

# Fact Sheet about Down Syndrome for New and Expectant Parents

Reviewed by the National Society of Genetic Counselors Down Syndrome Information Act Working Group, with assistance from the National Center for Prenatal and Postnatal Down Syndrome Resources

## OVERVIEW OF DOWN SYNDROME

Down syndrome is a genetic condition that is usually caused by an extra copy of the twenty-first chromosome. According to current data, about 250,000 people in the United States have Down syndrome. Studies show that about 1 in 800 babies are born with Down syndrome, and the chance of having a baby with the genetic condition increases with the age of the expectant mother. Down syndrome does not typically run in families and is not caused by anything either parent did or did not do.

Advances in medical care and research over the years have given people with Down syndrome better overall health. The traits, medical conditions, and abilities of people with Down syndrome vary widely and cannot be predicted before they are born. They generally have mild to moderate cognitive delays, low muscle tone, and higher chances for a variety of other health issues over their lifespan. Because of advances in health care, education, and public attitudes, the outlook for people with Down syndrome has improved significantly over the past few decades.

## UNDERSTANDING DOWN SYNDROME

- Children with Down syndrome are more similar to other children than they are different.
- Individuals with Down syndrome have a variable range of intellectual disability from mild to moderate (not typically severe).
- Babies with Down syndrome usually have developmental delays and benefit from early intervention, including physical, occupational, and speech therapy, to help them meet their milestones.
- 80% of babies with this condition have hypotonia or low muscle tone at birth. This usually improves with time, and physical therapy can help.
- 50% of babies with Down syndrome will have one or more health issues: 40–60% of babies with Down syndrome have a heart condition and 12% have gastrointestinal condition, which may require surgery. Referrals to specialists are appropriate for identified complications.
- Babies with Down syndrome also have higher chances for feeding and digestive issues, hearing loss, vision impairments, and respiratory infections. Most of these conditions can be treated with good health care.
- Currently, the average life expectancy for people with Down syndrome is about 60 years.
- Raising a child with Down syndrome may involve more time commitment than typical children.
- Individuals with developmental disabilities can participate in community sports, activities, and leagues.
- Individualized education programs can help children with Down syndrome reach their potential. Special education services at school can range from inclusion in the typical classroom with extra help to small group instruction. There are also over 250 college programs for people with intellectual disabilities.
- Individuals can be employed competitively or with supports; live independently or in a group home; and have friends and intimate relationships. As a result of improved public attitudes and acceptance, many people with Down syndrome are thriving as active and valued members of the community. This includes children who are involved in social and school programs with their peers and many adults who are

employed and live independently or with some support. Research shows that the majority of adults with Down syndrome report that they are happy with their lives.

#### GETTING MORE SUPPORT

Patients can learn more from genetic counselors who can offer information about testing options and results, the accuracy and limitations of different prenatal screens and tests, reproductive options (continuing a pregnancy, termination, and adoption), recurrence chances for future pregnancies, the genetics of Down syndrome, and local resources, such as local support organizations and connections to other families. A directory of genetic counselors can be found at the National Society of Genetic Counselors (NSGC) website: [nsgc.org](http://nsgc.org).



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Down Syndrome  
**Readability Assessment**

*Readability tools used:*

Fry-based Grade Level

Flesch-Kincaid Grade Level

SMOG Grade Level

**ORIGINAL Grade Level Range: 11th-15th (Mean 12.7)**

