

Seek Early Intervention: When your child has a birth defect, early intervention is usually the best strategy. An early intervention team is a group of experts put together to assess your child's needs and develop a program of treatment. Their services may include feeding support, identification of assistive technology that may help your child, occupational therapy, physical therapy, speech therapy, nutrition services and social work services.

Use a team approach: Most children with birth defects require a team of professionals to treat them. Even if your child needs to see only one specialist, that person will need to coordinate care with your child's primary doctor. As soon as you are able, get to know the different team members. Make sure they know who else will be caring for your child and that you intend to play a key role with your child's health care.



What Causes Birth Defects?

Most babies with birth defects are born to two parents who have no health problems or risk factors. A woman can do everything her doctor recommends to deliver a healthy child and still have a baby with a birth defect.

Genetics play a role in some birth defects. Every cell in the body has chromosomes containing genes that determine a person's unique characteristics. One missing or faulty gene can cause a birth defect.

The number or structure of chromosomes can cause a birth defect. An error during the formation of an egg or sperm can cause a baby to be born with too few or too many chromosomes or with a damaged chromosome. Birth defects caused by a chromosome problem include Down Syndrome. The risk of this type of birth defect often increases with the age of the mother.

When a mother has certain infections (such as rubella) during the pregnancy, it can cause a birth defect. Alcohol abuse by the mother causes fetal alcohol syndrome and certain medications taken by the pregnant mother can cause birth defects.

Although there are steps you can take to prevent birth defects, remember that a birth defect can happen even if you or partner have no history of birth defects in your families or if you've had healthy children in the past.

Common Birth Defects include: Down Syndrome, Spina Bifida, Heart Defects, Cerebral Palsy, Cystic Fibrosis, Tay-Sachs Disease, and Fetal Alcohol Syndrome.



When Your Baby has a Birth Defect



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Having a Baby with a Birth Defect

Defect

We see images of and tend to hear about only healthy babies but many babies are born with problems called birth defects. A birth defect is an abnormality of structure, function or body chemistry that will require medical or surgical care or could have some effect on a child's development.

There is a wide range of birth defects, from mild to severe, they can be inherited or caused by something in the environment. In many cases, the cause is unknown. Often, doctors can detect a birth defect when they do prenatal tests. Some of the tests they may do are:

- Ultrasounds or magnetic resonance imaging (MRI), which are sometimes combined with blood tests to determine the risk of having a child with certain birth defects.
- Maternal blood screening to determine the risk of chromosomal abnormalities.
- Amniocentesis and chorionic villi sampling

If you have just found out that your child has a birth defect, you are probably experiencing many emotions. Parents in your situation often say they feel overwhelmed and uncertain whether they will be able to care for their child properly. Fortunately you aren't alone-with little effort, you'll find that there are lots of people and resources to help you.

How to Cope with Your Child's Birth Defect

As the parent of a child with a birth defect, it is important for you to:

Acknowledge your emotions: Parents of children with birth defects experience shock, denial, grief and even anger. Acknowledge your feelings and give yourself permission to mourn the loss of a healthy child you thought you'd have. Talk about your feelings with your spouse or partner and other family members.

Seek support: Talk to your doctor or a social worker and ask them if they know any other parents in the area with children who have the same condition as your child. Talking to other parents who have gone through the same experience, can be very helpful and informative and can offer you support when you need it.

Celebrate your child: Enjoy your child the same way any parent would-by cuddling, playing, watching for developing milestones (according to your child's condition milestones may be delayed), and sharing the joy your child brings you with family and friends. The fact that your child had a birth defect doesn't mean you shouldn't be excited about the new addition to your family.

Seek Information: The amount each person would like to learn varies from parent to parent, but try to get some information on your child's condition. Start by asking your doctor lots of questions and record the answers. If you are not satisfied with your results, don't be afraid to seek a second or third opinion. It's a good idea to keep a journal with a list of questions and answers you have, as well as any suggestions and any material the doctor may give you. Also keep an updated list of all health care providers and emergency numbers so that if you need them they are easily accessible.

