

Spina Bifida Fact Sheet *for*

Parents and Families

What is Spina Bifida?

Spina Bifida literally means “split spine.” Spina Bifida happens when a baby is in the womb and the spinal column does not close all of the way. Every day, about eight babies born in the United States have Spina Bifida or a similar birth defect of the brain and spine.

What are the different types of Spina Bifida, and which one affects my child?

- ❑ **Occult Spinal Dysraphism (OSD):** Infants with this have a dimple in their lower back. Because most babies with dimples do not have OSD, a doctor has to check using special tools and tests to be sure. Other signs are red marks, tufts of hair or small lumps. In OSD, the spinal cord may not grow the right way and can cause serious problems as a child grows up. Infants who might have OSD should be seen by a doctor, who will recommend tests.
- ❑ **Spina Bifida Occulta:** It is often called “hidden Spina Bifida” because about 15 percent of healthy people have it and do not know it. Spina Bifida occulta does not cause harm, has no signs and the spinal cord and nerves are fine. People usually find out they have it after having an X-ray of their back.
- ❑ **Meningocele:** It causes part of the spinal cord to come through the spine like a sac that is pushed out. Nerve fluid is in the sac, and there is usually no nerve damage. Individuals with this condition may have minor disabilities.
- ❑ **Myelomeningocele (Meningomyelocele):** This is the most severe form of Spina Bifida. It happens when parts of the spinal cord and nerves come through the open part of the spine. It causes nerve damage and other disabilities. Seventy to ninety percent of children with this condition also have too much fluid on their brains. This happens because fluid that protects the brain and spinal cord is unable to drain like it should. The fluid builds up, causing pressure and swelling. Without treatment, a person’s head grows too big, and may have brain damage. Children who do not have Spina Bifida can also have this problem, so parents need to check with a doctor.

What Conditions are Associated with Spina Bifida?

Children and young adults with Spina Bifida can have mental and social problems. They also can have problems with walking and getting around or going to the bathroom, latex allergy, obesity, skin breakdown, gastrointestinal disorders, learning disabilities, depression, tendonitis and sexual issues.

What Physical Limitations Exist?

People with Spina Bifida must learn how to get around on their own without help, by using things like crutches, braces or wheelchairs. With help, it also is possible for children to learn how to go to the bathroom on their own. Doctors, nurses, teachers and parents should know what a child can and cannot do so they can help the child (within the limits of safety and health) be independent, play with kids that are not disabled and to take care of him or herself.

Can Children with Spina Bifida Grow Up and Live a Full Life?

Yes. With help, children with Spina Bifida can lead full lives. Most do well in school, and many play in sports. Because of today’s medicine, about 90 percent of babies born with Spina Bifida now live to be adults, about 80 percent have normal intelligence and about 75 percent play sports and do other fun activities.