

SCHOOL HEALTH MANUAL

SPINA BIFIDA

MAINE SCHOOL HEALTH ADVISORY COMMITTEE

with input from

MAINE DEPARTMENT OF EDUCATION

MAINE DEPARTMENT OF HUMAN SERVICES

AND OTHER RELATED ORGANIZATIONS

COMMENTS

The School Health Manual is available electronically. Each section of the Manual is available as a separate electronic file from the WEB PAGE. This will allow for sections to be updated on an ongoing basis. The Table of Contents includes the dates of the current sections.

Comments may be given to members of the School Health Advisory Committee or sent to the below.

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AVAILABLE ON THE WEB PAGE <http://www.maine.gov/education/sh/index.html>

SPINA BIFIDA

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Spina Bifida means cleft spine, which is an incomplete closure of the spinal column. There are three types of spina bifida:

SPINA BIFIDA OCCULTA: There is a opening in one or more of the vertebrae (bones) of the spinal column without apparent damage to the spinal cord.

MENINGOCELE. The meninges, or protective covering around the spinal cord, has pushed out through the opening in the vertebrae in a sac called the “meningocele,” but the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.

MYELOMENINGOCELE. This is the most severe form of spina bifida, in which a portion of the spinal cord itself protrude through the back. In some cases, sacs are covered with skin; in others, tissue and nerves are exposed. People use the terms “spina bifida” and “Myelomeningocele” interchangeably.

Approximately 40% of all Americans may have spina bifida occulta, but very few ever know that they have it. Meningocele and Myelomeningocele are known collectively as “spina bifida manifesta,” and occur in approximately 1/1000 births. About 96% of the infants with spina bifida manifesta have the Myelomeningocele form.

The effects of Myelomeningocele may include muscle weakness, paralysis or loss of sensation below the area of the spine where the incomplete closure (cleft) occurs, and loss of bowel and bladder control. About 70-90% of children born with Myelomeningocele have hydrocephalus, or accumulation of fluid in the brain. Hydrocephalus is controlled by a surgical procedure called “shunting,” which relieve the pressure of fluid buildup in the brain, thereby lessening the risk of brain damage, seizures, or blindness. This surgery can be performed as early as the first 48 hours of life.

Although spina bifida is relatively common, until recently most children born with a Myelomeningocele died shortly after birth, but now children with Myelomeningocele are much more likely to live. They must, however, have a series of operations throughout their childhood. School programs should be flexible to accommodate these special needs.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization, or the insertion of a tube to permit passage of urine. The courts have held that clean, intermittent catheterization is necessary to help a child benefit from and have access to special education and related services. Successful bladder management can be incorporated into the regular school day. Many children learn to catheterize themselves at a very early age.

In some cases children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school.

In adapting the school setting for the child with spina bifida, architectural factors should be considered. Children with Myelomeningocele need to learn mobility skills, and often require the aid of crutches, braces or wheelchairs. It is important that all members of the school team and parents understand the child's physical capabilities and limitations. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their non-disabled classmates.