

Common Myths About Spina Bifida

1. Many babies born with spina bifida are stillborn or do not survive early infancy.

Actually, the chances that a fetus with an isolated neural tube defect (spina bifida and no other problems) will be stillborn is 5% or less. It is difficult, however, to be precise when discussing the chances that a child born with spina bifida will not survive the first weeks or months of life because treatment of this condition is constantly improving and people with spina bifida are living longer, healthier lives. In addition, some babies with spina bifida do have other medical problems such as a heart defect or a problem with their chromosomes which may cause additional medical complications. Information published by the Centers of Disease Control and Prevention shows that from 1989 through 1994 (the most recent years for which information is available) 91% of babies born with spina bifida survived the first year of life. In comparison, for 1979-1983 that figure was 82.7% and for 1984-1988 it was 88.5%. These figures are for all babies born with spina bifida, even those with additional medical problems.

2. Individuals with spina bifida die at a young age.

Again, it is difficult to give exact information when discussing the life span of people with spina bifida, primarily because of the continuous improvements in treatment which have greatly extended their life expectancy. In addition, they must be followed for many many years in order for us to know how those individuals do. This is difficult because it requires a great commitment in terms of time and financial resources for both the doctors and their patients and few such reports are available for review. One study published in 2001 looked at survival in children with spina bifida who were born between 1975 and 1979. In that group of 118 children, 76% were alive at 20-25 years of age. The most common cause of death was an unrecognized problem with function of the shunt. Remember, however, that treatments have continued to improve since these children were born. At this time we cannot be more specific than to say that most children born with spina bifida will survive *at least* into early adulthood.

3. Most children with spina bifida are severely retarded

Children with spina bifida are all individuals and cover the usual broad spectrum of human development and achievement. While factors such as a shunt infection or an episode of respiratory arrest (stopping breathing) can significantly adversely affect the intellectual outcome of children with this condition, the average IQ of a child with spina bifida is 80-85, which is in the low normal range. Information on one group of 173 children with spina bifida who were born between 1963 and 1971 showed that 63% with shunts had an IQ above 80, while in those children without shunts 87% had an IQ above

80. Of course these are averages, some of them had an IQ that was higher and some had an IQ that was lower. Regardless of IQ, most children with spina bifida do have learning problems and many require some special education services. Below is a table which will help put these IQ numbers in perspective.

Classification	IQ Score
Very Superior	130 and above
Superior	120-129
High Average	110-119
Average	90-119
Low Average	80-89
Borderline	70-79
Extremely Low	69 and below

4. When the spina bifida defect is covered by a sac the prognosis is better (or worse) than if there is no sac.

Actually, it makes no difference whether or not a sac covers the myelomeningocele defect. The most important factor in determining how much paralysis there will be is where on the spinal cord the opening begins. Since normal nerve development and function do not occur at or below the level of the open spine, the higher up the spinal cord the spina defect occurs, the greater the degree of paralysis. For example, if the opening starts at the waist, more of the body will be paralyzed or partially paralyzed than if it starts below that level. In addition, it is important to remember that when a spina bifida defect is covered by a sac made up of the thin tissues which normally enclose the spinal cord (these tissues are called the “meninges”) but *not* by skin, the defect is considered to be *open*, not closed, and will need to be treated surgically soon after birth. Only a defect covered by skin is considered closed. It is possible that some of the confusion stems from the fact that there is a much rarer condition called a *meningocele* where only the coverings of the spinal cord protrude from the back and the spinal cord itself is intact and complete. However, a *meningocele* is a totally different condition than the type of spina bifida which occurs when the spinal cord has not completed its development.

5. If the fetus has the “lemon sign” the baby will be born with a lemon-shaped head.

The lemon sign is something which is seen in a fetus during a prenatal ultrasound examination. The lemon sign is a descriptive term which refers to the fact that the front of the skull loses its normal round shape and appears flattened and sometimes even inwardly depressed. Thus, the head has the overall shape of a lemon – generally oval but somewhat pointed in the front, in the area of the forehead. Several explanations have been proposed for the presence of the lemon sign, but at this time the reason why a particular baby may have the lemon sign is not known. What is known is that the lemon

sign almost always disappears in the third trimester of a pregnancy, with the skull taking on the more usual rounded shape. Babies with spina bifida in whom the lemon sign is seen during a prenatal ultrasound are NOT born with a marked point at the top or front of their head.

6. Prenatal diagnosis (testing done before your child is born) is only important for families who will terminate the pregnancy if a problem is found.

There are many valid reasons for having prenatal testing to determine if the fetus has any diagnosable abnormalities; terminating the pregnancy is only one such reason. A crucially important reason is to give parents time to learn about their child's condition and to find medical facilities where their child will be able to get the specialty care they will need. In the past, it was usually in the delivery room where parents found out that their baby had an abnormality. They were therefore placed in the very difficult position of trying to rapidly educate themselves about a complex medical issue and make on the spot decisions about where to get care for their child. Thankfully, because of our ability to diagnose spina bifida prenatally in most cases, it is rare for parents to find themselves in this situation today.

7. When hydrocephalus (enlarged fluid cavities within the brain) is seen on ultrasound (sonogram) the overall prognosis for the child is much worse than if it is not seen.

Actually, the vast majority of infants with spina bifida will develop hydrocephalus, either during the pregnancy or soon after the spina bifida defect is closed after birth. The presence of hydrocephalus in a fetus or infant with spina bifida does not make the case particularly unusual or severe.

Most children with hydrocephalus will require treatment with a shunt (a thin flexible, straw-like device which is implanted in the fluid cavities of the brain to control the build-up of cerebrospinal fluid). A small percentage of children with an open spina bifida will not require a shunt.

8. The most important thing in determining how a child with spina bifida will do in life is where the spina bifida is located along the spine.

The location of the spina bifida in the back does determine how much paralysis there will be in the legs and feet. The higher up the spinal cord the spina bifida starts, the greater the degree of paralysis. However, it is a mistake to consider only the level of the spina bifida and resulting paralysis when thinking about how an individual will do in life. Many great men and women have been paralyzed and have used wheelchairs to get around. Although they did not have spina bifida, President Franklin Roosevelt and renowned scientist Steven Hawkins are two such individuals. Intellectual strengths and the ability to find a place in life where the person is happy and functioning at their best

also play enormously important roles. It is not possible to predict how an individual child with spina bifida will do in life (just as it is not possible to predict that for any child), but parents can make an enormous difference. They can do this by working with educators to find the educational program that best meets their child's needs and by letting their child grow, mature and accept responsibilities commensurate with their mental and physical abilities. It is natural to want to protect a child from disappointment and possible failure, but we all need to make mistakes and to learn from them. An individual who is not allowed to learn from experience may never fulfill their potential.