

DOWN SYNDROME

March of Dimes • University of South Florida • Florida Department of Health

Welcoming your new baby into your family.

Your baby has been identified as having a special condition. This condition is known as Down syndrome. We know this is not easy for you and you may not know how to feel. That's okay. Parents of children with Down syndrome at first feel shock, denial, grief, and even anger. It is all right to feel like this and no one will blame you. It will get better. You are not alone. Soon you will find lots of people and programs to help you. You may want to join a support group. Get to know your baby. Enjoy your baby.

What is Down syndrome?

Down syndrome is a congenital condition (something you are born with). It affects how you grow and learn new skills (development). Babies with Down syndrome:

- develop slower than other children without Down syndrome (mental retardation);
- may have some health problems; and
- have special features, such as:
 - almond shaped eyes
 - flat nose
 - large tongue
 - short neck
 - smaller head and hands
 - wide feet with short toes
 - poor muscle tone (appear to be floppy)
 - joints are more flexible than usual (hyperflexibility)

All babies with Down syndrome are different. Some babies are born with a few of these signs. Other babies may have more signs.

You should know also that it is not caused by anything you did or did not do during pregnancy.

How many babies are born with Down syndrome?

Each year about 4,000 children with Down syndrome are born in the United States. This means that 1 baby in 800 to 1,000 babies has Down syndrome.

What causes Down syndrome?

Down syndrome is caused by an extra chromosome. Chromosomes are tiny strings that carry people's genetic information or genes. Our genes are in charge of how our body is formed, how it works, how we look (hair color, eye color), and, in part, how we act (personality).

Most babies with Down syndrome are born with three, instead of two copies of chromosome number 21 (that's why Down syndrome is also known as trisomy 21). Each person gets 23 chromosomes from his/her mother and 23 chromosomes from his/her father. Sometimes there is an error in the way chromosomes are shuffled and the baby gets an extra chromosome number 21. You did not do anything to cause it. We know that mothers 35 and older have a higher chance of having a baby with Down syndrome. We do not know why.

If we have more children, will they have Down syndrome?

- Once you have one baby with Down syndrome your chances of having another child with the condition go up.
- If you plan to have another baby, be **sure** to talk to your doctor before you are pregnant. Your doctor may refer you to a genetic counselor (a person who can help you understand your risk).

Is there a cure for Down syndrome?

There is no cure for Down syndrome. But there is treatment for some of the health problems (like medicine and surgery). Also, infant stimulation (playing with your baby) and special education can help children with Down syndrome in their development.

Will my baby have health problems?

It is common for babies born with Down syndrome to have some health problems. Most of these problems can be treated.

- problems of the heart and thyroid gland are common
- a lot of head colds and infections (of ear, lungs)
- eyesight problems (crossed eyes, near- or far-sightedness, cataracts)
- hearing loss

This does not mean that your baby will have all of these health problems. Each baby is different. Many babies with Down syndrome have heart problems. Your baby's doctor will refer him/her to the pediatric cardiologist (a doctor who knows about heart problems in children) if there is any sign of heart problems.

Will my baby learn things?

Yes! Your baby will learn but it will take him/her a little longer than other babies. Children with Down syndrome learn to sit, walk, talk, and play later than children without Down syndrome. Your baby will need extra help to learn some skills. Your baby will have his/her own gifts and talents.

What's in store for my baby's future?

- A person with Down syndrome can now live 50, 60, or more years. With the right education and help, most can work and live on his/her own.
- They are usually very friendly and get along well with children and adults.

What can I do to help my baby?

- Get help early
- Be patient
- Learn about how your baby grows and learns new skills
- Help him/her learn
- Do not compare him/her to other babies
- Give your child a loving home
- Help his/her brothers and sisters and other family members understand that baby is different
- Keep a positive attitude

Where can I go for help?

Call the Early Steps Program in your county right away. They offer free services to help your child grow and learn. They help you care for your child. First they check (evaluate) how your baby is growing and learning (development). Then, together, you will make a plan to get help for your child and for you.

Early Steps programs will:

- tell you where you can learn more about Down syndrome,
- teach you to care for your child at home,
- tell you where you can find free services,
- provide vision and hearing tests,
- provide speech and physical therapy

Other Resources:

- Children's Medical Services (CMS): call your local county health department for a CMS clinic in your area or visit: www.cms-kids.com
- Florida Directory of Early Childhood Services: 1-800-654-4440.
They will refer you to your local Early Steps Program and other programs.
- For more information call:
March of Dimes: visit marchofdimes.com
National Down Syndrome Congress: 1-800-232-6372
National Information Center for Children with Disabilities: 1-800-695-0285
- For parent support groups in your area, call the
National Down Syndrome Society at 1-800-221-4602 or
National Parent-to-Parent Support and Information System: 1-800-651-1151.
- The Arc-Florida offers a guide with resources for parents: 1-904-921-0460

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