

## Down Syndrome

### What is Down syndrome?

Down syndrome is a relatively common birth defect caused by extra genetic material from chromosome 21 (ie, there are 3 copies of chromosome 21, rather than 2). This syndrome affects the physical development and intellectual development of the child.

### How common is it?

- About 6,000 children with Down syndrome are born in the United States each year.
- Females of any age can have a baby with Down syndrome, but the risk increases in women older than 35 years.

### What are some common characteristics of children who have Down syndrome or of Down syndrome as children present with it?

- Down syndrome causes intellectual disabilities and characteristic facial and physical features, and it can be associated with internal malformations.
- All children with Down syndrome are affected differently and will have various levels of ability, which should be thoroughly evaluated and treated case by case.
- The degree of intellectual disability can be mild, moderate, or severe.
- Medical complications may include heart defects, hearing loss, frequent ear infections, sleep apnea, thyroid disease, and eye disease, including cataracts.
- Other rare complications include leukemia, intestinal blockage (atresia), seizures, and hip dislocation.
- A condition called *atlantoaxial instability*, in which the neck bones can slide and cause spinal cord compression, is a risk.
- Some children with Down syndrome can have behavioral problems, attention-deficit/hyperactivity disorder, and features of autism spectrum disorder.
- Children with Down syndrome have some common characteristics. They
  - Tend to be short
  - Tend to have low muscle tone
  - May develop overweight
  - May be more prone to dental and gum diseases
  - May be more susceptible to or may develop more complications from respiratory tract infections (eg, colds).



Child with Down syndrome

### Who might be on the treatment team?

- Children with Down syndrome frequently receive services from an early intervention program or special child health services for physical, occupational, or speech-language therapy.
- Children who are younger than 3 years (ie, 36 months) may receive therapies through *early intervention* services. Early intervention is a system of services to support infants and toddlers with disabilities and their families.
- For children 36 months and older, *special education and related services* are available through the public school to provide the accommodations necessary for school achievement.
- Children with Down syndrome will have a pediatrician/primary care provider in their medical homes and may have subspecialists involved in their care if they have other specific medical conditions (eg, a pediatric cardiologist for a congenital heart problem).

## Down Syndrome *(continued)*

### What adaptations may be needed?

#### Medications

- Children with Down syndrome do not need specific medications for the syndrome, but they may take medications for an associated condition, such as a heart defect or a behavioral problem.
- Children with heart defects may take a diuretic to reduce fluid in their bodies or a medication to make their hearts contract better.
- Children with thyroid disease may take medication to control their conditions.
- All staff who will be administering medication should have medication administration training (see Chapter 6).
- All children and staff should be fully immunized, including with influenza vaccine.

#### Dietary Considerations

A special diet may be recommended if a medical complication such as obesity or a heart condition is present.

#### Physical Environment and Other Considerations

- The following special equipment should be considered:
  - Children with Down syndrome who have hearing loss may need to wear hearing aids. (See page 133 for adaptations for hearing loss and deafness/hard of hearing.)
  - Children with eye disease may need glasses or eye patches. (See page 201 for adaptations for visual impairments.)
- Develop strategies for accommodating children with Down syndrome. Suggestions include
  - Children with poor muscle tone, coordination challenges, or limited mobility may need additional help, special exercises, or customized activities.
  - Because of the risk of atlantoaxial instability, activities with extreme neck flexion, such as somersaults, should be avoided. The benefit of doing special radiography to help determine the risk of neck problems is controversial.

- Early intervention services such as physical, occupational, and speech-language therapies may be required and can often be incorporated into other program activities.
- Other children may need help in understanding the differences in these students.
- Children with Down syndrome often have good social skills and can serve as a model for other children.
- Placement of the child in a class depending on age and developmental capabilities may need to be discussed with parents/guardians. Extra supervision is frequently needed.

### What should be considered an emergency?

- No special medical emergencies are expected in children with Down syndrome other than those associated with medical complications such as congenital heart defects.
- In general emergency situations, such as an evacuation, children with Down syndrome may require extra preparation, time, and supervision.

### What types of training or policies are advised?

- Teachers and caregivers may need training on how to adapt daily lessons and schedules to accommodate these children.
- Medication administration training may be needed.
- Specific training about the individual child's special needs may be necessary.
- The child's schedule may need to be adapted if individual therapy (ie, physical, occupational, speech-language) will take place at the program.

### What are some resources?

- The Arc: [www.thearc.org](http://www.thearc.org), 1-800-433-5255
- National Down Syndrome Congress: [www.ndsccenter.org](http://www.ndsccenter.org), 1-800-232-NDSC (1-800-232-6372)
- National Down Syndrome Society: [www.ndss.org](http://www.ndss.org), 1-800-221-4602

