

What Is Down Syndrome?

Down syndrome (DS) is a genetic condition that happens when a person is born with an extra copy of chromosome 21. Most people have 46 chromosomes, but people with Down syndrome have 47, which affects how the body and brain develop.

People with Down syndrome often have almond-shaped eyes, shorter height, lower muscle tone, different speech patterns, and mild to moderate learning delays.

There are three types of DS. **Trisomy 21** is the most common, when every cell has an extra 21st chromosome. **Translocation**, when the extra chromosome 21 attaches to another chromosome, is sometimes inherited. **Mosaic** occurs when some, but not all, cells have the extra chromosome.

Frequently Asked Questions (FAQ)

How common is Down syndrome?

Down syndrome is one of the most common genetic conditions in the world. While the chance of having a child with DS increases with a mother's age, most babies with DS are born to mothers under 35 because younger women have more babies overall.

How will I know if my child has Down syndrome?

Some parents choose prenatal testing, but it's optional. After birth, if you or your medical providers suspect DS, the condition can be confirmed with a blood test.

What should I do if my child has Down syndrome?

It's normal to feel shocked or sad at first. Give yourself time – it's okay to grieve. Remember: your baby is still your baby! Love them, care for them, and take care of yourself, too.

Talk to a medical provider who can refer you to specialists familiar with Down syndrome. It's always okay to ask questions or get a second opinion.

What kind of help is there for Down syndrome?

There is no cure for Down syndrome. But there is a lot of support:

- **Therapies and education:** Speech, physical, and occupational therapies are offered through Early Intervention (under age 3), your local school district (age 3+), and privately.
- **Home and community services:** New York State's Office for People with Developmental Disabilities (OPWDD) offers services for individuals with disabilities.
- **Medical care:** Regular checkups, visits with specialists, and following guidelines that are specific to Down syndrome will help with managing related health conditions.

- **Support groups:** Connecting with other families, online or in person, can be very helpful.

What other conditions are common in people with Down syndrome?

Common medical conditions that occur with DS include: heart problems, ADHD, poor vision, hearing loss, digestive issues, sleep apnea, thyroid disease, and a weakened immune system.

Talking with a Medical Provider

When talking with medical providers or specialists, you might want to:

- **Be informed and organized:** Learn about DS and keep your child's medical information up to date.
- **Work as a team:** Make sure your child's providers can share information and test results.
- **Speak up:** If a medical provider doesn't take your child's needs seriously, you can find a new provider and report discrimination.

What You Can Do at Home

While waiting for services and providers you can:

- **Create routines:** Keep a regular schedule. Use checklists and pictures to show what's next.
- **Give clear instructions:** Use short, simple sentences and allow your child time to respond.
- **Have fun:** Even with therapy and support, your child will grow at their own pace. Focus on connection and joy, not "fixing" them.

Learning about Down syndrome and getting help is a journey. You're not alone.

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About This Series

This series of handouts on health conditions was written by clinicians in Weill Cornell Medicine's Pediatric Mental Health Integration Program, partners in the ACT for Youth CYSHCN Program Center of Excellence at Cornell University.

