidelines are based on the Clinical Practice Guidelines of the American Academy of Pediatrics and the National Down Syndrome Society.

“Health Supervision for Children with Down Syndrome”
Pediatrics (Vol 128, No. 2, August 1, 2011, pp. 393-406)

“Down Syndrome Health Care Guidelines”
National Down Syndrome Society



DOWN SYNDROME

A Parent’s Guide to Medical Care



CHILDREN – 5 to 13 years



HEALTHCARE GUIDELINES

CHILDREN — 5 to 13 years

Your Child's Growth

Children with Down syndrome are at increased risk of obesity. Ask your child's doctor to review the Down syndrome-specific growth charts with you, if available, at each visit. A good way to help avoid obesity is to establish a routine of healthy eating and exercise. Ask your child's doctor for a consult with a nutritionist if your child is overweight.

Gastrointestinal Health

Children with Down syndrome may have additional problems with their digestive tract. Tell your doctor if your child has problems with constipation (hard or infrequent stools). Additional testing for celiac disease may be indicated if your child is having symptoms such as diarrhea, excessive gas, bloating, poor appetite, abdominal pain or weight loss.

Heart Health

If your child has been diagnosed with a heart condition, their doctor will continue to monitor for signs of heart failure. Your child's cardiologist (heart doctor) will recommend whether antibiotics are needed before any medical or dental procedure.

Blood Tests – Iron-Deficiency Anemia

Annual tests for anemia should continue. This may consist of a simple finger-stick blood test or blood draw. If there are signs of anemia, your doctor may explore additional testing.



Blood Tests – Thyroid Function

Children with Down syndrome are at increased risk of thyroid disease. Thyroid function tests should be obtained once every year in this age group, or sooner if there are additional signs or symptoms. Talk to your child's doctor about signs of thyroid disease.

Your Child's Hearing

A hearing exam should be performed every six months until both ears test normal. Once both ears test normal, hearing exams can be performed once per year. A referral to a pediatric ear, nose and throat (ENT) specialist should be made following any abnormal hearing test.

Ears, Nose, Throat and Lungs

Respiratory tract infections (infections of the ears, sinuses, nose, throat and lungs), as well as sleep apnea, are more common in children with Down syndrome. Continue to monitor your child for signs of sleep apnea, even if they have had a normal sleep study in the past.

Eyes

All children should have an eye exam by a pediatric ophthalmologist (eye doctor) or an ophthalmologist familiar with the healthcare problems of children with Down syndrome every two years, or sooner if concerns arise.

Development

Children with Down syndrome are typically delayed in motor, language and intellectual development. Referrals to speech therapy, physical therapy and occupational therapy can be made, if indicated. It is important to know that your child is not exempt from other diagnosis such as autism or ADHD (attention deficit hyperactivity disorder) that can affect learning.

Dental Care

Routine dental care is very important. The risk of tooth decay can be greatly decreased if your child establishes a regular tooth-brushing and flossing routine. Regular dental visits also play a major role in your child's oral health.

Parental and Family Support

Despite cognitive and developmental delays, children with Down syndrome walk, talk, play and attend school just as other children do. Children with Down syndrome have many wonderful attributes, and can contribute to society in many positive ways. Local and national support groups can continue to be a source of information, as well as a forum in which to discuss your concerns and fears as you step into the school years.

Vaccines

Children with Down syndrome should receive all routine childhood immunizations, including the seasonal influenza vaccine, unless there are specific contraindications.

Safety

It is important to talk to your child about personal boundaries and appropriate behavior. It is also not unusual for children with Down syndrome to begin wandering off at this age; ongoing supervision is important.

Children with Down syndrome are at increased risk of neck injury. If your child wishes to participate in sports, a cervical spine (neck) X-ray should be obtained ahead of time. Trampoline use should be avoided for all children under the age of 6 years. Over age 6, use of a trampoline should only occur with professional supervision and only after clearance is obtained from your child's doctor.

Transition

Continue to work with your child on independence with self-help skills. You may also begin to think about guardianship, conservatorship and financial planning for the future.