

## Spina Bifida

Ages: 0-3

<p>What kind of doctors should I talk to?</p>	<p><b>General physician</b> – addresses general health needs</p> <p><b>Neurosurgeon (pediatric neurosurgeons)</b> – for consultation and about surgery that may be needed immediately after birth, or to place shunt (drainage tubes) in cases of hydrocephaly</p> <p><b>Orthopedists</b> - assesses bone and muscle development as your child grows</p> <p><b>Podiatrist</b> – addresses special needs for your child’s feet, which are often affected in spina bifida</p> <p><b>Physical Therapist</b> – addresses musculoskeletal and mobility impairments</p> <p><b>Occupational Therapist</b> – helps your child interact with the environment and learn independence</p> <p><b>Speech Therapist</b> - helps your child communicate effectively</p> <p><b>Nutritionist</b> - addresses your child’s nutritional health</p> <p><b>Urologists</b> - addresses the health and function of the kidneys and bladder</p> <p><b>Psychologist</b> – cares for the emotional and social health of your family</p>
<p>What other conditions may affect my child?</p>	<p><b>Chiari malformation</b> - some babies’ lower part of the brain is pressed against the bones of the skull and may cause damage. Pressure can be relieved by surgically removing some of the bone.</p> <p><b>Orthopedic complications</b> - depending on the nerve damage, spina bifida can lead to foot and hip deformities. Casting or surgery can correct foot deformities, and hip deformities require surgery. Surgery for the hip and foot are only recommended if it will help the child learn to walk.</p> <p><b>Skin infections</b> – if there is a loss of skin sensation, it is important to inspect the skin every day for infections.</p> <p><b>Latex allergy</b> – very common for those with spina bifida. Latex is a rubber product that is used to make toys and health care supplies (like gloves).</p> <p><b>Arthritis</b> - because patients with spina bifida often have an atypical walking pattern, they may develop arthritis in the hip or knees.</p> <p><b>Shunt malfunction</b> - If your child has a shunt (a surgically implanted drainage tube), it important to recognize if it begins to malfunction. Signs and symptoms of malfunction are: abnormal increase in head size, change in function of the upper extremities, regression in milestones or school performance, neck pain, headache, loss of balance. These signs do not necessarily mean a malfunction, but you should still contact your neurosurgeon should any of these occur.</p>
<p>What kind of surgeries will my child need?</p>	<ul style="list-style-type: none"><li>• Surgery is usually performed close to the 24 hours after birth in order to close the opening of the spinal cord – this minimizes the risk of infection and preserves the remaining spinal cord.</li><li>• A shunt (or drainage tube) may be surgically placed to drain cerebrospinal fluid in cases of hydrocephalus (where there is increased pressure on the brain from excess fluid) to relieve pressure.</li></ul>

	<ul style="list-style-type: none"> <li>• If spina bifida is detected during pregnancy open fetal surgery can be performed for severe cases.</li> <li>• Ongoing surgical treatments may be needed to prevent and manage complications with spina bifida.</li> </ul>
<p>What kind of assistive devices are available?</p>	<p>Adaptive devices are commonly used for children with spina bifida, especially to help with proper body positioning and mobility. Please use the informational list of adaptive devices, consult your physician, or check out the websites listed below.</p> <p><b>Car seats, stroller, and push chairs</b> – help with proper positioning and posture while doing everyday activities</p> <p><b>Orthotics</b> (particularly for the foot) – to correct some bone deformations and make walking easier, prevent hip migration, and prevent joint contractures</p> <p><b>Tricycles</b> – not only for recreational use, but also used for physical therapy purposes</p> <p><b>Walkers and gait trainers</b> – help support your child while walking (and learning to walk)</p> <p><b>Toileting chairs, Sleeping aids, Table and chairs, Bathing aids</b> –used to make everyday activities more manageable</p> <p><b>Special handles and grips</b> - for eating utensils, pens, pencils, making it easier for your child to hold things.</p> <p><b>Communication aids</b> – such as a book or poster to spell out messages, and specialized computers that can talk for your child is he/she is difficult to understand.</p> <p><b>Computer technology</b> – can help with multiple daily activities, like scanning documents, typing, pointing, etc. This can be very helpful if your child is non-verbal.</p> <p>Helpful websites:  <a href="http://pattersonmedical.com/">http://pattersonmedical.com/</a>  <a href="http://www.ottobockus.com/">http://www.ottobockus.com/</a>  <a href="http://www.especialneeds.com/home.php">http://www.especialneeds.com/home.php</a></p>
<p>What kind of therapy and treatment is available?</p>	<p><b>Physical therapy</b> helps keep muscles strong and flexible, which is important for children with spasticity. PT can help with walking, using a wheelchair, walker or braces, standing, climbing stairs, and using gross motor skill to kick a ball or ride a bike.</p> <p><b>Occupational therapy</b> helps to teach your child how to care for him/herself and establish independence. This can range from toileting to dressing to writing.</p> <p><b>Speech therapy</b> helps your child learn to use throat and face muscles properly to communicate, eat, and breathe properly.</p> <p><b>Catheterization</b> helps those with kidney and urological impairments.</p>

	<p><b>Bowel management plan</b> is useful for patients with spina bifida who do not have sensation to feel when they need to go to the bathroom. Plans to manage bowel movements are implemented once the child starts eating solid food.</p> <p><b>Counseling</b> may be necessary for your child and family to help with psychological, social and behavioral development.</p>
What sort of expectations should I have for my child's physical development?	Physical development for children with spina bifida depends on the type of spina bifida and the location on the spinal cord. Some patients have very few deficits in motor ability, while others have significant paralysis. Consult with your doctor to learn more about the specific needs of your child.
What sort of expectation should I have for my child's intellectual development?	Usually, children with spina bifida have IQs within the normal range. However, they often have a learning disability as well. Acknowledging this allows for easier recognition and appropriate help in the classroom to ensure your child can learn to their full potential. Learning disabilities associated with spina bifida often affect: organizational skills, language comprehension, attention, memory, handwriting, mathematics, solving problems and making decisions.

### Spina Bifida

Ages: 4 – 12

From the ages of 4-12 you will still need to continue using the same information as above about what doctors to consult and therapies that are available, so please refer back to the chart for ages 0-3. This chart includes additional things you may need to do after your child turns 4.

What should I continue to do?	<ul style="list-style-type: none"> <li>- Keep regular appointments with your doctors and therapists.</li> <li>- Monitor musculoskeletal changes, especially scoliosis (a curvature of the spine) which often occurs with spina bifida.</li> <li>- Ongoing surgical treatments may be necessary to prevent and manage complications with spina bifida, especially with shunt maintenance.</li> <li>- Enjoy your child!</li> </ul>
What kinds of therapies are available?	<p>Again, this is not an exhaustive list, but continue with therapies listed above and consider these types of therapies as your child gets older:</p> <p><b>Massage therapy</b> – may help to relax tense muscles, improving mobility.</p> <p><b>Counseling</b> – to help modify behavioral and emotional difficulties in children and in your family life too.</p> <p><b>Hippotherapy</b> – a new type of therapy which involves interacting with horses to aid in achieving normal balance, improving posture, movement, muscle strength, and overall coordination.</p>
What will my child do for school?	<p>Going to school is important for emotional and social development of your child. Your child has a right to attend public school and receive the same free education as every other child. Before sending them to school, you should know if your child has a learning disability or physical disability that may impair their learning. If he/she does, then they qualify for special education assistance. Depending on the school district, your child may be "mainstreamed" and placed in general</p>

	<p>education classes with everyone their age, but with a modified work to accommodate their learning disability. This is known as “inclusion” in the public schools. Your child may also be placed in a special education classroom with other students who qualify for special education accommodations.</p> <p>Additional information about Individualized Education Programs (IEP):  <a href="#">US Department of Education</a></p>
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### Spina Bifida

Ages 12-18

<p>What new challenges will my child experience as he/she gets older?</p>	<p>Puberty can be a difficult time, but it may be especially challenging for teens with spina bifida. Rapid growth can cause weight gain and clumsiness in any teen, but can make it even more difficult for someone with spina bifida to move around. Continue with regular appointments with your doctors to monitor your child’s health and consider how surgeries and adaptive devices described above may help your child.</p>
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### Spina Bifida

Ages 19 and beyond

<p>What new challenges will my child experience as he/she gets older?</p>	<p>Although spina bifida is not a progressive disease, it is important to continue with regular appointments with your doctors to ensure that no complications arise. The type of wheelchair or walker a person with CP uses may need to change based on their life style. Please look at the list of adaptive equipment, other websites, and talk with your doctor if you feel you need to modify the type of devices you use.</p>
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### References

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