

Spina Bifida Care

Newborn to
Young Adult



Overview

This guide is designed for you, the family of a child with spina bifida. It is meant to give you a basic understanding of the condition. You may choose to share it with other family members, friends, and people in your community including daycare providers, teachers, and coaches.

This guide has general descriptions of:

- Spina bifida (myelomeningocele)
- Health concerns
- Tips for staying healthy
- Common tests
- Roles of the healthcare team members
- Local, state, and national resources
- Transitions

Please know that every person with spina bifida is unique. Not everything in this booklet will apply to you and your child. You and your child's healthcare team will work together to meet your child's individual needs and goals. You are the best expert on your child's life. Share your concerns. Trust your instincts. Ask questions. Explore options. Provide feedback.

Some families find it helpful to talk with other families who have a child with spina bifida. We can connect you with another family if you would like to talk about your experiences and choices.

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I. What is Spina Bifida (Myelomeningocele)?

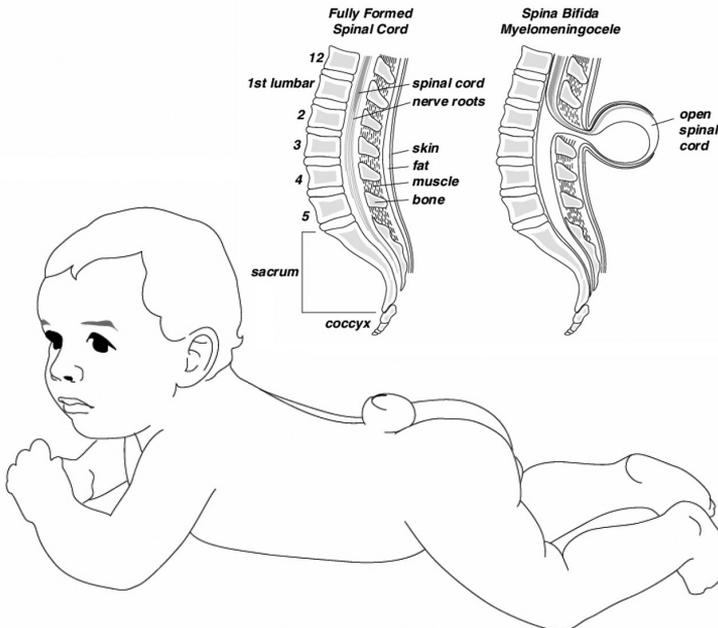
Spina bifida is an open neural tube defect that affects the spine in the first few weeks of pregnancy. There are different types of spina bifida. Some forms are so mild, they are never diagnosed. The most severe type, “myelomeningocele,” is described here.

Spina bifida happens in the first few weeks of pregnancy – even before a woman finds out that she is pregnant. In myelomeningocele, the spinal column does not completely close and there is a hole in the back. Part of the spinal cord and the nerves come through the opening in the back. The bones and the skin over the spinal cord

are also affected. Surgery is needed in the first 24-48 hours of life to close this opening.

The spinal cord runs along the back bones (“vertebrae”) within the spinal column. Usually the spinal column is shaped like a tube to hold the spinal cord. The top of the spinal cord comes down from the brain. The bottom of the cord floats in the spinal column.

The spinal cord is made up of nerves. Nerves send and receive messages from the brain to the rest of the body. For example, when your foot steps on something sharp, the nerves send a signal to the brain about the pain. The brain then sends a message to the muscles to quickly move the foot off of the sharp object.

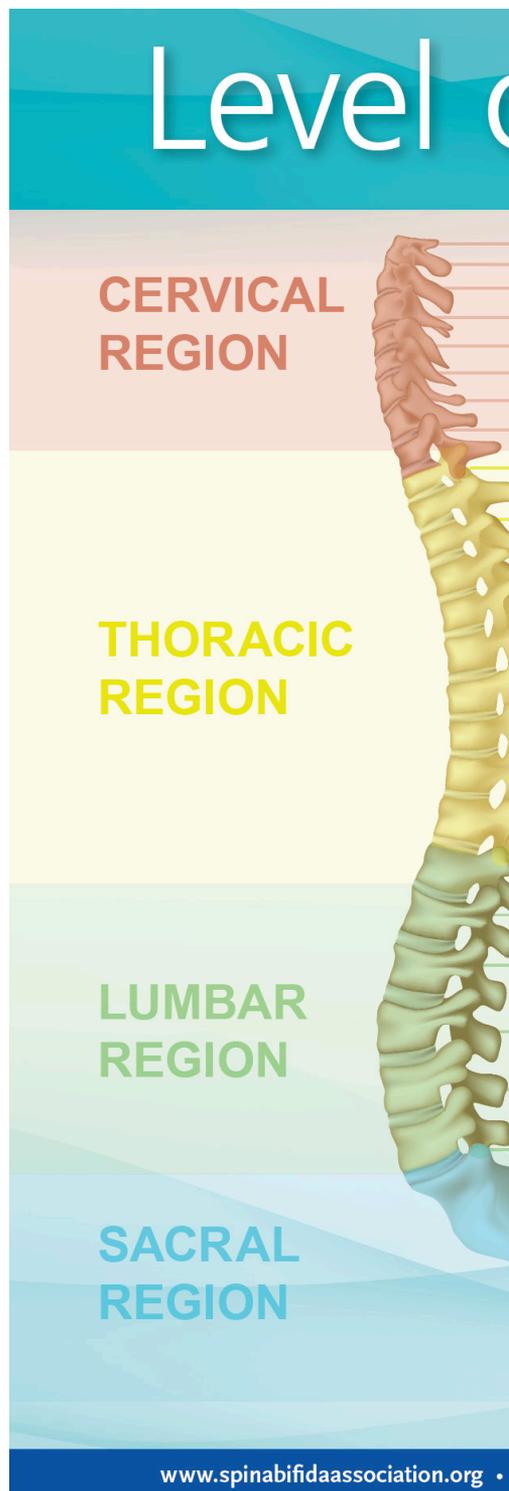


Spina bifida causes physical disabilities that range from mild to severe. When a child has spina bifida, the nerves are damaged and the messages to and from the brain do not flow correctly. Nerve damage is linked to where the opening is on the back. If the opening on the back is high, more nerves are damaged. Most children with spina bifida have decreased feeling in their legs and feet and some loss of usage with their legs, bowels and bladder. But if the opening is high in the back (thoracic region of the spine instead of lumbar region), the child has complete paralysis in the legs.

Everyone with spina bifida is affected differently. Some walk. Some use a wheelchair. Some go on to college. Some raise families of their own. Not all people born with spina bifida have the same needs. Treatment will be different for each person.

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Level c

**CERVICAL
REGION**

**THORACIC
REGION**

**LUMBAR
REGION**

**SACRAL
REGION**

of SB Function

C1

C2

C3

C4

C5 Elbow flexors: Partial upper extremity function

C6 Wrist extensors: Standing with stander/orthotics

C7 Elbow extensors

C8 Finger flexors

T1

T2 Complete upper extremity function

T3–T8 Standing with stander/orthotics

T4 Possible exercise ambulation

T5

T6

T7 Partial function of trunk muscles

T8

T9–T12 Exercise ambulation

T10–L2 Bladder: Sympathetic input from hypogastric nerve

T11 Some function of trunk muscles

T12–S5 Sexual function varies

L1 Complete trunk function: exercise ambulation, sometimes household ambulation

L2 Hip flexor muscles present: exercise ambulation, household ambulation

L3 Knee extensors or Quadriceps muscles present: household ambulation, possible community ambulation

L4 Medial knee flexors present. Ankle dorsiflexors, 3/5 strength

L4–S5 Community ambulation

L5 May walk with or without crutches in home

S1 Hip abductors, 3/5 strength

S2 Hip extensors, 4/5 strength. Ankle, plantarflexors, 3/5 strength. May walk with or without crutches

S2–S4 Bowel and bladder function varies. Bladder: parasympathetic input from the pelvic nerve. Somatic input from pudendal nerve to urethral sphincter

S3 All muscle activity may be within normal limits

S4

S5 and above Be aware of signs and symptoms of shunt malfunction and tethered spinal cord

Spine Level	Possible Muscle Function	Possible Orthopaedic Concerns	Possible Orthotics Needed	Possible Equipment for Functional Mobility
T6-9 T9-12 L1	Upper trunk (abdominals) No LE function Abdominals + paraspinals = some pelvic control Complete trunk function Lower trunk (abdominals) Hip flexors (weak) 2/5	Kyphoscoliosis, Lumbar hyperlordosis Coxa valga—hip dislocation Decreased bone density Fractures Contractures: Hip: abduction, flexion, external rotation Knee: flexion, extension Foot: heelcord, clubfoot	TLSO Night splints: body, hip abduction, KAF, AF Early: Parapodium, (10 months of age and up to 2 years) Later: stander, RGO, HKAFO, KAFO Caution: Preserve UE function with level transfers, stable seated posture. Maintain strength + flexibility of shoulders/ arms.	Community: Wheelchair, wheelchair cushion, transfer board Home: Walker/Crutches (for household or exercise walking), Raised, padded commode seat. Bath bench Mirror for skin checks Stander: 1 hour/day minimum starting at 10 months of age. Driving with hand controls Learn public transportation
L2 L3	Hip flexors 3/5 Hip adductors 3/5 Knee extensors 3/5	Scoliosis, Overuse of UE's Lumbar hyperlordosis Hip subluxation Coxa valga—hip dislocation Decreased bone density Fractures Contractures: Hip: flexion Knee: flexion, extension Foot: Heelcord, clubfoot	Night hip abduction splint Early: Parapodium (10 months of age up to 2 years) Later: Stander, RGO, HKAFO, KAFO (if quads are less than 3/5 strength) L3-5 May be temporarily addressed by twister cables or derotations straps	Community: wheelchair cushion Home: Stander: 1 hour/minimum Early: may use walker or crutches Later: wheelchair in home
L4 L5	Medial knee flexors 3/5 Ankle dorsiflexor 3/5 Hip abductors (weak) 2/5 Lateral knee flexors 3/5 Ankle invertors 3/5 Long toe extensors (palpate at ankle)	Lumbar hyperlordosis Coxa valga Contractures: Hip: flexion Knee: flexion (avoid crouch gait) Foot: Progressive calcaneus (tight heelcord) Calcaneovalgus Equinovarus—Clubfoot Paralytic Vertical Talus	Night hip abduction splint Early: Parapodium Later: RGO, HKAFO, KAFO, AFO (L3-L4 CCAFO) L4-5 Toeing in gait and weak gluteals may be temporarily addressed by twister cables and/or rotation straps Consider shunt malfunction and/or tethered cord	Community: wheelchair, walker, crutches, cane Strong medial hamstring needed for community gait Home: early on may need no support Later: may require UE support
S1 S2	Hip abductors 3/5 Hip extensors (weak) 2/5 Plantar flexors (weak) 2/5 Hip extensors 4/5 Plantar flexors 3/5 Toe flexors 3/5	Monitor hips closely Contractures: Foot: Calcaneus (tight heelcord) Calcaneovalgus Pes Cavus, Clubfoot Toe clawing (flexion) Heel/foot ulcers	AFO, SMO (supra malleolar orthotics), shoe inserts or no orthotics S1-2 Toeing out gait Use of crutches may decrease the valgus forces at the knee and also improve endurance	Community: walking with walker, crutches, cane. Gluteus lurch/ Trendelenburg gait aide cane or crutches. Long distance alternative: lightweight wheelchair, scooter Home: May need no support
S3-5	All muscle activity + bowel/bladder function may be normal	None	None or shoe inserts	None

Shunt malfunction and/or tethered cord: May cause deterioration of daily living skills, progressive weakness, muscle contractures or orthopaedic deformities of the legs, scoliosis, back pain at the site of closure, deterioration of gait, changes in bowel and/or bladder function.

t ity	Possible Cognition, Executive Function
r/ s ise d	<p>Executive function impairments can impact educational, social and self help skills.</p>
-12 ols on	<p>Cognitive function can vary with the degree of hydrocephalus number of shunt infections, and the involvement of the nervous system. Function may not be related to level of lesion or ability to walk. Support early assessment of attention difficulties, sensorimotor integration, visual perception, visual motor ability, psychosocial development in addition to fine/gross motor + communication ability.</p>
+ day r me	<p>Independent living: Occupational Therapy Goals: Basic activities of daily living (BADLs) or bathing, dressing, grooming, bowel/bladder program, skin care, moving/transportation in your home/community. Instrumental activities of daily living (IADLs). Shopping, meal preparation, use of home appliances. Early learning/practice of all ADLs is vital.</p>
g gait ed	<p>Physical/ Occupational Therapy/ Gross Motor Goals:</p> <ol style="list-style-type: none"> 1. Achieve/maintain full ROM. 2. Achieve/maintain full strength in intact muscles for ADL's and mobility. 3. Locomotion activities including ambulation skills (falling down, getting up), walk on various terrains, transfer to various surfaces (chair, car, bed). 4. Achieve maximal sitting tolerance with skin intact. 5. Attain cardiovascular endurance for function. 6. Ability to perform or direct care including care + maintenance of orthotics + equipment. 7. Obtain recommendations re: home modifications. 8. Document medical appts, follow up, surgical history.
th d by ve: bike, port.	<p>Transition to adult self care begins at birth.</p>
es	

Muscle Grades:

5 = normal

4 = good

3 = fair

2 = poor

1 = trace

Flexion = bend

Extension = straighten

Adduction = bring toward

Abduction = take away

Invert = move in

Evert = move out

Medial = inner

Lateral = outer

T = thoracic

L = lumbar

S = sacral

O = orthosis

RGO = reciprocating gait orthosis

H = hip

K = knee

A = ankle

F = foot

CC = crouch control

Gait = walking style

Coxa = hip

Calcaneus = heel bone

Talus = ankle bone

UE = upper extremities/arms

LE = lower extremities/legs

II. Health Concerns

A. Brain and Spinal Cord

1. Hydrocephalus

Our brains are surrounded by a fluid called “cerebrospinal fluid” (CSF). CSF starts in chambers inside the brain called “ventricles.” CSF then flows through the spaces around our brains.

Most people with spina bifida have hydrocephalus (“hydrocephalus” is a Latin word meaning “water” and “head”) Hydrocephalus happens when the CSF in the ventricles or around the brain does not flow properly. CSF builds up in the ventricles and makes them too large. Extra CSF puts too much pressure on the brain. This pressure can damage the brain. Hydrocephalus affects 70% to 90% of people with a myelomenin-gocoele.

Common signs of hydrocephalus are:

- Rapid head growth in babies
- Bulging soft spot (“fontanelle”) in babies
- Weak or hoarse cry in babies
- Difficulty swallowing
- Nausea
- Sleepiness
- Vomiting
- Headache

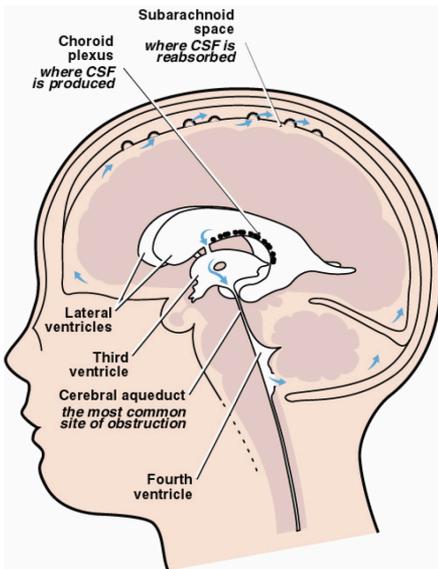
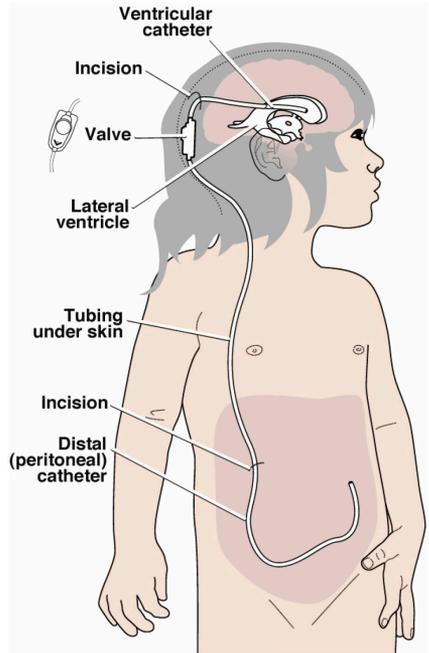
- Blurred vision
- Inability to look up
- Irritability
- Behavior problems
- Memory problems

Hydrocephalus must be treated through surgery. One surgery is shunt placement. A shunt is a thin, flexible tube that is placed in the ventricles. It drains extra CSF out of the ventricles. The other end of the shunt goes to the “peritoneum” (abdomen or belly). This is called a “ventriculo-peritoneal” or “VP” shunt. When the end of the shunt cannot be placed in the peritoneum because of scarring, previous surgery or infection, it can be placed in the chest around the lung (“ventriculo-pleural shunt”), or in the heart (“ventriculo-atrial shunt”). Shunts can fail by getting blocked or by coming apart. They can also get infected and have to be temporarily removed until the infection is treated. Most people will have one or more shunt failures in their lifetime.

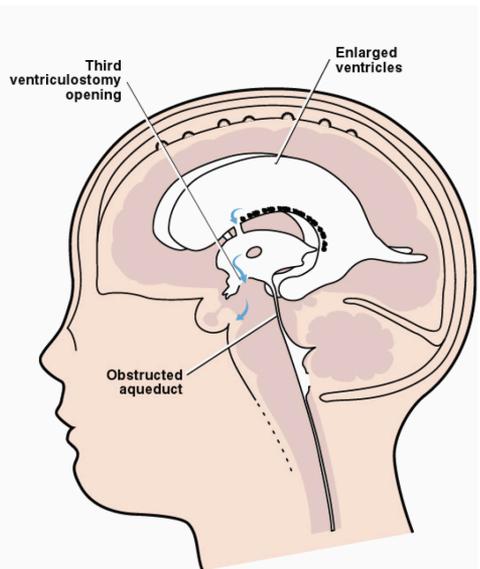
Another surgery to treat hydrocephalus is called “endoscopic third ventriculostomy” (ETV). ETV is like an internal shunt without the hardware. In this surgery, the surgeon uses a tool called an “endoscope” to make an opening in the bottom of the brain’s third ventricle. The endoscope moves like a tiny telescope inside the brain. Once the opening is made, CSF drains through the opening in the third ventricle.

Sometimes the ETV stops working and surgery is needed right away to prevent the ventricles from getting too big and putting pressure on the brain.

Know the signs of hydrocephalus. Call your neurosurgery clinic right away if you see these. If a failed shunt or ETV is not fixed right away, this may result in permanent neurological problems or death.



Normal Ventricles



Hydrocephalic Ventricles

2. Chiari II Malformation

A Chiari II Malformation is common in people with spina bifida. Usually the back of the brain sits in an indented space in the lower part of the skull. In a Chiari II malformation, the back of the brain comes down into the top of the spinal canal.

Not everyone will have symptoms with a Chiari II Malformation. In most cases, symptoms are due to a shunt failure. Symptoms are similar to hydrocephalus symptoms. If these symptoms happen, please call the neurosurgery clinic right away. The neurosurgeon will want to make sure the shunt is working properly.

3. Tethered Cord

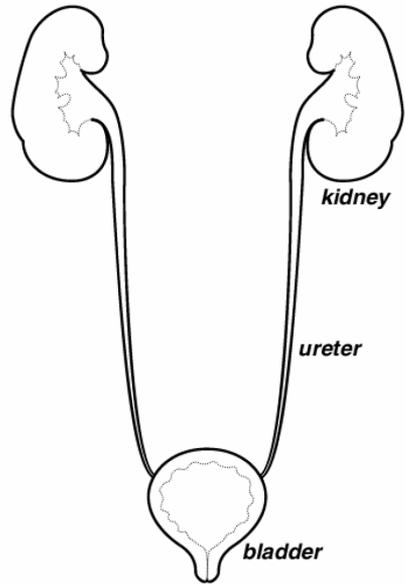
Usually the nerves at the bottom of the spinal cord hang loose in the spinal canal. When the cord is “tethered” it is stuck to scar tissue in the spinal column at the site of the original closure. This stretches the nerves. There is a risk of permanent damage to the nerves if the tethered cord is not fixed with surgery. If symptoms occur, surgery will be needed to untether the spinal cord (take away the scar). Because the cord always appears tethered on MRI, the surgeon will not suggest surgery based on the MRI, but rather on symptoms.

Signs and symptoms of tethered cord:

- “Syrinx” or “syringomyelia” (large water cyst inside the spinal cord)

- New or increasing “scoliosis” (curve in the back)
- New or increased back or leg pain
- New or increased muscle weakness
- New or increased numbness in the back or legs
- “Spasticity” (tightness and spasms in the legs)
- Worse bladder or bowel function

B. Bladder



Kidneys make urine and ureters drain the urine into the bladder. The bladder holds urine until it is full.

Most people with spina bifida have problems with their bladders. In spina bifida, the nerves between the bladder and the brain are damaged. This is called a “neurogenic bladder.” There is no cure for the nerve

damage but there is treatment for a neurogenic bladder.

If the bladder muscles cannot stay tight and hold the urine, urine might leak out. This is called “urinary incontinence.” Medicines and emptying the bladder with a “catheter” helps to keep the bladder and kidneys healthy and prevents incontinence. A catheter is a thin, flexible tube that is inserted into the bladder that allows the urine to drain out of the body.

If the bladder muscles cannot relax to completely empty the urine, this is called “retention.” Retention can lead to increased pressure in the bladder, ureters, and kidneys. The pressure in the kidneys can cause “hydronephrosis.” Hydronephrosis damages the kidneys.

Children with nerve damage to their bladder may also have “vesicoureteral reflux.” This is when urine swishes backwards from the bladder into the kidneys. If there is reflux, any bacteria in the urine enter into the kidneys.

The goals of bladder care are:

- Keep the kidneys healthy by:
 - Keeping bladder pressure normal
 - Making sure the bladder is emptied
 - Reduce incontinence, possibly with catheterization
 - Reduce urinary tract infections

People who use a catheter to empty their bladder will have bacteria in their urine. This is called “colonization”

of the bladder. Bacteria in the urine without obvious signs of infection do not always require treatment. Please call urology clinic before beginning any antibiotic to treat a bladder infection.

Symptoms of a UTI that may require treatment:

- Fever over 101° F
- Abdominal pain
- Back pain
- Pain with urination
- Vomiting

C. Bowels

It is common to have bowel problems such as “constipation” or “stool incontinence.” These problems happen because of the nerve damage in the spinal cord. This is called “neurogenic bowel.”

Most people with spina bifida take care of their neurogenic bowel with a “bowel regimen.” This means they pay close attention to their bowel habits. They make sure their bowels empty every one to two days by drinking fluids, eating a high fiber diet, enema use, and/or using medicines. They make sure their stools are soft. The bowel regimen helps to prevent constipation and incontinence. Constipation can also worsen the bladder problems by pushing on the bladder.

D. Orthopedics

People with spina bifida may have joints that are pulled into different positions. This happens because some muscles work better than others, and some do not work at all. The severity of joint problems is due to how high the opening was in the spine. Most people need “assistive devices” to move around. This may include a wheelchair, crutches, walker, or braces.

People with spina bifida often have some differences from one side to the other. For example, the right leg may move more easily than the left leg or have a better sense of touch or feel. Sometimes there are differences on the same side so that one part of the leg works differently or has a different sense of touch and feel than another part.

Common orthopedic concerns are:

- Scoliosis (a curve in the spine from side to side)
- Kyphosis (a curve in the spine from front to back)
- Dislocated hips
- Clubfoot
- Movement problems with the hips, knees, ankles, and feet
- Osteoporosis (weak bones)

Changes in the shape of the spine, such as scoliosis and kyphosis, can be a sign of a tethered cord. Other things can also cause the spine to curve. Stronger abdominal muscles

pulling on the back, back bones not staying in place because their shape is different, or a growth spurt (which is common in teenagers) can all cause the spine to curve.

A severe curve in the spine may lead to many problems. It can make it more difficult to breathe. Big curves also make it hard to sit in the usual position. This can put too much pressure on the skin and result in a pressure sore. The child may need to use his or her arms to maintain balance while seated. This prevents the child from using the arms for other tasks. Bracing is used in some children to try to keep the curve from getting worse but often surgery is needed to make the spine straight.

Many children with spina bifida have dislocated hips. Some are born this way, and others have their hips dislocate after they are born. In people with spina bifida, dislocated hips almost never hurt because the nerves to the muscles that help hold the hips in place do not function well. For most individuals, if one or both of the hips are dislocated, it is better to leave the hip out of the socket. A flexible dislocated hip is better than a stiff reduced hip. Hip dislocation will not prevent the ability to walk. If the hip dislocation causes skin problems, surgery may be done to allow someone to sit more evenly in the wheelchair.

Some children with spina bifida are born with clubfeet. Infants usually begin treatment with casting once the spina bifida closure is healed. Casts are changed every week for

2-3 months and a surgery is done to cut the Achilles tendon in the heel. Sometimes a bigger surgery is needed to make the foot straight and flat. Infants and children wear a brace to keep their feet in position.

Children with spina bifida that walk usually need a brace for extra support. Braces help the child move well and prevent the joints from getting too tight. If children have trouble moving their feet, they may wear a brace that only supports their feet. A longer brace can be used if a child has trouble moving their knees. There are many braces that do different things. The goal is to find the one that is best for each child.

If tight joints cause problems, surgery may be an option to change the position or to hold the joint in a better position. Surgery is commonly done at the knees, ankles and toes.

If a child rarely or never walks, their bones may be weaker than normal. If the child falls, bones break more easily. However, due to nerve damage, the child may not feel any pain and may not notice the broken bone. A parent may be the first to notice swelling. Breaks often happen through the growth plate so they can be hard to see on x-ray. Usually a difference can be seen if x-rays are taken on the other leg. Breaks are treated with either braces or casts. Healing often takes a very long time. Occasionally surgery is needed. Rarely, infection can cause swelling. If a bone break is not seen on x-ray, other tests may need to be done

right away to figure out if infection is causing the swelling. Infections need to be treated quickly to prevent it from getting worse. Always call the orthopedic clinic right away if you notice any swelling on your child's hips, legs, or feet.

E. Skin

Nerve damage causes lack of feeling in the skin. Usually all of the skin that is below the opening on the spine has less sensation. As a result, people cannot feel pain, heat, cold, or pressure against their skin. Therefore your child may have a sore or infection without even knowing it is there.

It is very important to protect your child's skin. Check the areas of the skin that your child cannot feel every day for red spots and sores. Stop using shoes or braces that cause red spots or sores on the skin. Sores can lead to blood and bone infections.

Some ways to prevent sores:

- Keep skin dry
- Make sure braces and shoes fit well
- Do not walk barefoot
- Wear swim shoes in pools and lakes
- Avoid dragging skin against any surface, including the floor, bed, or cushion, when moving
- Maintain a healthy weight
- Good nutrition

F. Rubber & Latex Allergies

Rubber and latex comes from trees and are found in many commonly used objects. Many people with spina bifida are allergic to rubber and latex. This can be life-threatening to some. Avoid all products with rubber and latex. People who have had a severe reaction should wear a medic-alert bracelet and carry an epi-pen.

Some items with rubber and latex include:

- Rubber tub toys
- Rubber cement
- Diapers with rubber
- Waterproof bed pads that have rubber coating
- Dolls made with rubber
- Rubber bands
- Pens with comfort grip or rubber coating
- Remote controls for TVs and VCRs with rubber grips or keys
- Bath mats and floor rugs with rubber backing
- Toothbrushes with rubber grips or handles
- Rubber water hoses
- Rubber electrical cords

G. Learning

People with spina bifida often have average IQs but may still have some learning difficulties. Some people with spina bifida have problems with “executive function.” This means that it is harder to stay organized, pay attention to and remember details, plan projects, remember sequences, and independently start a task or activity. Some people have poor hand-eye coordination which makes it harder for them to use tools, read and write. Many find math more challenging.

All of these issues can be overcome. There are many programs and methods to help your child be successful.

H. Reproduction

Many women with spina bifida can become pregnant. Taking folic acid reduces the risk of spina bifida. Because of the risk of unplanned pregnancy, the CDC recommends that every sexually active woman take a folic acid supplement. Women with spina bifida (or who have already had a child with spina bifida) and who are sexually active should take 4 mg of folic acid per day regardless of whether or not they are planning to get pregnant. This dose of folic acid is much higher than the dose that women without spina bifida take in a multi-vitamin (0.4 mg) so a prescription is needed.

Women with spina bifida should see a high risk OB/GYN (“perinatologist”) while pregnant. They should discuss

possible pregnancy complications and the best way to deliver the baby.

Many men with spina bifida can father a child. They should discuss concerns or issues with their urologist.

I. Overweight & Obesity

People with spina bifida are at greater risk of being overweight or obese. This is most likely due to the fact that they are less mobile than someone with normal leg function.

People are considered overweight or obese when they weigh more than they should for their height. For children who cannot stand, we measure their arms from fingertip to fingertip since this is the same as height in almost all people. While children are growing, it can be hard to tell if the child is overweight or obese, but your healthcare team uses special graphs to identify this. For adults, specific numbers are used: Body Mass Index (BMI) of 25-30 = overweight, BMI over 30 = obese.

A heavy or obese body:

- Limits the ability to move and exercise, causing more weight gain
- Puts more pressure on the skin, increasing the risk of sores
- Makes it harder to keep clean
- Makes it harder to move independently
- Makes bracing harder
- Makes surgery riskier

- Can have other health problems
 - High blood pressure
 - Diabetes
 - Stroke and heart attack

Parents can help by:

- Modeling healthy eating and exercise early in life
- Keeping fruits and vegetables in the home
- Not buying fatty and sugary snacks
- Not buying juices, sweetened drinks, and sodas
- Find exercises you can do together
 - all kids enjoy being active!
- Getting children into adaptive sports

III. Staying Healthy

The same basic rules apply to people with spina bifida.

- Have a primary care provider
- Keep immunizations up to date
- Eat a healthy diet that includes fresh fruits and vegetables
- Avoid juices, sweetened drinks, and soda
- Avoid junk food
- Drink water every day
- Brush your teeth and dental floss every day

- See a dentist every 6 months
- Stay at a healthy weight
- Exercise
- Get involved in activities at school and in your community
- No smoking
- Avoid alcohol
- Take medicine at the same time every day
- Do not take extra medicine when you remember a missed dose

Extra care for people with spina bifida includes:

Allergies

- Avoid rubber and latex

Bladder

- Wash hands before every catheterization
- Stay on schedule with catheterizations
- Know the signs of a urinary tract infection and when to call
- Know that your child has a right to privacy for bladder care

- See the urologist every 6 months

Brain

- Know the signs of hydrocephalus
- See the neurosurgeon every 6 months until age 5 and then every year

Bone Health

- Watch for new or worsening scoliosis
- Nearly half the people with spina bifida have osteoporosis in their 20's or 30's
- Ways to reduce the risk of osteoporosis are:
 - Exercise
 - Eat a healthy diet
 - Get enough vitamin D and calcium
 - Limit caffeine
 - No smoking
 - Avoid alcohol

Bowels

- Avoid constipation and know when to call your doctor
- Know that your child has a right to privacy for bowel care

Cardiovascular Health

- People with spina bifida are at greater risk for “hypertension” (high blood pressure)
- Hypertension damages kidneys and causes stroke and heart attack
- Lifestyle choices that improve blood pressure are:
 - Salt restriction
 - Weight loss
 - Stress management

- Regular exercise
- No smoking
- Avoid alcohol

Emotional Health

- It is common to feel stressed, sad, or mad about spina bifida
- If you or your child have these feelings, share them with your health care team
- There are providers who can work with you and your child to deal with these feelings

Skin

- Check your child's skin every day
- Protect your child's skin from injury

Spine

- Know the signs of a tethered cord

IV. Common Tests: Imaging, Procedures, Labs, and Measurements

Blood Pressure: Learn your child's blood pressure numbers. Know if it is high or normal. If it is high, we will recheck it. If it stays high, please get treatment.

Body Mass Index (BMI): This is based on measurement of height and weight. If it is over 25, please ask about diet and exercise changes.

Magnetic Resonance Imaging (MRI): MRI uses a powerful magnet to take

pictures of the brain, spine, and other organs.

Neuropsychological Testing: These tests give an overall impression of how the brain reasons, remembers, problem solves, and concentrates. The results help decide the best way your child can learn.

Renal Bladder Ultrasound (RBUS): RBUS uses sound waves to take a picture of the kidneys and bladder. It checks for kidney growth, hydro-nephrosis, and overall appearance of the kidneys.

Swallow Study: This special x-ray checks that food goes down the "right tube" and that there is no problem with swallowing.

Urinalysis (UA): Tests on urine that show how well the kidneys are working including an infection screen. This takes a few hours.

Urine Culture: Tests for bacteria in the urine and which antibiotics treat the infection. This takes 1 to 3 days.

Urodynamic Testing or Cystometrogram (CMG): A catheter is placed in both the bladder and the rectum. Sterile water is placed into the bladder. This test measures bladder compliance, bladder control, sensation, and uninhibited contractions. This test takes 1 1/2 to 2 hours.

Vitamin D Blood Test: If the Vitamin D level is low, your child should take a supplement. Low Vitamin D increases the risk for broken bones.

Voiding Cystourethrogram (VCUG):

This checks for reflux of urine backwards into the kidneys and the appearance of the urethra.

X-Ray: This is a picture of the bones. It shows if the bones are the right shape, if the bone is broken, and if the joints line up correctly.

V. The Healthcare Team

There is a team of healthcare workers involved in your child's care. You and your child are the most important members of the team. We work with you and your child to provide the best possible care.

Members of the healthcare team include:

- **The child with spina bifida**
- **Other family members: Parents, siblings, grandparents, and other loved ones**
- **Advance Practice Nurse or Nurse Practitioner (NP):** This is a registered nurse with advanced training in a specialty area. The NP provides some of the same services as a doctor and works together with a doctor. The NP works closely with nursing staff in coordinating patient care.
- **Case Manager:** The case manager assures that plans of care and target lengths of stay are in place. The case manager works with the healthcare team to initiate the discharge planning process. If there are concerns with supplies, equipment, or home

healthcare after discharge, the case manager can assist.

- **Child Life Specialist:** A child life specialist helps children and families adjust to and cope with the stress of hospitalization. The child life specialist provides opportunities for therapeutic and medical play. The child life specialist also prepares patients for, and provides support during, medical tests and procedures.
- **Faculty Physician (MD):** The faculty physician, also called the staff physician or attending physician, heads your child's healthcare team and is the leader of your child's overall care. When your child is in the hospital, the attending physician examines your child, monitors daily progress, oversees treatment and directs care. Depending on your child's condition, the attending physician may call on one or more specialists with expertise in additional selected specialty areas to help care for your child.
- **Health Psychologist:** A health psychologist provides services such as assessment of mood, intelligence, and behavior. Health psychologists provide therapy and consultation regarding patient and family coping with the stress of illness or injury, pain management, lifestyle and body image changes, grief, adherence to medical regimen, post traumatic stress symptoms, and more.

- **Neuropsychologist:** A specialist that checks your child's thinking and problem solving skills. Tests might look at the ability to problem-solve, remember things, think quickly, pay attention, use language, and do well in school. Results should be shared with the school so that the school meets the child's needs.
- **Neurosurgeon:** A doctor that monitors the brain and spinal cord. A neurosurgeon closely checks your child for hydrocephalus, tethered cord, and nerve function. A neurosurgeon operates on the brain and spinal cord.
- **Nurse:** A nurse has many roles. In the clinic, most teach patients and families about home care and when to come in for an exam. In the hospital, a nurse provides daily care.
- **Nutritionist or Registered Dietitian (RD):** A RD is interested in your child's growth, weight changes, and any difficulties with eating. A RD may help you adjust your child's diet to provide the best nutrition. A RD teaches you and your child about special diets and nutritional supplements.
- **Occupational Therapist (OT):** An OT assesses motor, sensory, cognitive, perceptual, and psychosocial development. The OT's goal is maximum independence in daily care, play, and school activities.
- **Orthopedic Doctor:** A specialist that takes care of muscles, joints, and bones. These doctors pay close attention to the shape of the spine and how the hips, legs, and feet are working. Sometimes a brace, a cast, or surgery is needed to straighten the bones.
- **Orthotist:** A specialist that fits braces and casts which help the legs, ankles, and feet stay in good position. Orthotists work closely with PT and the orthopedic doctor.
- **Pharmacist:** A specialist that advises doctors and other health care team members about proper medication selection, dosage, and administration. Pharmacists also monitor drug therapy to ensure patients receive the most effective treatment. Pharmacists counsel patients on safe medication use.
- **Physical Therapist (PT):** A PT evaluates patients' developmental and functional skills. A PT treats physical, developmental, and neurological problems. A PT also teaches exercises to help children learn how to use their bodies and muscles.
- **Primary Care Provider or Pediatrician (PCP):** A nurse practitioner or doctor that provides general health care, including immunizations and preventative care, and makes sure your child's growth is on the right track. It is important to have regular primary care.

- **Rehabilitation Medicine:** A specialist that takes care of mobility and function for daily living skills and thinks of ways for your child to maximize function.
- **Residents (MD):** A resident is a physician that is receiving additional training after obtaining a doctor of medicine degree. Residents, supervised by attending physicians, are in the hospital 24 hours a day and have close contact with patients and families.
- **Social Worker:** A social worker helps families with emotional, physical, and economic concerns related to a child's illness, treatment, hospitalization, discharge, and return to school. A social worker may refer families to financial and social service resources, and help coordinate with community and educational agencies near the child's home.
- **Speech Pathologist:** A speech-language pathologist focuses on speech and language development and related disorders, including feeding and swallowing problems. A speech pathologist evaluates a disorder and recommends therapy or other treatments to correct or lessen the problem.
- **Spiritual Caregiver:** This includes ministers, chaplains, priests, rabbis, and other clergy that offer support.
- **Students:** Students (medical, nursing, pharmacy, and many others) work under close supervision of fully-trained team members. Students

are active and helpful in patient care, but they do not make any independent decisions about your child's care.

- **Urology Doctor:** A specialist that takes care of the bladder and bowels. Urologists do surgery on the urinary tract. They pay close attention to the overall health of the urinary tract system, including the bladder and the kidneys.
- **Vocational Rehabilitation Therapist:** A specialist that assists your child with school and work concerns. If there is a problem, they help you work with the schools to provide services to the child.

VI. Local, State, and National Resources

Spina Bifida Association: Since 1973, the Spina Bifida Association (SBA) has served adults and children who live with spina bifida. This agency is focused on education, advocacy, research, and service. Please visit the SBA website to learn more about health concerns, camps, research, and much more.

Website: www.spinabifidaassociation.org

Wisconsin First Step: This is a 24 hour hotline. Staff has access to a database of over 3,000 agencies and services. Services include:

- Support groups
- Financial assistance

- Medical resources
- Transportation
- Advocacy
- Assistive devices
- Early intervention, including Birth to 3
- Child care
- Respite care
- Help communicating with schools
- Home health

Call: 800-642-7837

Website: www.mch-hotlines.org

Wisconsin Department of Public

Instruction: Students with spina bifida may need special services, starting in preschool. For more information on working with your school, please visit this website.

Website: http://sped.dpi.wi.gov/sped_parent

Wisconsin Department of Workforce Development – Vocational Rehabilitation:

Vocational Rehabilitation helps people with disabilities find a job. They help with career guidance, transportation, and many more things.

Website: <http://dwd.wisconsin.gov/dvr/jobseek.htm>

Families Helping Families

Family Voices of Wisconsin: This is a network of families who have children

with a special health care need. They provide information, training and leadership opportunities for families so that they can be informed and effective partners in their child's care.

Call: 608-220-9598

Website: www.fvofwi.org

Spina Bifida Family Network (SBFN):

This is a group of families raising children with spina bifida. Parents share experiences and learn from each other. Children come to gatherings where they can play together.

Website: www.sbfm.org

Parent to Parent of Wisconsin:

This is a phone matching service for parents and caregivers to connect with a parent of a child with a special healthcare need. This give parents a chance to talk to someone who knows the challenges of raising a child with a disability.

Call: 888-266-0028

Website: www.p2pwi.org

Funding and Legal Assistance

ABC for Health: A non-profit public interest law firm that helps individuals and families that have disability or children with special health care needs. They are dedicated to connecting people to health coverage.

Call: 800-585-4222

Website: www.abcforhealth.org

Disability Rights Wisconsin: This is a private, non-profit organization that defends the rights of individuals with disabilities throughout Wisconsin.

Call: 800-928-8878

Website: www.disabilityrightswi.org

Family Support Program: Provides limited funding to buy services and goods to help care for a severely disabled child to live in the home.

Website: www.dhs.wisconsin.gov/children/fsp/

VII. Transitions

Transition means to move from one place to another. We have many transitions in life. These times may be a bit disruptive until adjustment occurs. Extra planning can make a transition easier.

Transitions for New Parents

Becoming a new parent is a time of joy but it can be very challenging as well. Infants with spina bifida may have a rough start.

- Early intervention services may help the infant overcome some of the challenges of spina bifida
- Consider joining a parenting or support group
- Include siblings in care of your infant, as appropriate
- Make a binder where you keep track of your infant's health information. It is never too late to start!

- Bring the binder to medical appointments
- Important information to include in the binder:
 - Names and phone numbers of all doctors
 - Insurance information
 - Dates and results of medical tests
 - Surgeries and dates
 - Medications – doses, reason for taking, when the medication was started
 - Add new information whenever there is a change in treatment
 - Treatments or medicines that did not work well

Transitions for Toddlers and Preschoolers

- Allow your child to explore, go outside, be active, and play with others
- Start to get a good bladder and bowel regimen so that your child is not incontinent

Transitions for School Aged Children

- Most children with spina bifida attend a regular classroom
- At the start of every school year, parents and the student should meet with the teachers and the school nurse to review the disability and any special instructions

- Your child may need an Individualized Education Plan (IEP) or a 504 Plan—update this every year and as needed
- Teach your child about their condition, medications, and symptoms that need quick attention
- Teach your child about the importance of bladder and bowel care – allow your child to do this with supervision
- Include your child in a daily skin check.
- Promote independence
- Encourage your child to talk to the health care team and ask questions
- Expect your child to help with some household chores

Transitions in adolescence

Teens and young adults with spina bifida want to be like everyone else. This can be a challenging time for all adolescents.

- Continue to teach your teen about their condition, medications, and symptoms that need quick attention
- As your teen takes more responsibility, continue to talk about the importance of good self-care
- Teach your teen how to obtain supplies and medication
- Teach your teen about their health history – share their health information binder

- Let your teen do most of the talking to the medical providers
- Allow private time with the medical providers

Transition to Adult Care

A young adult can take good care of their health, without assistance, when the following are in effect. Start learning the answers to these questions long before you move to adult care.

- Educate yourself about your health. Keep good records of your surgeries, medications, and doctors who have cared for you.
- When you tell your health team about your disability does it sound the same as what your parents tell the team?
- Do you know what surgeries you have had? When you had them?
- Carry your health information, including the names of your doctor, the clinic phone number and insurance ID in your wallet or cell phone.
- Do you know the names and numbers of all of your doctors?
- Do you know how your health insurance coverage works?
- Schedule your own medical appointments.
- Do you know how to contact your doctors?

- Write down questions before your medical appointments.
- Do you communicate directly with your health team?
- Make a Power of Attorney and Advance Directive. Make sure the clinics and hospitals where you get care have a copy.
- Do you have a plan for healthcare decisions if you are unable to make your own decisions?
- Know your family health history.
- Do you know if there are other types of illnesses, such as heart disease or diabetes in your siblings, parents, or grandparents?
- Know how to stay healthy.
- Do you take care of yourself without your parents reminding you?
- Know your allergies
- Do you know if you have allergies?
- If you do have allergies, what happens to you when you have an allergy attack?
- Know how and where you can get medications and supplies.
- Do you know who to call?
- Do you know how long it takes for your medicines and equipment to arrive?
- Know how your medication works and why you need it.
- Do you know why you are taking the medicines you take?
- What would happen to your body if you stopped the medicine?

Phone Numbers

American Family Children's
Hospital General Information:
(608) 890-5437

American Family Children's
Hospital Gift Shop & Pharmacy:
(608) 890-8398

Billing, Hospital Bill:
(866) 841-8435

Billing, Physician Bill:
(866) 565-0505

Housing Coordinator:
(608) 890-8000

Interpreter Services:
(608) 262-9000

Kohl's Safety Center:
(608) 890-8043

Patient Relations:
(608) 263-8009

Pediatric Anesthesiology
(608) 263-8100

Pediatric Neurosurgery Clinic:
(608) 263-6420

Pediatric Orthopedic Clinic:
(608) 263-6420

Pediatric Urology Clinic:
(608) 263-6420

Pediatric Specialty Clinics:
(608) 263-6420

Positive Image Center:
(608) 890-8166

Rehabilitation Clinic, Middleton:
(608) 263-8412

Spiritual Care:
(608) 263-8547

Tyler's Place & Sibling Services:
(608) 890-8037

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Pediatric Pulmonary Center

UNIVERSITY OF WISCONSIN SCHOOL OF MEDICINE AND PUBLIC HEALTH