



Welcome

A *Parent's Guide to Medical Care* was 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 Hospital – Family Resource Center
(559) 353-6178

Based on the Clinical Practice Guidelines of the American Academy of Pediatrics

"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



ADOLESCENTS – 13 to 21 years



HEALTHCARE GUIDELINES

ADOLESCENTS – 13 to 21 years

Adolescent Growth

Ask your teen's doctor to review the Down syndrome-specific growth charts with you at each visit. Consultation with a nutritionist is recommended for overweight adolescents.

Gastrointestinal Health

Continue to monitor your teen for constipation, diarrhea, excessive gas, bloating, poor appetite, abdominal pain or weight loss.

Down syndrome is not easy.
WE'RE HERE TO HELP.

Heart Health

If your adolescent has a known heart condition, your child's 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 procedures.

Blood Tests – Iron-Deficiency Anemia

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

Blood Tests – Thyroid Function

Individuals with Down syndrome are at increased risk of thyroid disease. Thyroid function tests should be obtained once every year in this age group, and sooner if there are additional signs or symptoms.

Hearing

Hearing exams should be performed once a year. A referral to an 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 individuals with Down syndrome. Continue to monitor your child for signs of sleep apnea.

Eyes

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

Development

Your adolescent may have been receiving additional therapies for any identified delays in development. Continue with these therapies if indicated. This is also the time to talk with your teen's doctor about pubertal, social, psychological and behavioral changes associated with adolescence.



Dental Care/Hygiene

Ongoing routine dental care is very important. Hold your teen to some basic rules of personal hygiene that are not negotiable.

Parental and Family Support

Raising a teen isn't easy, even under the best of circumstances. Raising a teen with Down syndrome comes with additional challenges. It is important to know that your teen will experience the same needs and desires as their typical teenage friends regarding sexual and social development. Continue to network with local support groups and parents as your child begins the transition into adolescence and adulthood.

Vaccines

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

Safety, Transition & Independence

Many individuals with Down syndrome are fairly independent of their families by the time they reach age 20. It is important to continue speaking to your teen about appropriate behaviors and boundaries. Included in preparing your teen for the transition into adulthood is teaching them personal safety and how to advocate for themselves. Individuals should be taught how to call 9-1-1, and what to do in case of emergencies. Those who are not driving can obtain a non-driver's ID to carry on them at all times.

If you have not already, begin to think about guardianship and conservatorship, financial planning, vocational training, independent living skills, linkage to social groups, post-secondary education programs, group homes and work settings.