

# Helping Your Child Live with Down Syndrome



Down syndrome is a genetic disorder. It is also called trisomy 21. It includes certain birth defects, learning problems, and facial features. A child with Down syndrome may have heart defects. They may have problems with vision and hearing. How severe or mild these are varies from child to child.

## How is Down syndrome treated?

There is no cure for Down syndrome. But a child with Down syndrome may need treatment for problems such as:

- **Heart defects.** About half of babies with Down syndrome have heart defects. Some defects are minor. These can be treated with medicines. Or the heart problem may go away in time. Others may need surgery. All babies with Down syndrome should have an echocardiogram (heart ultrasound) and be seen by a pediatric cardiologist. This exam and test should be done soon after birth. This is so that any heart defects can be found and treated.
- **Intestinal problems.** Some babies with Down syndrome are born with intestinal problems that need surgery.
- **Vision problems.** Common problems include crossed eyes, cataracts, or being nearsighted or farsighted. Most eyesight problems can be made better with eyeglasses, surgery, or other treatments. Your child should see an eye care provider (pediatric ophthalmologist) before they turn 1 year old.
- **Hearing loss.** This is caused by fluid in the middle ear, a nerve defect, or both. Your child should get regular hearing tests. Any problems should be treated early. This will help with language development.
- **Other health problems.** Children with Down syndrome may have thyroid problems and leukemia. They tend to have many colds, as well as bronchitis and pneumonia. Your child should get regular medical care and stay up-to-date on vaccines.
- **Learning problems.** These vary widely from child to child. They can be mild, moderate, or severe. But most learning problems are mild to moderate. Many children will have early intervention and special education.

Some people claim that giving high-dose vitamins to children with Down syndrome will improve their learning and development problems. No research studies have proved that this works.

Talk with your child's healthcare providers about the risks, benefits, and possible side effects of all treatments.

## Your young child's development

Children with Down syndrome can often do most things that any young child can do. They can walk, talk, dress themselves, and be toilet trained. But they often do these things at a later age. The exact ages of these milestones are different for each child.

Early intervention programs that start when a child is a baby can help the child reach their potential. Your child may need physical, occupational, and speech therapy to help with their development.

## School programs

A child with Down syndrome can go to school. Programs starting in the preschool years help children with Down syndrome develop skills as fully as possible. Many children are helped with early intervention and special education. They can enter a regular classroom. Many will learn to read and write. They can take part in childhood activities, both at school and in their community.

## Work programs and community living

There are work programs designed for adults with Down syndrome. Many adults with this disorder can hold regular jobs. More adults with Down syndrome live semi-independently in community group homes. They take care of themselves and do household chores. They develop friendships. They do leisure activities and work in their communities.

## Intimate relationships

Some people with Down syndrome marry. Most men with Down syndrome can't father a child. In any pregnancy, a woman with Down syndrome has a 1 in 2 chance of having a child with Down syndrome. Many of the pregnancies are miscarried.

## Connecting with others

Talking with other people can help you learn what to expect. You can learn what may be helpful in raising a child with Down syndrome. You can talk with:

- Your child's healthcare providers
- Other families
- National Down syndrome support groups

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