



# SPINA BIFIDA

## Who Owns Your Body?

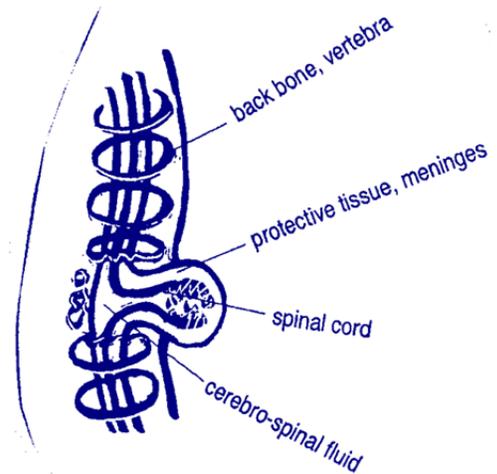
Young people with physical disabilities may have difficulties learning to take care of themselves. Ask yourself the following:

- Do your parents do things for you because it's faster or easier?
- Do your parents teach you about self-care techniques or about special equipment?
- Do you let others look after you because learning to take care of yourself is hard?

\* It may be hard to take care of yourself—but you can do it, and you should do it! Here is what you need to know.

## What Is Spina Bifida?

Before birth, while the spine is developing, one or more of the bones of the back, called vertebrae, fail to develop properly leaving a gap or split. The spinal cord pokes through this gap. It forms a bubble or fluid-filled sack covered by a thin layer of skin. This spinal material includes protective tissue, the meninges, that surrounds the spinal cord. It also include cerebrospinal fluid which bathes and protects the brain and spinal cord.



Spina bifida means open spine.

In the most serious form of spina bifida, the spinal cord nerves poke through the gap in the backbone. This can cause damage and the nerves may fail to develop properly.

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### Special Other Topics of Interest

- A Guide to Driving
- Planning For Your Future
- A Guide to Independence

## Knowing Your Body:

- Take control of your own life.
- Depend less on your parents.
- Be able to explain your needs to others.
- Know how to keep yourself healthy.
- Be aware of danger signals.
- Make sure you're getting proper medical treatment.
- Know what questions to ask when visiting health professionals.

The Good News is that you can live as long as anyone else if you look after yourself! The Bad News is that Spina Bifida is for life; it won't go away.

**Good News –  
you can live  
as long as anyone  
else if you  
look after  
yourself!**

## Mumbo Jumbo Words

***Lypomenigocele*** is a mild form of spina bifida. There is a fatty tumor over the spine. There may not be much nerve damage, but there may be urinary and bowel problems.

***Meningocele*** is a type of spina bifida where the protective tissue, the meninges, of the spinal cord pokes out between malformed bones of the spine; usually there is not much nerve damage.

***Myelomenigocele*** is the most involved type of spina bifida. The spinal cord pokes out between malformed bones in the back, causing nerve damage.

***Spina Bifida*** is a fault in the spine where the bones of the back fail to form properly, leaving a gap.

***Spina Bifida Occulta*** is a very mild type of spina bifida with bone defect but no nerve damage.

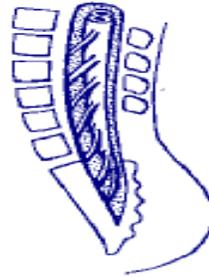


**Know what the  
words mean.  
Understand  
yourself!**

# Types Of Spina Bifida

## Occulta

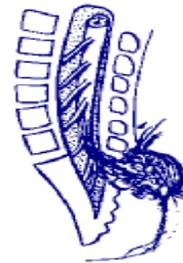
- One or two of the backbones do not form properly before birth.
- Sometimes there is a dimple, scar, or hairy patch on the back.
- There is NO nerve damage.



**Occulta: The bones are not formed properly; there is no nerve damage.**

## Lipomeningocele

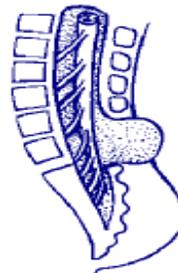
- Lipomeningocele is a soft swelling made of fatty tissue covered with skin over part of the spine.
- Because SOME nerves are damaged, there is often urinary control problems.
- After birth the back is repaired as much as possible to prevent further damage.



**Lipomeningocele: A tumor consisting of fatty tissue.**

## Meningocele

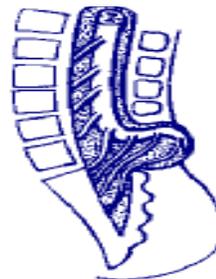
- The protective covering (meninges) of the spinal cord pokes out between damaged or missing bones of the back.
- The spinal cord stays in its proper place.
- Usually there is NOT A LOT of nerve damage.
- After birth the back is repaired as much as possible leaving a scar.



**Meningocele: The sack contains spinal fluid.**

## Myelomeningocele

- Both the spinal cord and its protective covering poke out between damaged or missing bones of the back.
- This is the most involved, as there is nerve damage.
- After birth the back is repaired as much as possible.



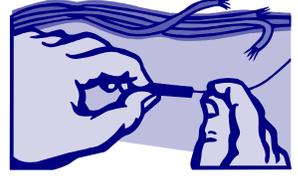
**Myelomeningocele: Nerves are pushed out in a sack.**

What type of spina bifida do you have?

- Occulta
- Lipomeningocele
- Meningocele
- Myelo-  
meningocele

## Your Spine

**Nerves** – or message lines – run up and down the spinal cord. Your spine works a lot like a phone: a message comes into your house along phone wires and the phone rings. With spina bifida, the wires are damaged and the phone doesn't ring.



Nerves are like phone wires.

**Spinal Cord** – allows you to move and feel. The spinal cord takes messages to and from your brain to all parts of your body. Damage to the spinal cord causes paralysis, loss of feeling, and sometimes problems with bowel and bladder control.

The higher the area of damage on your spine, the more areas of your body can't get messages to and from the brain. This is why both the type of spina bifida and the position of the lesion are important.

The type of spina bifida and the lesion site are important.

## Mumbo Jumbo Words

**Cerebrospinal Fluid** is clear, saltwater-like fluid that surrounds the brain and spinal cord.

**Lesion Site** is the place on your spine where the vertebrae didn't develop properly.

**Meninges** is the protective covering of the spinal cord.

**Spinal Column** is the spinal cord plus vertebrae.

**Spinal Cord** is a major bundle of nerves that carry nerve impulses to and from the brain to the rest of the body.

**Vertebrae** are rings of bone that surround and protect the spinal cord.



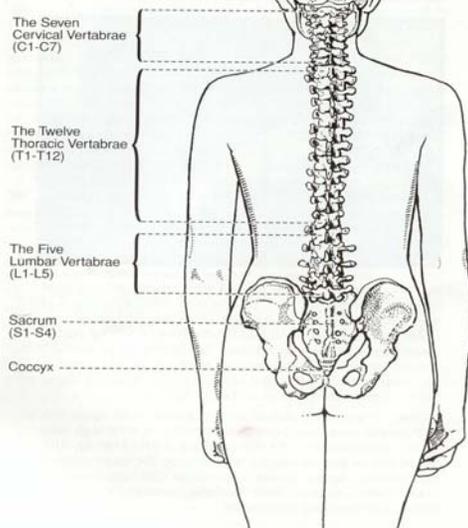
Know what the words mean. Understand yourself!

# The Scar On Your Back

A scar marks the spot where the spinal cord or its protective covering, or both, were operated on shortly after you were born. This place is called the **LESION** site.

The higher it is, the more areas of your body will have been affected by any nerve damage.

**Figure 2**  
Levels of the Spinal Column  
This drawing shows the various levels of the spinal column. Spina bifida can occur at any level.



Where is your lesion site?

What areas are affected?

- head
- neck
- shoulders
- arms
- hands
- fingers
- chest
- stomach
- lower back
- hips
- legs
- knees
- feet
- bowel
- bladder
- other

Your scar shows the location of your lesion site.

## Mumbo Jumbo Words

**Cervical Vertebrae** are the first seven bones of the spinal cord.

**Thoracic Vertebrae** are the twelve bones between the neck and waist.

**Lumbar Vertebrae** are the five vertebrae in the lower back, below the ribs.

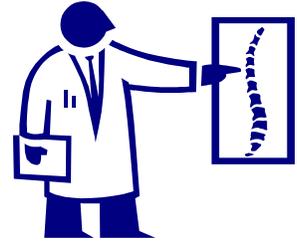
**Sacrum** describes five fused vertebrae in the lowest part of the spine.



**Know what the words mean. Understand yourself!**

## Tethered Spinal Cord

The spinal cord is the **thick bundle of nerves** within the backbone. It is surrounded by fluid and moves with your movements.



A tethered cord cannot move freely.

A **tethered spinal cord** cannot move freely because scar tissue, small cysts, or fatty growths tie down the cord. When this happens, tiny blood vessels that feed the spinal cord are stretched whenever you move. This reduces the blood supply to the spinal cells and the function of the spinal cord suffers.

Symptoms usually get worse gradually. If you notice any change, talk to your doctor right away.

## Who Can Get A Tethered Spinal Cord?

Anyone with spina bifida can have a tethered spinal cord. Symptoms may appear during growth spurts. You can develop a tethered spinal cord more than once. An operation is needed to release it.

**Pay close attention and look for the following symptoms:**

- You have pain in the back, neck, leg, or along nerves that go out from the spine after exercise, bending your neck, or sitting for a long time.
- You have increased bladder or bowel problems, or signs of a urinary tract infection.
- You have increased trouble walking; you feel stiff or awkward.
- You develop Scoliosis (spinal curvature), or see an increase in the curve of the spine.



These are warning signs.

**If you notice any change, talk to your doctor right away!**

## How Will The Doctor Tell What Is Wrong?

Several tests can be done to tell for sure if you have a tethered spinal cord.

- A CT scan uses x-rays to show slices or sections of your body.
- A MRI uses a large magnet, radio waves, and a computer. It is a painless way to look inside the body and make detailed pictures. It provides more information than regular x-rays.
- A Urodynamics study determines how well your bladder works.



The doctor will look inside to see what is wrong.

## What Can Be Done For A Tethered Spinal Cord?

A tethered spinal cord can be repaired by an operation to remove the scar tissue, cysts, or fatty growths. This procedure lets the spinal cord fluid flow freely around the spinal cord. Unfortunately, it is not always possible to tell before the operation whether or not any lost function may return.

A tethered spinal cord can be repaired but lost function may or may not return.

## Mumbo Jumbo Words

**Computed Tomography (CT)** is a computerized picture of sections or slices of the body. Tomo means “slice or section,” and graphy means “describing.”

**Cysts** are small sacs.

**Magnetic Resonance Imaging (MRI)** is a special test that takes pictures of the body using a computer, radio wave, and special magnets.

**Scoliosis** is when the spine is curved to one side.

**Tethered** means attached or bound together.

**Urodynamics** are tests to find out how well your bladder is working.

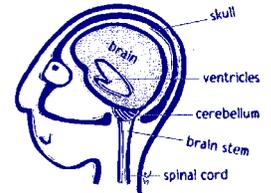


Is the light coming on?

## What Is Hydrocephalus?

Each day your brain produces up to two cups of cerebrospinal fluid which flows through the brain cavities, or ventricles, over the brain, and down the spinal cord, until it is absorbed by your body.

In most people with myelomeningocele spina bifida the flow of this liquid is blocked. Extra fluid builds up in the brain, pressing against brain tissues and causing damage to the brain.



**Hydrocephalus means**  
"water on the brain."

This is called hydrocephalus. To prevent damage from hydrocephalus a shunt is surgically implanted. A shunt carries the extra fluid away from the brain, preventing damage.

The shunt carries extra fluid away from the brain, preventing damage.

## Arnold Chiari Malformation

People who have myelomeningocele and hydrocephalus almost always have an Arnold Chiari Malformation. With this condition the cerebellum may be elongated and drop down along the lower brain stem into the cervical canal, and may become bent, stretched, or squished.

Sometimes surgery is needed to remove a bit of the skull to give this portion of the brain enough room.

## Mumbo Jumbo Words

**Arnold Chiari Malformation** occurs when the cerebellum and the brain stem area are pulled into the cervical canal.

**Cerebellum** is the base of the brain that is responsible for balance and coordination.

**Cerebrospinal Fluid** consists of a clear, saltwater-like fluid that surrounds the brain and spinal cord.

**Hydrocephalus** is the extra amount of spinal cord fluid surrounding the brain.

**Ventricles** are fluid filled cavities in the brain.

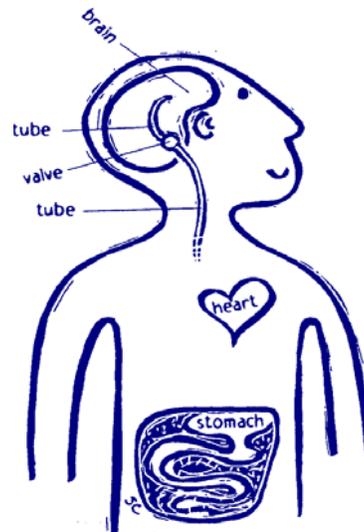


**Know what the words mean. Understand yourself!**

## Your Shunt

If you have a shunt you have hydrocephalus. In people with hydrocephalus, the liquid that surrounds the brain can't flow away to be absorbed by your body. This liquid, the cerebrospinal fluid, builds up in the brain, pressing against delicate brain tissue and causing damage.

A shunt carries the extra cerebrospinal fluid away from the brain cavity to a valve. The valve opens when there is extra fluid. The valve is attached to plastic tubing that carries the fluid to your heart or an open area around your stomach.



VP shunt goes to the stomach area.  
VA shunt goes to your heart.

Where does your shunt go?

- To your heart
- To your abdomen

## Warning Signs

If your shunt isn't working you may:

- Feel dizzy
- Lose your balance
- Feel sleepy
- Have seizures
- Have trouble seeing
- Have a headache
- Experience pain in your neck
- Feel confused
- Have a fever
- Have sensitivity to noise
- Feel nauseous

If you have any warning signs, call your doctor and get help right away!

## Kidneys

You have one set of kidneys. Kidneys can not be fixed and you need your kidneys to stay alive.

- Kidneys filter blood and clean out waste – like a filter in a swimming pool.
- Kidneys flush waste out as urine down tubes called ureters. Ureters run from each kidney to the bladder.
- The bladder stretches like a balloon when filled with urine. This sends a message to the brain that the bladder is full and needs emptying. The brain then sends a message to open the valves and empty the bladder.

With spina bifida, messages don't get through to the kidneys.

- Urine can sometimes flow back into the kidneys from the bladder. This is called vesicoureteral reflux, or just REFLUX. This condition leads to **kidney infection** that can make you very sick and can even cause kidney damage which is extremely serious.

With spina bifida the messages don't get through. The bladder may become rigid, the valves don't work very well, and there can even be bladder spasms.

## Mumbo Jumbo Words

**Reflux** is a back up of urine into the kidney.

**Renal Scan** is a test to show how well and how fast each kidney filters blood.

**Renal Ultrasound** is a test that takes pictures of your kidneys, ureters, and bladder using sound waves.

**Ureter** is the tube connecting kidney to bladder.

**Urethra** is the tube opening from the bladder.

**Urologist** is a doctor who helps keep your kidneys and bladder healthy.

**Voiding Cystourethrogram (VCUG)** is an x-ray test to show the flow of urine from the bladder to the urethra.



New words

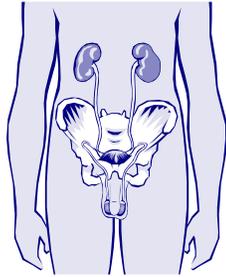
## Keep Your Bladder Happy

### Keep clean:

- Unless you keep yourself clean, germs from bowel movements, ones that grow in urine, on skin or clothes, can get into your bladder.
- The first step in keeping germs out is to keep them away from the urethra opening and off your hands.

### Drink Lots:

- About 8 glasses of water or juice a day helps flush out any germs in the bladder.



Your bladder holds the waste from your kidneys.

### Stay away from:

Caffeine and carbonation cause the bladder not to work well.

- Carbonation is found in soft drinks or drinks with fizz or bubbles.
- Caffeine is found in coffee, tea, chocolate, and soda.

### Don't let your bowel bully you!

- Follow your bowel program, so that a full bowel doesn't crowd your bladder.

If you have the signs of a bladder infection,

- Call your primary care doctor.

## How Do You Know If You Have A Bladder Infection?

- Cloudy or smelly urine
- Increase in urine output
- Fever higher than 101° F
- Mood change—irritable, cranky, or grumpy
- Blood in urine or at the urethral opening
- Pain in lower back or abdomen

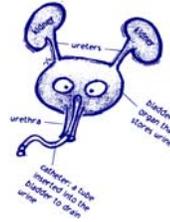


Know when to see your doctor.

## Why Catheterize?

If your bladder isn't getting messages from your brain then you have to use a catheter.

- To empty bladder and prevent infections.
- To prevent urine from going back into kidneys and causing them damage.



**The brain sends the message.**

## Stuff To Remember About Catheterizing

- Wash hands for 10 seconds before starting.
- Keep the catheter clean.
- Catheterize at regular times.
- Remove the catheter slowly.
- Wash and rinse catheter well after using.
- Store in a clean dry container.



**Wash hands for 10 seconds.**

**Germs love moist places to grow. It is most important to be clean.**

## When To Call The Doctor

- When fever is present (101° F or above).
- When pain is present at the fleshy part of the side between the hips and ribs.
- When bloody discharge is noted.



**Follow the directions .**

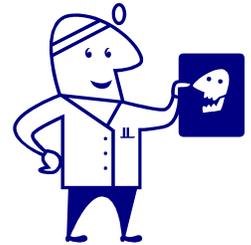
The lab should check your urine for an infection. The physician will order an antibiotic if needed.

**TAKE ALL OF YOUR MEDICATIONS AS DIRECTED BY YOUR DOCTOR.**

## Checking Out Your Water Works

### Renal Ultrasound

- A Renal Ultrasound takes picture of your kidneys, ureters, and bladder using sound waves.
- The test shows any swelling or scarring of the kidneys or ureters, how the wall of the bladder looks, and bladder size, shape, and urine content.



You should have a renal ultrasound yearly.

### Renal Scan

- A Renal Scan looks at how well and how fast each kidney filters blood.
- This painless test may show any scarring or damage.

### Urodynamics

- An Urodynamics study measures how well your bladder works.

### VCUG (Voiding Cystourethrogram)

- VCUG is an X-ray of the bladder to show the flow of urine from the bladder through the urethra. The test consists of inserting a special liquid into the bladder.
- The test shows whether reflux – back up of urine into kidneys – is happening.

**Everybody with spina bifida should have a urologist.** A Urologist is a doctor who helps keep your kidneys and bladder healthy.



Who is your urologist?

Everyone with spina  
bifida should have  
a urologist.

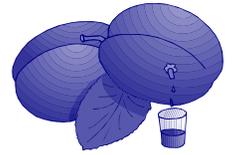
Get one today!

Who is your urologist?

\_\_\_\_\_

## Establish A Bowel Routine

The key to bowel management is to have a bowel movement at the same time every day, preferably after a meal. Establishing a bowel routine takes time and patience.



Prune juice can sometimes help.

### A Natural Schedule

You already may have a natural internal schedule. About 20 to 30 minutes after a meal, there is a natural body response to evacuate the bowel. Watch for a week or two and use your own natural schedule, if possible, when choosing a daily time. After breakfast or supper works for many.

The key to bowel management is to have a bowel movement at the same time every day.

### No More Than 2 Days

Never let more than 2 days go by without a bowel movement. The longer between bowel movements the harder and drier the stool gets. For some people combining a regular toileting schedule, for example, 5 to 10 minutes at the same time every day, with a high fiber diet of fruits, vegetables, whole grains or bran, and plenty of water is all that is needed.

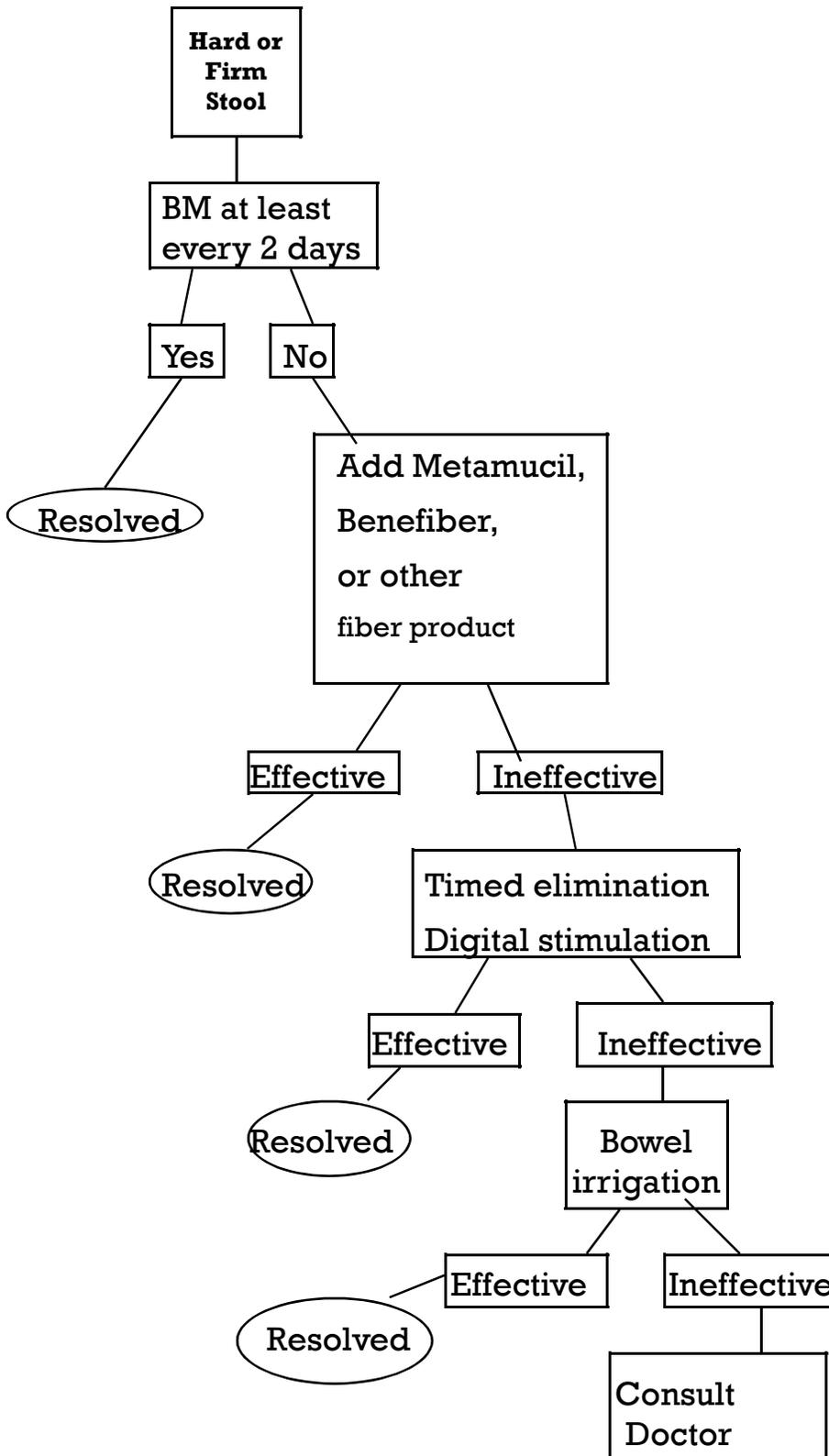


Drink at least 8 glasses of water a day.

### Special Help

Sometimes a suppository, stool softener, bulk former, or laxative will be needed if your bowel tone is not normal. To empty the bowel completely before any of these can be effective, an enema may be needed. Discuss any use of medication with your doctor.

# Map For Bowel Care



Never go more than two days without a bowel movement.

## Latex (Rubber) Allergy

When you touch latex, do you get:

- Skin rash
- Itching
- Eye tearing or irritation
- Coughing
- Throat or chest tightness
- Difficulty breathing
- Fainting or unconsciousness
- Hives, welts, swelling, or redness anywhere on the body



**A latex allergy can be serious.**

**If you have a latex allergy,**

- Avoid contact with latex things.**
- Wear a medical alert bracelet.**
- Discuss carrying an EpiPen kit with your doctor.**

### Objects that Often Contain Latex

- Band-Aids
- Rubber gloves
- Condoms
- Paint or markers
- Balloons
- Balls
- Elastic
- Foam rubber
- Rubber bands



**Many toys have latex or rubber in them.**

### Anaphylactic Shock

Some people have a serious reaction to latex, such as hives, difficulty breathing, and low blood pressure. This can happen within minutes of being touched by a latex object and can lead to death if not treated immediately.

## What Should You Do?

- Avoid touching rubber latex things – look for vinyl, silicone, or plastic products instead.
- At the beginning of each visit, remind your doctor, dentist, or hospital about your allergy to latex.
- Get and wear a medical alert bracelet printed with “allergy to natural latex rubber.”
- Learn how to give injections of adrenaline, or epinephrine, using an EpiPen kit (you need a prescription, so talk with your physician).



**Avoid touching anything latex.**

## If You Have An Allergic Reaction

- Remove the latex object.
- If you come into contact with latex, wash your skin with large amounts of water.
- If you have any trouble breathing or chest tightness give an adrenaline injection using an EpiPen kit. Call 911 immediately for emergency medical help.

**Can a latex allergy get worse?**

**Yes!**

## Are You Likely To Get A Latex Allergy?

- You are most at risk of having a latex allergy if you have other allergies.
- You are in a high risk group, if you need frequent surgeries or are often in contact with latex products.

## Can A Latex Allergy Get Worse?

Yes! Even if you only have a minor latex allergy don't use any latex products. This will prevent you from becoming more sensitive. The more you are exposed to latex, the more allergic you may become.



**A latex allergy can be a life threatening emergency.**

## What Medications Are You Taking?

Most people with spina bifida are taking some medications. It is up to you to:

- Keep track of what pills you take and what they are for,
- Learn how you should take them, and
- Recognize any side effects.



**Know your medications.**

Medications are powerful tools that help us take care of ourselves and manage our health better. They must be treated with respect. Never change the amount or stop taking any medication without first talking to your doctor.

**Never change the amount or stop taking any medication without first talking to your doctor.**

## Questions About Your Medications

- What is the name of the medication? Is this the brand or generic name?
- What is the medication supposed to do? How does it affect you?
- How and when do you take it – and for how long?
- What foods, drinks, other medications, or activities should you avoid while taking this medication?
- Could there be a possible reaction between this medication and any other non-prescription, over-the-counter medication you might use?
- What are the possible side effects? What do you do if they occur?
- How and where do you store the medication?
- Do you need to refill the prescription?
- Do you need any lab tests while taking the medication?
- Is there any written information available about the medication?



**Ask questions about your medications.**

## Mumbo Jumbo Words

- **Antibacterials or antibiotics** treat urinary tract infections by preventing, decreasing, or killing the germs that cause the infection. Common names are Bactrim, Macrobid, Macrochantin, and Furadantin. **Side effects** may be nausea, vomiting, diarrhea, abdominal pain, or decreased appetite. Call your doctor immediately if you have a skin rash, hives, or breathing problems.
- **Stool preparations** are medications that help soften or move along the bowel movement. Common names are Metamucil, Benefiber, Senokot, Surfak, Lactulose, and Colace. **Side effects** may be stomach cramps or diarrhea.
- **Bladder muscle relaxers** are medications that relax bladder muscles to increase the amount of urine your bladder can hold; decrease bladder pressure so urine does not back up (reflux) into your kidneys; and help keep you DRY. Common names are Ditropan, Imipramine, and Detrol. **Side effects** may be dry mouth, flushing (problems with overheating), difficulty sleeping, mood changes, constipation, or drowsiness.



Know the  
adverse  
reactions and  
side effects.

Store medication in  
the refrigerator only  
when clearly labeled  
“Store in  
Refrigerator”  
or “Refrigerate.”

## Medication Tips

Store your medications in a cool, dry place. Don't keep them in your bathroom medicine cabinet or the kitchen cabinets near the stove. These areas are too warm.

Store medications in your refrigerator only if they are clearly labeled “Store in Refrigerator” or “Refrigerate.”

Keep all medications out of the reach of children.

Never use someone else's medication.



Store as directed.  
Keep out of reach  
of children.

# Pressure Sores

Pressure sores are caused by the lack of normal blood flow to the skin.



The skin is squeezed between bones and something that is hard.



This cuts off the blood supply to the skin.

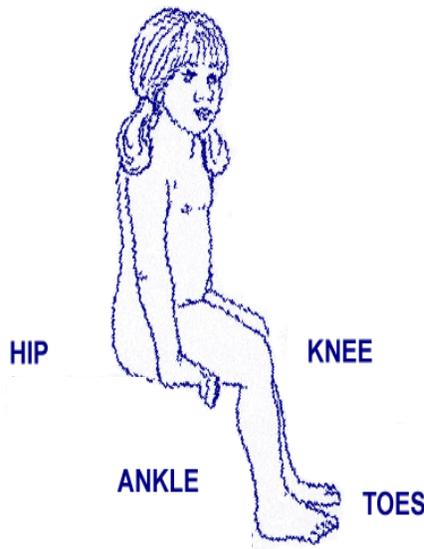


The skin sends a message to the brain to move.



With spina bifida the message doesn't get through to the brain. Because the blood supply is cut off, oxygen and nutrients don't get to the skin -

**THE SKIN BEGINS TO DIE!**



These are common areas of pressure sores.

Did you check your pressure sores today?

→ Check these spots every day with your mirror.

- Elbows
- Hips
- Butt
- Behind knees
- Feet
- Ankles
- Heels



Use your mirror daily to see all of your body.

## Between a Bone and a Hard Place

Pressure sores, skin ulcers, bedsores, decubitus, and tissue trauma are all caused by skin pressing or rubbing between the bone and something that is hard. Pressure sores can be caused by your wheelchair, leg brace, or even a fold in your clothing. Because of the pressure there is abnormal blood flow to that area and the skin is starved of oxygen.

## Why You Don't Want Pressure Sores

- They take a long time to heal.
- You may need skin grafts - more surgery.
- You may have to spend days - or even weeks - lying on your stomach, and that is VERY BORING!



Pressure sores may require surgery.

Prevention is easier than repairing and healing from a pressure sore.

## Four Stages of Pressure Sores

- **Pressure Sore—Decubitus Ulcer— Tissue Trauma**
- In **Stage I**, the skin is red, and the color of the skin does not return to normal with relief of pressure.
- In **Stage II**, the skin is blistered, although damage is still superficial.
- In **Stage III**, the skin is broken. A full thickness of skin is lost and bloody drainage may be seen.
- In **Stage IV**, a deep craterlike ulcer has formed. The full thickness of skin and tissues are destroyed. Tissue, bone, or muscle under the ulcer are exposed and may be damaged.

## What Are You Going To Do To Prevent Pressure Sores?

- Recognize where pressure sores are likely to develop.
- Relieve pressure and increase circulation with daily exercise.
- Move and shift positions frequently during the day.
- Change positions with pillows, pads, etc. to relieve pressure.
- Keep your weight healthy.
  - overweight = extra pressure
  - underweight = no padding
- Eat a well balanced diet.
- Check that you have not outgrown your wheelchair, braces, or shoes – review these once a year with a physical therapist.
- Use good transfer techniques to reduce friction.
- Maintain good skin hygiene.
- Keep your skin clean and dry. Wet skin is more likely to get pressure sores, so change pads or wet clothing as soon as possible.
- Use a mirror and check your backside daily.
- Treat any redness early by cushioning the area to relieve the pressure.

**Pressure sores  
may appear  
in a matter  
of hours.**



**Eat a well  
balanced diet.**

## The Big Test

1. Who owns your body?
2. Why should you understand spina bifida?
3. What type of spina bifida do you have?
4. Where is your lesion site?
5. What are the signs of a tethered cord?
6. Do you have a shunt?
7. What type of shunt do you have?
8. What are the signs that your shunt is not working right?
9. If you use a catheter, what size do you use?
10. What are the signs of a urinary tract infection?
11. Why should you avoid latex?
12. What medications do you take?
13. What are the side effects of your medication?
14. How should your medication be stored?
15. What is a pressure sore?
16. How can you avoid a pressure sore?
17. Are you ready to take charge of your future?

It's your future.

GO

For

It!



**TAKE CHARGE  
OF YOUR  
FUTURE!**



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