

# Care of children With Down Syndrome



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Children with Down Syndrome benefit from the same care, attention, and inclusion in community life that help every child grow. Every child deserves to be surrounded by people who love, respect and admire all children.

## What is Down syndrome?

Down syndrome is a disorder that includes a combination of birth defects; among them, some degree of mental retardation, characteristic facial features and, often, heart defects, increased infections, problems with vision and hearing, and other health problems. The severity of all of these problems varies greatly among affected individuals. Down syndrome is one of the most common genetic birth defects, affecting approximately one in 800 to 1,000 babies. An extra chromosome generally causes it. Life expectancy among adults with Down syndrome is about 55 years, though life span varies depending on the individual and his or her medical condition.

## What causes Down syndrome?

Normally, each egg and sperm cell contains 23 chromosomes. The union of these creates 23 pairs, or 46 chromosomes in total. Sometimes, an accident occurs when an egg or sperm cell is forming, causing it to have an extra chromosome number 21. When this cell contributes the extra chromosome 21 to the embryo, Down syndrome results. All of the features and birth defects associated with Down syndrome result from having this extra chromosome 21 in each of the body's cells. *Down syndrome also is called trisomy 21 because of the presence of three number 21 chromosomes.*



Normal 21



Trisomy 21

## Who has the greatest risk of having a baby with Down syndrome?

Parents who have already had a baby with Down syndrome, mothers or fathers who have a rearrangement-involving chromosome 21, and mothers over 35 years old are at greatest risk. The risk of Down syndrome increases with age, from



about 1 in 1,250 for a woman at age 25, to 1 in 1,000 at age 30, 1 in 400 at age 35, and 1 in 100 at age 40. However, about 80 percent of babies with Down syndrome are born to women who are under age 35, as younger women have far more babies.

## How will I take care of my baby with Down syndrome?

Just like any other newborn, your baby will need to be fed, dressed, diapered, cuddled, held, talked to, played with and loved. However, your baby will probably have some health problems that will require some extra care.

## Can a child with Down syndrome go to school?

Yes. There are special programs beginning in the preschool years to help children with Down syndrome develop skills as fully as possible. Along with benefiting from early intervention and special education, many children are integrated in the regular classroom. The outlook for these children is far brighter than it once was. More mildly affected children can learn to read and write and participate in diverse childhood activities both at school and in their neighborhoods.

While there are special work programs designed for adults with Down syndrome, many people with the disorder can hold regular jobs. Today, an increasing number of adults with Down syndrome live semi-independently in community group homes where they take care of themselves, participate in household chores, develop friendships, partake in leisure activities and work in their communities.

## What are the health problems that might affect my baby?

Most babies with Down syndrome don't have good muscle tone. This makes it harder for them to learn to roll over, to sit up and to walk. Physical therapy can help with these problems. There's a chance that your baby may have some kind of heart defect--a little less than half of these babies have a heart problem. An *ultrasound* exam of your baby's heart will show if there's a problem. Surgery can fix the heart problems of Down syndrome.



Some babies with Down syndrome have problems in swallowing, or they may have blockages in their stomach or intestines (bowels). Surgery can fix these problems. Once they are fixed, they usually cause no further harm.

Some babies have eye problems, like cataracts (cloudy lenses) or crossed eyes. Surgery can help these problems, too.

Children with Down syndrome may have colds, ear infections and sinus infections more often than other children. They are more likely to have thyroid problems, hearing loss, seizures and bone and joint problems. It's also common for these children to be late in teething.

### **Will my child have learning problems?**

*Intelligence ranges from below normal to retarded (slow to learn) in people with Down syndrome.* If you can keep your child physically healthy, he or she will be better able to learn. At birth, it isn't possible to tell yet how smart a baby with Down syndrome will be. Many adults with Down syndrome have jobs and live independently.

### **What other special care will my baby need?**

You may need to give your baby medicine for a heart defect or some other medical problem. Your doctor will probably want to check your baby more often to be sure that he or she is growing well and isn't developing problems from birth defects. Your baby may need to have *physical therapy every week to help with building up* muscle tone and coordination. Later on, speech therapy and occupational therapy (to help with hand coordination) may be helpful for your child.

### **How serious is the mental retardation?**

The degree of mental retardation varies widely, from mild to moderate to severe. Most fall within the mild to moderate range, and studies suggest that, with proper intervention, fewer than 10 percent will have severe mental retardation. There is no way to predict the mental development of a child with Down syndrome based upon physical features.

### **What can a child with Down syndrome do?**



Children with Down syndrome usually can do most things that any young child can do, such as walking, talking, dressing and being toilet-trained. However, they generally start learning these things later than other children. The exact age that these developmental milestones will be achieved cannot be predicted. However, early intervention programs beginning in infancy can help these children achieve their developmental milestones sooner.

### **Can Down syndrome recur in subsequent pregnancies?**

When a child with Down syndrome having 47 chromosomes (trisomy chromosome No. 21) has been born, the risk of recurrence in subsequent pregnancies is only about 1%. This is a very low risk.

### **Is the risk higher under some circumstances?**

A small percentage of cases of Down syndrome have a different chromosomal abnormality called translocation. Here the extra chromosome no. 21 is present, but is attached to another chromosome such as no. 21 or 22 or 14. In these cases chromosomal analysis of the parents should be done. If either of the parents have a balanced abnormality, risk of recurrence is higher.

### **Can the birth of a child with Down syndrome be prevented in high risk situations such as advanced maternal age, or where a previous child with Down syndrome has been born?**

*Yes, prevention can be done by determining the chromosomes of the unborn baby.* This is done by examining the Amniotic Fluid cells or by Chorionic Villi Biopsy. For Amniotic cell studies about 20 ml of amniotic fluid is removed at 16 weeks of pregnancy by putting a needle through the abdominal wall. This is simple and safe procedure. Diagnosis of Down syndrome is made by growing the amniotic fluid cells and counting the number of chromosomes in the cells. If the fetus has Down syndrome, the



choice is left to the parents to decide whether they would like to get the pregnancy terminated or not. Medical termination of pregnancy can be arranged in a Hospital before 20 weeks of pregnancy by safe techniques. Risk of fetal loss with amniocentesis is 0.5-1%.

Chorionic Villi Sample is collected at 10- 12 weeks of pregnancy by using a special catheter under ultrasound guidance through the vagina or the sample can also be collected through the abdominal route. This must be done by an experienced obstetrician. The Chorionic Villi cells are examined and the number and structure of chromosomes in the cells is determined. There is a risk of about 3-5% of fetal loss after this procedure.

If the parents are not willing for invasive tests like amniocentesis and chorionic villus biopsy, testing mother's blood for certain markers (*BIOCHEMICAL SCREENING*) around 11-12 weeks or 16-18 weeks of pregnancy and fetal ultrasonography can also give clues. But these tests are not confirmatory.



*"Of all the blessings God sends from above, the one most precious is a baby to love."*

For Further Information

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