# Developmental Expectations and Medical Issues for Children with Down Syndrome

## Introduction to Genetics

All human beings have 23 pairs of chromosomes in each of their cells. Chromosomes carry our genetic information (our genes), which gives each of us our initial blueprint (like whether we will be tall, have brown hair, or have blue eyes, for example). Most people inherit one copy of each chromosome from each parent, resulting in 46 total chromosomes. People with Down syndrome are born with an extra 21st chromosome. Nobody knows for sure why this happens, but we know that the extra chromosome is usually present in every one of their trillions of cells. This extra chromosome can potentially lead to different medical or developmental challenges, but it can also lead to many positive outcomes.

## Developmental Expectations and Milestones

Children with Down syndrome typically have some delays in different areas of development. Gross motor delays are delays in areas like sitting, crawling, and walking. Fine motor delays are delays in the purposeful coordination of the hands and fingers. Speech delays are delays in the onset and quality of speech development. All children develop at a different pace, and some may not have as many delays as others in these areas. On average, most children with Down syndrome take about 1.5 to 2 times as long to reach their developmental milestones as other children. It is important to remember that most children with Down syndrome reach the expected developmental milestones, but patience is needed while waiting for them to be attained.

The tables below take data from recent studies to provide a range when children learn particular developmental skills. Being outside a range does not by itself mean something is wrong, and being inside it is not a guarantee for future skills. Talk with your child's care team about your child's individual progress. Some ranges are quite wide, especially for skills that are learned later or that involve more steps, such as dressing or writing. This reflects how much the timing varies from child to child with Down syndrome.

© 2026
National Down Syndrome Congress

## Developmental Milestones

| Milestone | Typical Child (average)[3,7] | Child with Down syndrome: common range (months)[1,2,3,4] |
|---|---|---|
| Rolling Over | 6 | 5–8 |
| Crawling | 8 | 11–20 |
| Sitting Alone | 9 | 9–11 |
| Responding to own name | 9 | most by 14–16 |
| Talking (first words, signs, or pictures) | 12 | 8–18 |
| Standing | 12 | 19–25 |
| Using gestures to communicate | 12–15 | most by 14–16 |
| Walking | 18 | 21–29 |
| Talking (2-word phrases) | 24 | 23–63 (about 2–5 years) |
| Running | 24 | 26–61 (about 2–5 years) |
| Walking up stairs | 24 | 34–43 (about 3–4 years) |
| Jumping | 30 | 41–53 (about 3–4 years) |
| Riding a tricycle | 36 | 49–64 (about 4–5 years) |

## Developmental Skills

| Skill | Typical Child (average) [3,7] | Child with Down syndrome: common range (months) [1,2,3,4] |
|---|---|---|
| Finger Feeding | 15–18 | 9–20 |
| Scribbling with a crayon | 18 | 9–22 |
| Using a spoon | 24 | 28–42 |
| Using a fork | 36 | 28–66 (about 2–6 years) |
| Tracing simple shapes (lines and circles) | 22–36 | 31–60 (about 3–5 years) |
| Snipping paper with scissors | 23–29 | 37–60 (about 3–5 years) |
| Daytime toilet training (bowel and bladder) | 29–32 | 46–117 (about 4–10 years) |
| Dressing self | 47 | 59–170 (about 5–14 years) |
| Writing own name | 60–72 | 67–120 (about 6–10 years) |

© 2026
National Down Syndrome Congress

To help children reach these milestones and skills, it is important to involve early intervention services. These services are provided by each state and involve a variety of therapists, including developmental therapists (general development), physical therapists (gross motor), occupational therapists (fine motor), and speech therapists (language and communication skills). Many states also have dietitians and feeding specialists in early intervention. These programs are government-funded and are offered through the individual counties in each state. The services are provided from birth to age 3. After that, the local school districts take over the therapies.

# Medical Issues

Certain medical conditions occur more commonly in people with Down syndrome. The first set of Healthcare Guidelines was published in 1994, updated in 2001, 2011, and last revised in 2022[6]. The goal of these guidelines is to help identify medical issues and concerns before they become more problematic. What follows is an overview of these medical issues and any associated healthcare guidelines. Please remember that this is only an overview of potential issues that could develop; it does not mean that every child will have all of these problems. The vast majority of children with Down syndrome are healthy and thriving.

**Cardiac –** About half of babies with Down syndrome are born with a heart condition. Most commonly, the issue is with the structure of the heart and results in mixing of oxygen-rich blood with oxygen-poor blood. Some of these heart conditions will require surgery, but many can improve on their own with time and close monitoring. It is important that all children born with Down syndrome have an echocardiogram (an ultrasound of the heart) within the first 1 to 2 months after birth. If there are any abnormalities on the echocardiogram, the child should be seen by a pediatric cardiologist. After the newborn period, some adolescents and adults with Down syndrome can develop leaky heart valves that may result in a heart murmur that was not previously present. If this happens, a cardiologist should be consulted.

**Gastrointestinal (GI) –** About 5% of infants with Down syndrome are born with an obstruction of the intestinal tract. This can result in feeding problems, vomiting, or significant constipation soon after birth. The newborn nursery medical team should consider one of these possible obstructions if an infant with Down syndrome has any of these symptoms. If needed, pediatric surgeons can become involved to address the obstruction. After the newborn period, gastrointestinal issues that may be seen include reflux, constipation, celiac disease, and chewing or swallowing difficulties. If any of these issues become problematic, gastroenterology specialists are often involved. Routine screening for celiac disease in individuals with Down syndrome who have no symptoms is no longer recommended.

**Respiratory/Ear, Nose, and Throat (ENT) –** Many people with Down syndrome have what is called "midface hypoplasia." This simply means that the middle part of the face may be narrowed, which can make it difficult for fluids in that part of the face to drain. As a result, they can develop recurrent ear infections, recurrent sinus infections, recurrent croup, and sometimes hearing loss. Regular hearing screenings are recommended for people with Down syndrome, beginning at birth. After that, an audiologist should re-screen them every 6 months for the first 3 to 4 years of life to make sure their hearing is adequate for speech development. After about age 4, hearing screenings can

be done annually. If a child develops any of the recurrent ear, nose, and throat issues discussed above, they should be seen by an ENT (otolaryngology) specialist.

Another common issue related to airway narrowing in people with Down syndrome is obstructive sleep apnea (OSA). Many people with Down syndrome have OSA, which can present with symptoms such as snoring, mouth breathing, abnormal sleep positioning, or restless sleep. It can also occur without any symptoms. Therefore, all children with Down syndrome should have a sleep study at a pediatric sleep center by age 3-4 years old. If sleep apnea goes untreated, it can result in high blood pressure in the lungs (pulmonary hypertension), poor school performance, behavioral problems, poor growth, and possibly earlier onset of dementia in adulthood. If there is sleep apnea, an ENT specialist should be involved.

**Ophthalmologic (Eye) –** Children with Down syndrome often have vision difficulties that develop over time. The guidelines recommend an ophthalmologist exam at 6 months and 12 months of age, then annually until age 5, every 2 years from age 5 to 12, and every 3 years after that.

**Endocrinologic –** Children with Down syndrome can be born with hypothyroidism (underactive thyroid). This should be detected on the newborn screen if they were born in a US hospital. They can also develop hypothyroidism later in life at a much higher rate than the general population. The guidelines call for labs to check thyroid function at 6 months and 12 months of age, and then annually for the rest of their lives. If hypothyroidism is caught early, it can be easily managed with a once-a-day thyroid medication. Many doctors will refer to a pediatric endocrinologist for management of hypothyroidism. People with Down syndrome also develop hyperthyroidism (overactive thyroid) and type 1 diabetes at a higher rate than others.

**Hematologic –** Leukemia is a possible medical issue that parents understandably tend to be very concerned about. It occurs in 1% of children with Down syndrome, which means that 99% of children with Down syndrome do not get leukemia. The symptoms include unexplained fevers, weight loss, abnormal paleness, bleeding, or bruising. If those symptoms were seen, your doctor would send a blood count to evaluate and refer your child to a pediatric hematology/oncology specialist. Some babies are born with a type of leukemia called transient abnormal myelopoiesis (TAM). Therefore, all babies with Down syndrome should have a blood count at birth.

Iron deficiency anemia is more common in people with Down syndrome. They should be screened annually for anemia beginning at 12 months of age.

**Musculoskeletal –** Babies with Down syndrome typically have very low muscle tone at birth. This low tone continues to be present in their ligaments and joints as they get older. One joint that is commonly affected is the ankle. Because of lower tone, some children walk with flat feet and ankles that turn outward. Orthotics can be used to help stabilize the ankles if this occurs.

Lower tone can also affect a very important joint in the upper neck, just below the head, and result in atlantoaxial instability. This instability can rarely result in spinal cord compression. The symptoms of instability are neck pain, neck stiffness, sudden arm or leg weakness, loss of bowel or bladder control, a change in the way the child walks, and abnormal strength or reflexes on the doctor's exam. If any of these symptoms occur, the child should be evaluated immediately with a neck x-ray and

possibly referred to a neurosurgeon or orthopedic surgeon, depending on the referral pattern for this condition in the region. To protect against symptomatic atlantoaxial instability, children with Down syndrome should be protected from activities that could result in uncontrolled falls from heights (unattended horseback riding, trampoline use, etc.). Routine screening with a cervical spine x-ray in individuals with Down syndrome who have no symptoms is no longer recommended.

**Neurologic –** Seizures are more common in people with Down syndrome, occurring in about 5–10% of the population, primarily in infancy or later adulthood. If seizures are suspected, a neurology evaluation is indicated.

**Dental –** Children with Down syndrome tend to have delayed eruption of their teeth. Sometimes the first tooth may not appear until 18 to 24 months of age. The teeth also erupt in an atypical pattern, with the first teeth sometimes being the molars or canines. There can be crowding of the teeth as well. A dentist should start seeing children as early as the first tooth eruption, but at least by 2 to 3 years of age.

**General Pediatric Care –** Immunizations should be given to children with Down syndrome on the same schedule as for all children. Babies should also be protected against respiratory syncytial virus (RSV), either by RSV vaccination of the mother during pregnancy (at least 14 days before delivery) or by an RSV antibody given to the baby. A baby who is younger than 8 months and is born during or entering their first RSV season (usually fall through spring) can receive a single dose of either nirsevimab or clesrovimab, but generally does not need it if the mother was vaccinated herself during pregnancy at least 14 days before delivery. The American Academy of Pediatrics considers children with Down syndrome to be at increased risk of severe RSV, so they should also receive nirsevimab before their second RSV season if they are 8 to 19 months old. Additionally, children with Down syndrome who have any chronic cardiac or respiratory issue should receive the pneumococcal vaccine (PPSV23) once after age 2 years old.

## Medical Benefits of Down Syndrome

There are several medical benefits of having an extra 21st chromosome that are not frequently discussed. People with Down syndrome very rarely develop solid organ cancers, such as lung, liver, or brain cancer. It is not known why, but there may be something on the 21st chromosome that protects against these types of cancers. People with Down syndrome also do not seem to get cholesterol plaques in the arteries around the heart or high blood pressure, and their incidence of dental cavities seems to be lower than in other children. If children with Down syndrome do develop leukemia, their response to chemotherapy is much better in certain types of leukemia. Their response to treatment for specific childhood seizure conditions also seems to be better than in other children.

People with Down syndrome also seem to have strengths in visual memory. Many are able to recall specific life situations much more clearly than their peers without Down syndrome. They may remember specifics from their childhood birthday parties or the names of acquaintances much better than others. These visual memory skills can even help them excel at reading if their visual skills are used effectively.

# Conclusion

The vast majority of children with Down syndrome do very well in life. Thanks to better medical care and supports, people with Down syndrome now live much longer than in the past, from about 25 years on average in 1983 to around 60 years today.

By Kishore Vellody, M.D. – Children's Hospital of Pittsburgh
Medical Director, Down Syndrome Center of Western Pennsylvania
Audio information (English) is available at www.chp.edu/dscpodcast

# References

1. Tarawneh R, Pawlowski K, Baumer N, Zhang B, Mazumdar M. Developmental milestones for children with Down syndrome: revised estimates using moving average summaries. Annals of the Child Neurology Society. 2026;4:140–144. https://doi.org/10.1002/cns3.70065
2. Winders P, Wolter-Warmerdam K, Hickey F. A schedule of gross motor development for children with Down syndrome. Journal of Intellectual Disability Research. 2019;63:346–356. https://doi.org/10.1111/jir.12580
3. Frank K, Esbensen AJ. Fine motor and self-care milestones for individuals with Down syndrome using a retrospective chart review. Journal of Intellectual Disability Research. 2015;59:719–729. https://doi.org/10.1111/jir.12176
4. Onnivello S, Schworer EK, Daunhauer LA, Fidler DJ. Acquisition of cognitive and communication milestones in infants with Down syndrome. Journal of Intellectual Disability Research. 2021. https://doi.org/10.1111/jir.12893
5. Grieco J, Pulsifer M, Seligsohn K, Skotko B, Schwartz A. Down syndrome: cognitive and behavioral functioning across the lifespan. American Journal of Medical Genetics Part C. 2015. https://doi.org/10.1002/ajmg.c.31439
6. Bull MJ, Trotter T, Santoro SL, Christensen C, Grout RW; Council on Genetics. Health supervision for children and adolescents with Down syndrome. *Pediatrics*. 2022;149(5):e2022057010. doi:10.1542/peds.2022-057010
7. Zubler JM, Wiggins LD, Macias MM, et al. Evidence-informed milestones for developmental surveillance tools. *Pediatrics*. 2022;149(3):e2021052138. doi:10.1542/peds.2021-052138

© 2026
National Down Syndrome Congress