

## What is Spina Bifida?

Spina bifida is a medical condition that develops before a baby is born. It is the most common permanently disabling birth defect. Spina bifida occurs in 1 in every 2,875 US births each year.

To understand spina bifida, you need to understand the importance of your spine. Within the spine, nerves run from our brain out to all of our body parts. These nerves are like wires that carry the directions from our brain to our body parts. The body part then performs the action that the brain directed it to do. All of these nerves together are called our nervous system.

When a baby's spine develops, sometimes a gap develops in the spine. This is called Spina bifida occulta. Although this isn't normal, this rarely causes any significant problems. But sometimes, when there is a gap, the spinal fluid flows out and forms a sac outside of the spine. When there's only fluid in the sac, the nerves aren't usually damaged and disabilities are limited. This type of spina bifida is called Meningocele (muh·nin·juh·seel). But if the nerves and spinal cord move through the gap into that fluid sac as well, that's when they can get damaged and cause moderate to severe disabilities. The damage might prevent individuals from being able to walk, and cause them to have trouble going to the bathroom and eliminating waste. That type of spina bifida is Myelomeningocele (mai·uh·low·muh·ning·guh·seel).

Problems can develop above the gap as well. Another job of the tube that carries the nerves in our spine is to regulate the amount of fluid in our brains. This fluid has important chemicals that make our brains develop the best way. Sometimes, the fluid in the brain doesn't go where it's supposed to for individuals with spina bifida. Then different brain parts might not develop correctly causing memory and learning problems. An individual might need more time to process information, struggle with anxiety, or have trouble handling changes.

The fluid in our brain also drains through the tube that carries the nerves. Sometimes spina bifida prevents that from happening correctly. If too much fluid stays in the brain, it can create too much pressure and cause brain damage.

Therefore, some individuals with spina bifida also need a surgery to place a shunt, or draining tube, so the fluid doesn't get stuck and cause problems.

Doctors still do not know exactly what causes spina bifida. They have recognized the importance of a vitamin called folic acid that is important for mothers to take when carrying a baby. This vitamin helps ensure the tube for the nerves develops correctly.

They have also developed tests that can identify before a baby is born if it has a "split spine" - the literal meaning of spina bifida. Once identified, some babies can have a surgery to repair the hole in the baby's spine before the baby is born, called fetal surgery. By fixing the hole early, less or no damage is done to the nerves and the baby will be able to function without impairment. If the baby can't have the surgery before it is born, it will need to have the surgery after birth.

Regardless of the type of spina bifida, individuals are able to live productive, happy lives. With the help of physical therapy and choosing the best equipment for their needs, there is little they can't do: walk, drive, work or race!

For more information about spina bifida, consider these resources:

**The Spina Bifida Association**

<https://www.spinabifidaassociation.org/>

**The National Institute of Child Health & Human Development**

[https://www.nichd.nih.gov/health/topics/spinabifida/more\\_information/resources](https://www.nichd.nih.gov/health/topics/spinabifida/more_information/resources)

**The Center for Disease Control (CDC)**

<https://www.cdc.gov/spina-bifida/about/index.html>

**SpinaBifida•Hydrocephalus•Infomration•Networking•Equality - SHINE**

<https://www.shinecharity.org.uk/>

**The Spina Bifida Resource Network**

<https://thesbrn.org/>