



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: the way your child walks, 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 obstructive sleep apnea.

COMMUNITY RESOURCES

Down Syndrome Association of Central California (DSACC)
www.dsacc.org
4277 W. Richert Ave., #102
Fresno, CA 93722
559-228-0411

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

Exceptional Parents Unlimited (EPU) - Parent & Family Resource Center
www.epuchildren.org
4440 North First St.
Fresno, CA 93726
559-229-2000

Parenting Network
1900 N. Dinuba Blvd., Suite C
Visalia, CA 93291
559-625-0384

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

National Down Syndrome Congress
www.ndscenter.org
800-233-6372
Healthcare Website:
www.ds-health.com

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

Valley Children's Healthcare – Family Resource Center
www.DownSyndrome@valleychildrens.org
(559) 353-8880

CITI Kids
(Resources for 0-3 years of age)
965 N. Sunnyside Ave.,
#24 Clovis, CA 93611
(559) 327-8450

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



HEALTHCARE GUIDELINES

TODDLER AND PRESCHOOL – 1 to 5 years

Your Child's Growth

Children with Down syndrome are at increased risk for becoming overweight. Ask your child to review growth charts with you at each visit. If available, Down syndrome specific growth charts should be used. Consultation with a nutritionist is recommended 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. Talk to your child's doctor about additional signs you might observe.

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 specialist) will recommend whether or not antibiotics are needed before any medical or dental procedures.

Blood Tests – Iron-Deficiency Anemia

As with all toddlers, your child's doctor will test for signs of iron deficiency anemia at 1 and 2 years of age. This may consist of a simple finger-stick blood test. If there are signs of anemia, your doctor may consider additional blood testing.

Blood Tests – Thyroid Function

Children with Down syndrome are also 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 problems.

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 for 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. A sleep study to evaluate for sleep apnea is recommended by age 4, regardless of symptoms.

Eyes

All children in this age group should see a pediatric ophthalmologist (eye doctor) at least once per year.

Development

Children with Down syndrome are typically delayed in motor, language and intellectual development. As your child grows, you may continue to notice delays in motor skills, language and intellectual abilities. If your child has not established a relationship with the local Regional Center, ask your child's doctor for a referral.



Dental Care

Dental eruption is often irregular or delayed for children with Down syndrome. Your child's first tooth may not appear until after 1 or even 2 years of age. It is important to establish a routine of dental care even before that first tooth has erupted.

Down syndrome
MORE ALIKE THAN DIFFERENT

Parental and Family Support

By now you have probably become more comfortable with your child's care. Don't forget to take of yourself. Staying active and involved will help keep you strong and well-equipped to handle your many responsibilities.

Vaccines

Children with Down syndrome should receive all routine childhood immunizations, including the seasonal influenza vaccine, unless there are specific contraindications. For children over age 2 with chronic heart or lung disease, the 23-valent pneumococcal vaccine (also known as the pneumonia vaccine or Pneumovax) is recommended.

Safety

Toddlers with Down syndrome face many of the same safety concerns as other children their age such as choking on small objects and frequent falls. Unlike their peers, they are at increased risk for neck injury. For this reason, trampoline use should be avoided for all children under age 6. Speak to your child's doctor before starting any program that could put your child's neck at risk for injury such as gymnastics or sports with risk of high-speed collision. Your child's doctor may want to obtain a neck X-ray.