



What is Spina Bifida?

Spina bifida is a condition that affects the spine and is usually apparent at birth. It is a type of neural tube defect (NTD). Spina bifida can happen anywhere along the spine if the neural tube does not close all the way. When the neural tube doesn't close all the way, the backbone that protects the spinal cord doesn't form and close as it should. This often results in damage to the spinal cord and nerves.

Each year, about 1,500 babies are born with spina bifida. Hispanic women have the highest rate of having a child affected by spina bifida, when compared with non-Hispanic white and non-Hispanic black women. The cause of spina bifida is unknown but there is speculation that it is either genetic or environmental.

Three types of spina bifida:

Myelomeningocele

When people talk about spina bifida, most often they are referring to myelomeningocele. Myelomeningocele is the most serious type of spina bifida. With this condition, a sac of fluid comes through an opening in the baby's back. Part of the spinal cord and nerves are in this sac and are damaged.

Meningocele

Another type of spina bifida is meningocele. With meningocele a sac of fluid comes through an opening in the baby's back. But, the spinal cord is not in this sac. There is usually little or no nerve damage. This type of spina bifida can cause minor disabilities.

Spina Bifida Occulta

Spina bifida occulta is the mildest type of spina bifida. It is sometimes called "hidden" spina bifida. With it, there is a small gap in the spine, but no opening or sac on the back. The spinal cord and the nerves usually are normal. Many times, spina bifida occulta is not discovered until late childhood or adulthood. This type of spina bifida usually does not cause any disabilities.

Hydrocephalus

Many babies born with spina bifida get hydrocephalus (often called water on the brain). This means that there is extra fluid in and around the brain. The extra fluid can cause the spaces in the brain, called ventricles, to become too large and the head can swell. Hydrocephalus needs to be followed closely and treated properly to prevent brain injury.

If a baby with spina bifida has hydrocephalus, a surgeon can put in a shunt. A shunt is a small hollow tube that will help drain the fluid from the baby's brain and protect it from too much pressure. Additional surgery might be needed to change the shunt as the child grows up or if it becomes clogged or infected.

Mobility and Physical Activity

People affected by spina bifida get around in different ways. These include walking without any aids or assistance; walking with braces, crutches or walkers; and using wheelchairs. Many use multiple means to support mobility. People with spina bifida higher on the spine (near the head) might have paralyzed legs and use wheelchairs. Those with spina bifida lower on the spine (near the hips) might have more use of their legs and use crutches, braces, or walkers, or they might be able to walk without these devices.

Regular physical activity is important for all people, but especially for those with conditions that affect movement, such as spina bifida. CDC recommends 60 minutes of physical activity a day. There are many ways for people with spina bifida to be active.

Using the Bathroom

People with spina bifida often cannot control when they go to the bathroom (incontinence). They also can develop urinary tract infections. It is important to develop a plan for going to the bathroom that works and is as simple as possible. This can lead to increased health, participation, and independence, and avoid embarrassment for people with spina bifida. Healthcare providers can help develop a plan for each person. A tube (catheter) inserted in the bladder can help drain urine. In some cases, extra fiber can be added to the diet to keep bowel movements regular. Surgery also might be recommended.

Skin

People with spina bifida can develop sores, calluses, blisters, and burns on their feet, ankles, and hips. However, they might not know when these develop because they might not be able to feel certain parts of their body.

Outcome

It takes a team of dedicated parents, teachers, therapists and medical support provided by comprehensive Spina Bifida Clinics like the Spina Bifida Center at Cincinnati Children's Hospital Medical Center, as well as the commitment of individuals with spina bifida themselves, to achieve their maximum potential. Adults with spina bifida have a wide range of abilities, need varying degrees of intervention and experience unique medical complications throughout their lives. However, many can expect to be employed, drive, live independently and have full, productive lives.



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