

**Holland Bloorview**  
Kids Rehabilitation Hospital

# Understanding Spina Bifida

A handbook about spina bifida  
and hydrocephalus

Produced by health care professionals  
in the spina bifida service at Holland Bloorview  
Kids Rehabilitation Hospital



## Acknowledgements

Understanding Spina Bifida, originally published in 1998, was developed by health care professionals in the spina bifida service at Holland Bloorview Kids Rehabilitation Hospital, in partnership with the Spina Bifida and Hydrocephalus Association of Ontario (SB&H).

This handbook is the culmination of the work of many health experts in spina bifida. Special acknowledgement goes to Holland Bloorview Kids Rehabilitation Hospital and the health care professionals in the spina bifida service, who are commended for their persistence and dedication and the Spina Bifida and Hydrocephalus Association of Ontario for providing resources and adding valuable insights into the content, format and tone.

Every effort was made to ensure that statistical and medical data were as accurate as possible at the time of printing.

## Table of Contents

<b>Section A: Introduction</b>	<b>5</b>
<b>Section B: Understanding Spina Bifida</b>	<b>6</b>
How Does Spina Bifida Occur?	6
Myelomeningocele	7
Meningocele	7
Lipomyelomeningocele	7
Occulta	8
What Happens When a Baby is Born with Spina Bifida?	8
<b>Section C: Understanding Hydrocephalus</b>	<b>9</b>
What Is Hydrocephalus?	9
How Is Hydrocephalus Treated?	9
<b>Section D: Other Neurological Issues</b>	<b>11</b>
Understanding Chiari II Malformation	11
Tethered Cord	12
Syringomyelia or Syrxinx	12
<b>Section E: Bladder Function (Urinary System)</b>	<b>13</b>
Understanding the Urinary System	13
How Does Spina Bifida Affect the Urinary System?	13
How to Manage the Urinary System?	14
Urological Testing	15
<b>Section F: Understanding Bowel Function (Digestive System)</b>	<b>16</b>
How Does Spina Bifida Affect Bowel Function?	16
What Can Be Done to Manage Bowel Function?	16

**Section G: Muscles and Bones  
(The Musculo-Skeletal System) 19**

Bones	19
Nerves	21
How Does Spina Bifida Affect Leg Muscles?	21
What Will Happen as My Child Grows?	25

**Section H: Special Equipment and Mobility Aids 27**

**Section I: Skin and Sensation 30**

Skin	30
How Does Spina Bifida Affect Sensation?	30
How Can I Protect My Child's Skin?	30

**Section J: Hand Skills 32**

How Does Spina Bifida Affect Hand Skills?	32
How Can I Help My Child Develop Hand Skills?	32

**Section K: Special Considerations 33**

Fractures	33
Seizures	33
Eyes	33
Hearing Sensitivity	33
Latex Allergy	33
Complementary Health Care	34

**Section L: Language Development 35**

**Section M: Understanding Learning 37**

**Section N: Independence 40**

**Section O: Your Child's Self-Esteem 44**  
How Can I Help My Child? 44

**Section P: Sexual Development and Healthy Relationships 45**

**Section Q: Family Planning 46**

**Section R: Parenting 47**

**Section S: Planning for the Future 48**

**Glossary of Useful Terms 49**





## Section A: Introduction

The purpose of this book is to help children diagnosed with spina bifida and their parents/guardians, friends and others understand the condition so that they can make informed decisions regarding medical care, treatment and management in the present, as well as anticipate and plan for the future. This book, originally published in 1998, has been updated to reflect current knowledge, best practices, and social, medical and educational issues. It also includes practical and informative tips for children and parents.

The underlying philosophy of spina bifida care and management presented in this book is based on a multi-disciplinary, shared management team approach focused on family-centered care. Children with spina bifida and their parents/guardians are the prime decision-makers for their care. Health care providers offer professional expertise, opinions and options. At every stage of development, fostering and developing functional abilities, independence and high self-esteem are essential. These concepts are the foundation upon which information and suggestions are presented.

We have organized the information into descriptive sections and included suggestions for home management of spina bifida and preventative strategies for associated secondary conditions. A glossary is included for more detailed information. All italicized words are explained in the glossary.

We hope that this book provides you with the information you need to help you and your child understand and live life to the fullest with spina bifida.

For more information,  
please contact:

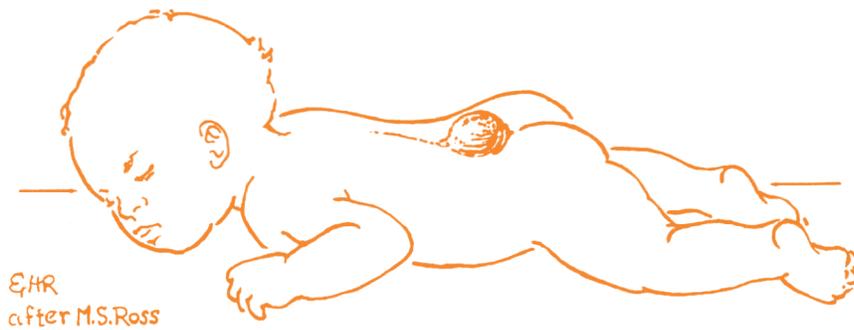
**Holland Bloorview Kids  
Rehabilitation Hospital**  
Spina Bifida Service  
150 Kilgour Road,  
Toronto, Ontario  
M4G 1R8  
1 800 363 2440 or  
416 425 6220  
[www.hollandbloorview.ca](http://www.hollandbloorview.ca)

**Spina Bifida and  
Hydrocephalus  
Association of Ontario**  
P.O. Box 103,  
Suite 1006,  
555 Richmond Street West,  
Toronto, Ontario  
M5V 3B1  
1 800 387 1575 or  
416 214 1056  
[www.sbhao.on.ca](http://www.sbhao.on.ca)

## Section B: Understanding Spina Bifida

Spina bifida occurs before birth and results in the incomplete formation of the spine and spinal cord. It may result in varying degrees of paralysis and loss of sensation in the legs, as well as affect the functioning of bowel and bladder, hand skills, vision, hearing and learning abilities.

Spina bifida can occur in any pregnancy and on average, 2.6 in 10,000 babies in Canada are born with some type of spina bifida. Spina bifida falls under the overall category/ heading of a neural tube defect (NTD). There are a number of factors that have been identified as playing a role in the development of spina bifida. The genetics of both parents, the mother's diet several months before conception and during the first 28 days after conception, and a number of yet unidentified environmental factors surrounding the time of conception and the early weeks and days of pregnancy are believed to be important factors for the development of spina bifida. It is important to note that no one factor alone is believed to be responsible. Rather, a combination of the factors noted above, possibly among other unknown factors, may contribute to the development of spina bifida.



NEWBORN WITH SPINA BIFIDA

### How Does Spina Bifida Occur?

The brain and *spinal cord* (central nervous system) develop within the first month of pregnancy. The formation of the *neural tube*, which is the nerve tissue from which the spinal cord and brain develop, occurs by the 28th day after conception. When the *neural tube* does not develop properly, *spina bifida* occurs. Bone, muscle, and skin cannot form around the spinal cord where the tube is open. The incomplete formation of the *spinal cord* creates an opening (lesion) through which *nerves* and *spinal fluid* may protrude and *create* a sac on the unborn baby's back called a "cele" (pronounced seal). That cele may contain fat tissue and is covered by skin or a thin membrane. As a result, the *nerves* around the cele are damaged or improperly formed. The number of spinal *nerves* involved, and the extent of damage to the areas controlled by these nerves, is dependent on the location of the opening, or cele, on the spinal cord. The higher the cele, the greater the potential for damage.

The most common types of *spina bifida* are:

## Myelomeningocele

(pronounced my-low-meh-NIN-go-seal)

*Myelomeningocele* is the most severe form of *spina bifida* whereby the bones fail to close around the *spinal cord*. The *meninges* (coverings of the *spinal cord*) and the *spinal cord* protrude through the opening in the spine to form a sac. This sac contains *cerebrospinal* (pronounced se-REE-bro-spy-nal) *fluid*. This sac is usually transparent and not covered by skin. The *spinal cord* fails to develop properly and spinal *nerves* are damaged.

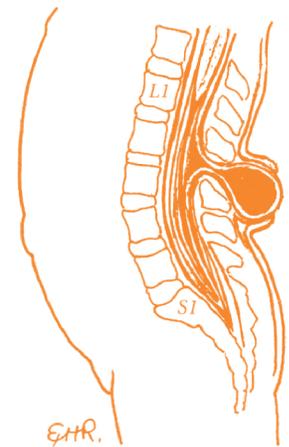


MYELOMENINGOCELE

## Meningocele

(pronounced me-nin- GO-seal)

*Meningocele* is a less severe form of *spina bifida* whereby the bones do not close fully around the *spinal cord*. The *meninges* are pushed out through the opening to form a sac containing *cerebrospinal fluid*. No portion of the *spinal cord* is pushed out into the sac – the *spinal cord* remains in the *spinal column* and the nerves are not as severely affected. The sac is often covered by skin. There may be motor or sensory changes after the sac is surgically repaired.



MENINGOCELE

## Lipomyelomeningocele

(pronounced ly-po-my-low-meh-nin-go-seal)

In *lipomyelomeningocele*, there is a protrusion of abnormal fatty tissue through a defect in the *vertebrae* of the lower spine. Damage to the *nerves* may occur from compression of the *nerves* by the fatty mass or due to abnormal formation of the *spinal cord*.

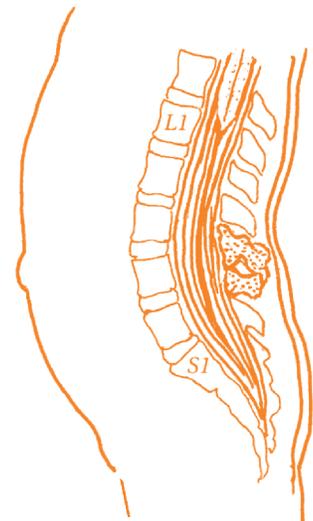
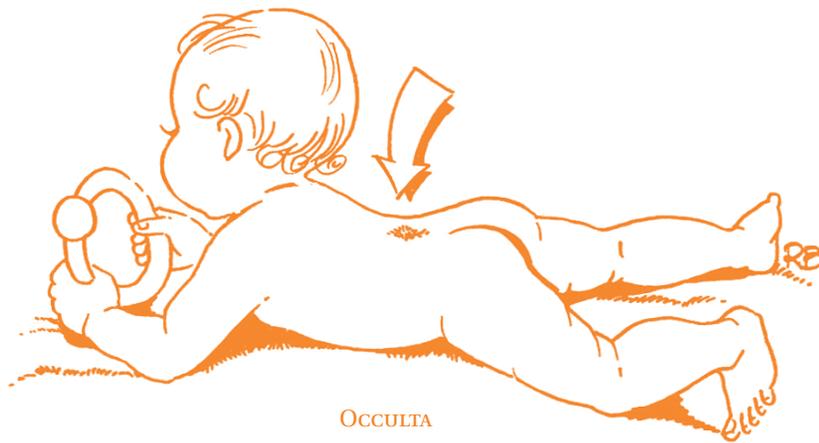
Symptoms of *lipomyelomeningocele* may include:

- A skin covered fatty mass in the buttock or lower spine area
- A pinkish patch, dimple or skin tag in the lower spine area
- Muscle weakness of legs
- Foot deformities
- Loss of sensation in patches on the lower legs, feet and buttocks
- Back pain
- Urinary or fecal incontinence

## Occulta

(pronounced o-cult-a)

This is a form of *spina bifida* where a small hole in the lower segment of the spine and the bones are not properly closed. It may involve an abnormality of the vertebrae or vertebrae and spinal cord. Many people have this condition and only become aware of it if they have unexplained *incontinence*, back ache, or changes in the muscles of their legs.



### What Happens When a Baby is Born With Spina Bifida?

When a baby is born with *spina bifida*, he/she is usually transferred to a specialized children's hospital shortly after birth. If the skin is not completely closed over the sac, *neurosurgeons* must repair the sac during the first few days of life. This surgery reduces the risk of further damage to the *spinal cord* and *nerves* but cannot repair the nerves that are already malformed. This damage is permanent. The baby usually stays in hospital for 1-2 weeks.

A multi-disciplinary team of health professionals (e.g. physicians, nurses, social workers, physiotherapists, occupational therapists) who specialize in the care of infants born with *spina bifida* will monitor the baby and be available to answer any questions.

Parents are involved in their baby's care as soon as possible and taught any special care while in hospital to foster early and effective teaching and learning. Once home, parents, local health care providers, and a *spina bifida* clinic will work together to help meet the needs of the growing child and the needs of the family for emotional support and specialized information related to community services and benefits.

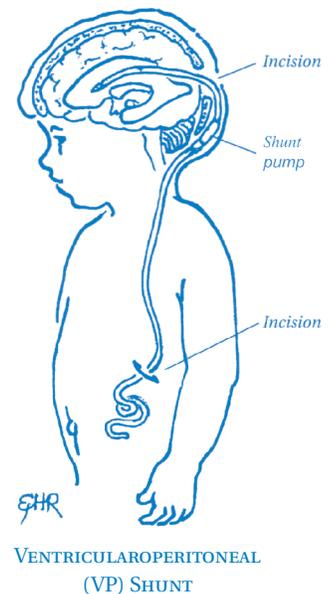
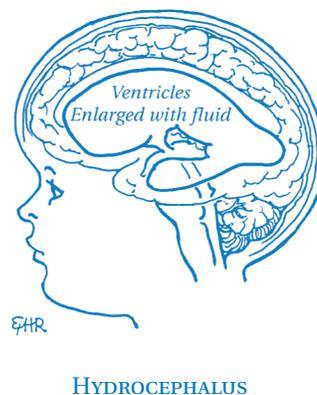
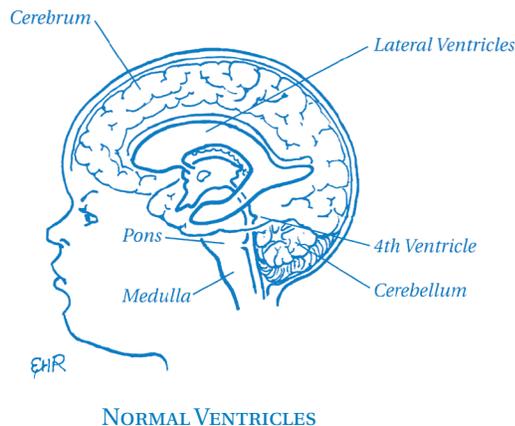
## Section C: Understanding Hydrocephalus

### What Is Hydrocephalus?

*Hydrocephalus* may develop in the womb or shortly after birth. Approximately 85-90 percent of individuals with *spina bifida* will also have hydrocephalus.

This neurological condition exists when excess *cerebrospinal fluid (CSF)* builds up in cavities, called *ventricles*, inside the brain. Everyone has this fluid circulating freely to protect the brain and spinal cord. However, in *hydrocephalus*, fluid accumulates in the *ventricles* when the body produces more *CSF* in a day than it can reabsorb. This accumulation causes enlargement of the ventricles, resulting in *hydrocephalus*.

Individuals with *hydrocephalus* often have physical consequences varying from weakness and *spasticity* to mild imbalance, limited fine motor control, headaches, nausea and tenderness around the *shunt* incision site. Seizures are common, as well as, sensitivity to external pressure, hearing sensitivity, visual problems, and constipation. Individuals with *hydrocephalus* often have difficulty with some aspects of learning.



### How Is Hydrocephalus Treated?

*Hydrocephalus* is usually surgically managed with a *shunt* (tube) to redirect the CSF into the abdomen where the fluid is reabsorbed. The tube, called a ventriculoperitoneal (VP *shunt*), drains the fluid from the ventricles in the brain to the abdomen cavity (peritoneal cavity).

Individuals with *shunted hydrocephalus* can enjoy most sports and activities, but should avoid contact sports, prolonged pressure on the head (e.g. head stands), and excessive stretching of the *shunt* tubing (e.g. somersaults).

The *shunt* may be needed throughout life. If it malfunctions due to a blockage, breaking, kinking of tubing, or develops a problem with the valve, the *shunt* must be surgically revised or replaced.

## Symptoms of shunt malfunction may include:

### Infant

- *Fontanel* (soft spot) is bulging when baby is upright and quiet
- Prominent scalp veins appear unnaturally full
- Swelling, discoloration or redness along the *shunt* tract
- Fever (infection)
- Vomiting (especially projectile)
- Unusual irritability
- Unusual tiredness
- Downward deviation of the eyes (sunset sign)
- *Seizures* (abnormal twitching)
- Gradual head enlargement

### Toddler

- Fever
- Vomiting (especially projectile)
- Irritability and tiredness
- Swelling, discoloration or redness along the *shunt* tract
- Loss of previous cognitive or motor abilities, walking, talking, coordination or balance
- *Seizures* (abnormal twitching)
- Headache \*
- Head enlargement caused by enlarged ventricles
- Visual disturbances: blurred or double vision, excessive squinting or blinking
- Downward deviation of the eyes (sunset sign)
- Change in personality, unable to concentrate
- Unusual tiredness/lethargy/ listlessness/sleepiness

*\*The headaches experienced by toddlers, children and adults are often at the front of the head on both sides. They are generally severe upon waking in the morning or following a nap, and may be relieved by sitting up.*

### Children/Adults

- Headache\*
- Nausea or vomiting (especially projectile)
- Unusual tiredness or difficulty staying awake
- Unusual irritability
- Arching of head backwards
- Fever
- Visual disturbances, blurred or double vision
- Personality change
- Loss of coordination or balance, gait disturbances; clumsiness
- Swelling, discoloration or redness along the *shunt* tract (infrequent)
- Difficulty in walking
- *Seizures* (abnormal twitching)
- Decline in school or work activities
- Dizziness or fainting
- Difficulty waking up from sleep
- Impairment of mental or motor performance
- Headaches unrelieved by pain medication

## What Should I Do If Symptoms of Shunt Malfunction Develop?

If symptoms are sudden and persistent, immediate medical attention is required. Go to your closest hospital emergency department. If symptoms are gradual or less severe, visit with your *neurosurgeon* as soon as possible to discuss options and treatment.

## Section D: Other Neurological Issues

### Understanding Chiari II Malformation

In children with *spina bifida*, the *brain stem* (lower part of the brain) is lower than usual and compresses the upper part of the *spinal cord* in the neck. Nearly all individuals born with *myelomeningocele* have *chiari II malformation*.

A small percentage of children with *chiari II malformation* develop severe symptoms such as *aspiration* (when food and liquid enter the lungs), *apnea* (when breathing stops for more than 5 to 10 seconds), or any of the other symptoms listed below.

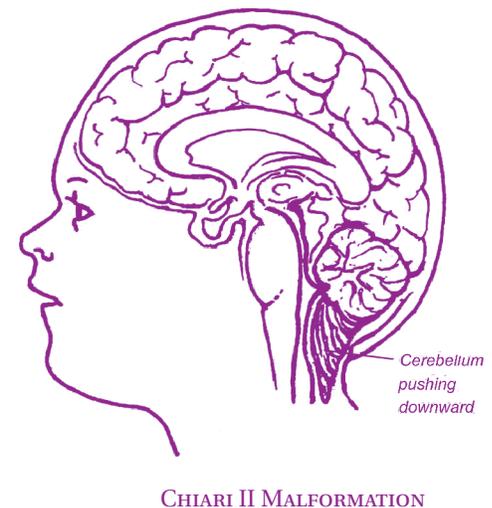
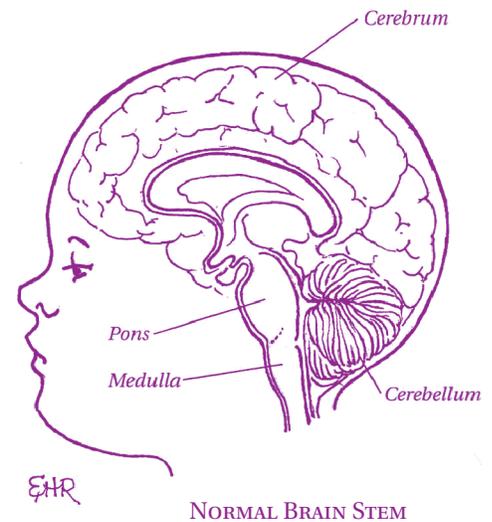
Symptoms of *chiari II malformation* may include:

- *Hypersensitivity* (increased sensitivity) to objects in the mouth (e.g. lumps in food, toothbrush), hypersensitivity to light and loud sounds
- Gagging
- Choking
- Vomiting
- *Stridor* (high-pitched “croupy” sounds)
- Tightness and/or weakness of arms
- Arching of head backwards
- Weak suck when feeding (bottle feeding or breast-feeding)

### What Should I Do if Symptoms of Chiari II Malformation Develop?

If your child develops symptoms of *chiari II malformation*, report it to your *neurosurgeon* or other health care professional. You and the *neurosurgeon* should discuss options and plan the treatment. If symptoms persist or are severe, surgery may be required to reduce the pressure in the brain stem area. Some children with *hypersensitivity* in or around the mouth may be helped by an *occupational therapist* or a *speech language pathologist*. A *physiotherapist* may provide suggestions for positioning to reduce neck arching and tightness of arms.

Children may outgrow the difficulties of choking and swallowing. The difficulties with eating and drinking may also diminish as they grow.



## Tethered Cord

The *spinal cord* is normally elastic. In children with *spina bifida*, the spinal cord can get stuck at the site of the *lesion* and is often stretched over time. That stretch can lead to injury of the spinal cord, which will cause symptoms called *tethered cord*.

Symptoms of tethered cord may include:

- Bladder changes - urgency and frequency in urinary wetness, increase in urinary infections, problems noted on x-rays or urodynamics (UDS)
- Bowel changes - urgency and frequency in bowel soiling, change in stool consistency
- Back pain - especially in the lower back and legs
- Leg and foot changes - increase in tightness of muscles, decrease in the range of movement or existing function, worsening of ankle and foot deformities, changes in walking, curling and clawing of toes
- Increasing curving of the spine, called scoliosis

What Should I Do if Symptoms of Tethered Cord Develop?

If your child develops any symptoms of *tethered cord*, report it to your neurosurgeon or health care professional. A *magnetic resonance imaging* (MRI) or other tests may be recommended and surgery may be necessary to release (detether) the *spinal cord*. This procedure may prevent the symptoms from getting worse, but it may not improve the present symptoms.

## Syringomyelia or Syrx

(pronounced Si-rin-go-my-EEL-ee-a or Si-rinx)

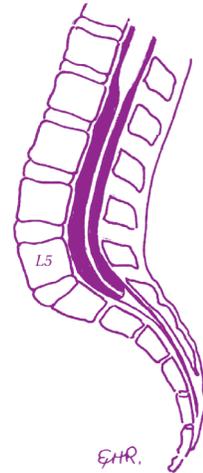
This is an abnormal pocket of *cerebrospinal fluid* which forms inside the *spinal cord*. This condition is caused by pressure from the *cerebrospinal fluid* within the central canal of the *spinal cord*.

Symptoms of syringomyelia may include:

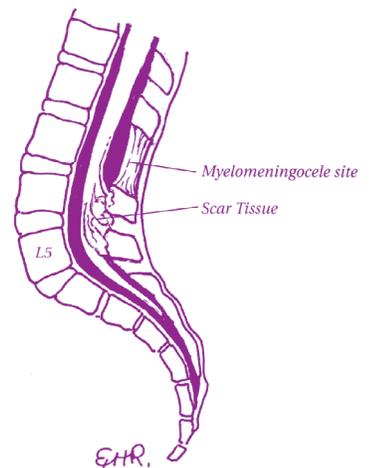
- Increased *scoliosis*
- Changes in sensation and/or weakness of the hands, arms (e.g. pins and needles, numbness)

What to Do if Symptoms of Syringomyelia Develop?

If your child develops any symptoms of *syringomyelia* or *syrinx*, report it to your neurosurgeon or health care professional. An MRI may be recommended and a *shunt* may be inserted or a *shunt revision* may be needed if the *shunt* is not working properly. A *spinal shunt* may be required to redirect the extra fluid away from the spinal cord to the abdomen.



NORMAL SPINAL CORD



TETHERED SPINAL CORD

## Section E:

# Bladder Function (Urinary System)

### Understanding the Urinary System

The kidneys filter waste products from the blood, forming urine. Urine flows through the ureters into the bladder. As the bladder is filling, the bladder muscles relax and the *sphincter* (pronounced sfink-ter) muscles stay tight (contract) to hold the urine in the bladder. When the bladder is full, it sends messages through the *nerves* of the *spinal cord* to the brain signaling the body to release the urine. The brain responds by sending messages back through the *nerves* of the *spinal cord* to the bladder. These messages signal the bladder muscles to tighten (contract) and the urethral sphincter muscles relax, opening the sphincter. Then urine flows out of the bladder.

### How Does Spina Bifida Affect the Urinary System?

Almost all children with *spina bifida* will have problems with their bladder function. Bladder function is controlled by the nerves at the bottom of the spinal cord and nerve damage may interrupt the messages from the brain to any part of the urinary system. Normal urination may not occur because nerve damage may limit bladder and *sphincter* muscle function and reduce sensation.

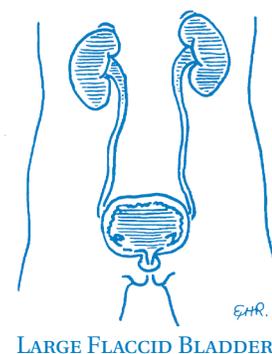
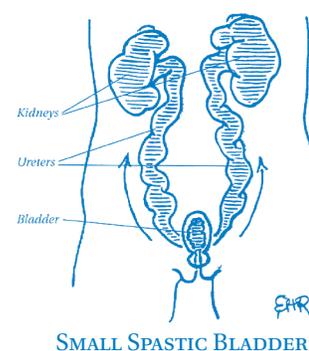
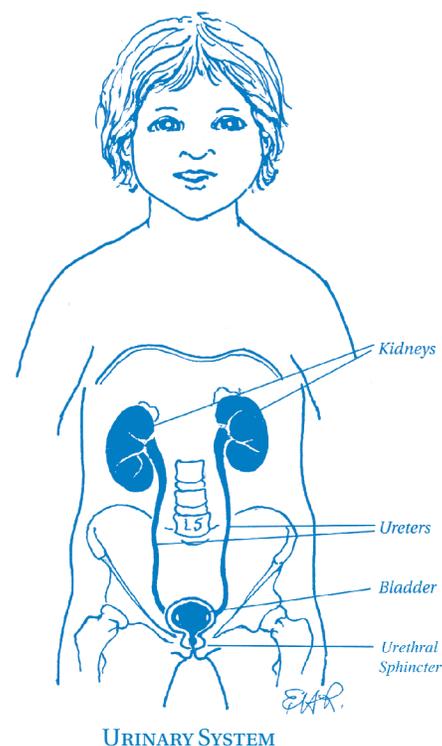
The following two types of bladder function problems may result and change over time:

#### Small spastic bladder:

- Results from uncontrolled contractions (tightenings) of the bladder muscles
- May lead to back up of urine to the kidneys (*reflux*), enlarged kidneys (*hydronephrosis*) (pronounced hydro-nef-ro-sis) and wetness
- Bladder becomes unusually small and holds little urine

#### Large flaccid bladder:

- Results from inability of the bladder muscles to contract properly
- May lead to frequent infections caused by poor emptying
- Bladder becomes unusually large with a relaxed *sphincter*



## How to Manage the Urinary System?

It is important to help your child protect his/her kidneys and bladder by doing the following:

- Talk to your *spina bifida* health team about toileting routines tailored to your child's needs.
- Clean Intermittent *Catheterization (CIC)* is a procedure whereby a clean *catheter* (tube) is inserted through the *urethra* into the bladder and removed after the bladder is empty. *CIC* is done every 3-4 hours during the day to empty the bladder regularly in order to prevent *reflux* and *hydronephrosis*.
- Medications (known as anticholinergics) may be prescribed to relax bladder contractions.
- Regular monitoring of bladder and kidneys is required (e.g. renal ultrasounds, voiding cystourethrogram (VCUG), urodynamic testing, renal scan).
- Occasionally, surgery may be required.

## Preventing and/or Reducing Bladder Infections

- Regular emptying of the bladder through *catheterization* is important to reduce the length of time the urine is held in the bladder to help prevent infections
- Extra water intake is encouraged (speak to your health care professional in the *spina bifida* service about the appropriate volume)
- Daily antibiotics may be prescribed
- *Bladder irrigation* may be recommended

## Preventing and/or Reducing Incontinence/Wetness

Strategies listed above will help reduce incontinence.

Urological surgery (e.g. *sphincter* tightening and *bladder augmentation*) may be recommended to improve the ability of the bladder to hold urine between catheterizations.

## Symptoms of Urinary Tract Infection (UTIs):

Children with *spina bifida* may develop symptoms of urinary tract infections. UTIs can be life threatening if left untreated. Symptoms and signs may include:

- Fever
- Abnormal wetting
- Irritability
- Cloudy, smelly urine
- Mid-back pain or pain during urination
- Blood-tinged urine

Most individuals living with *spina bifida* will require catheterizations for their entire life. However, with proper instruction and support many children will learn to do the procedure by themselves and as part of their daily routine. Some children may begin to catheterize themselves as early as kindergarten.

Parents are encouraged to provide their child with opportunities to practice the procedure as often as possible. Practicing on a doll can be a great teaching aid. Ask your *spina bifida* clinic about specialized instructions and supports that are available to help with practice.

## Urological Testing

The following urological tests may be ordered by a physician to examine your child's bladder function.

### Renal (Kidney) Ultrasound (U/S)

- Shows the size and shape of the kidneys and is used to check for *hydronephrosis* and kidney growth.

### Voiding Cystourethrogram (VCUG)

- X-ray taken after a special dye is instilled into the bladder through a *catheter*.
- Shows the shape, size and general appearance of the bladder and is used to check for *reflux*.

### Urodynamics (UDS)

- Pressure test of the bladder taken after water is instilled into the bladder through a *catheter*.
- Shows how the bladder fills, holds and empties urine as well as measures the urethral *sphincter muscle tone* which helps in determining urinary *continence* potential.
- A small *catheter* is also placed in the rectum to measure rectal tone.
- This test is most accurate when the bowel is empty and there is no bladder infection.

### Renal scan

- X-ray scan of the kidneys taken after a special dye is injected into the arm or leg through a tiny needle.
- Shows how well the kidneys are functioning.

## Cystoscopy

A scope that is inserted into the *urethra*, which allows a look at the inside of the bladder and the urethra using a thin, lighted instrument. Instruments can also be used to remove tissue samples and collect urine. Small bladder stones and some small growths can be removed using this scope. This procedure can also be used to find the cause of symptoms such as blood in urine, painful urination, urinary incontinence, urinary tract infections, and blockages like kidney stones.



## Section F:

# Understanding Bowel Function (Digestive System)

The bowel is the last section of the digestive system. Bowel function is controlled by the nerves that are located in the bottom section of the *spinal cord*. In children with *spina bifida*, bowel function is almost always affected.

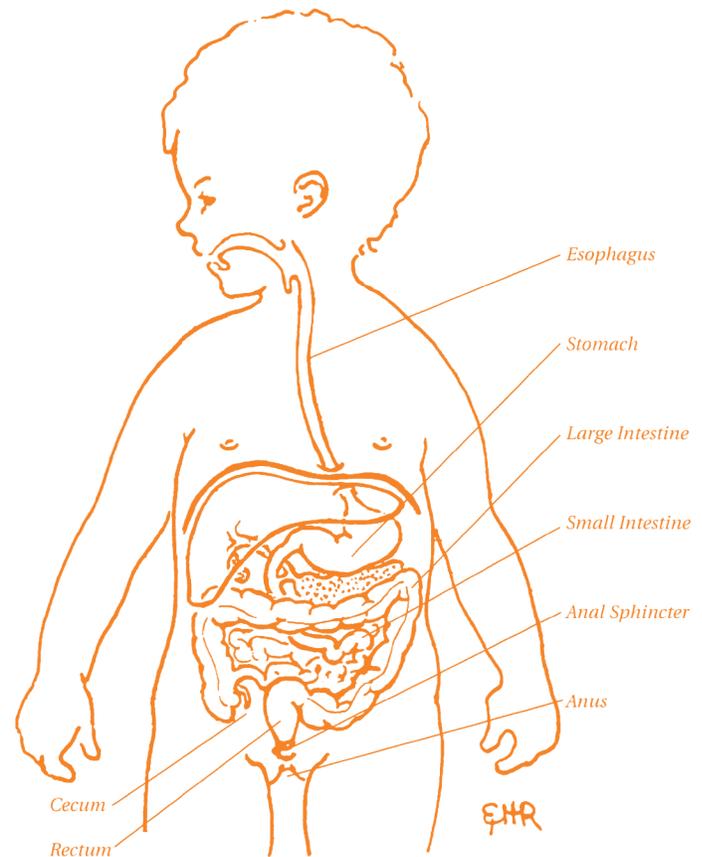
The digestive system (which is made up of the mouth, stomach, small intestine and large intestine) digests the food we eat, absorbs the nutrients needed by the body, and eliminates the waste in the form of *stool*. As the waste moves through the large intestine, water is absorbed into the body and the waste (*stool* or feces) becomes formed and solid.

When the last segment of the bowel (rectum) is full it sends messages through the *nerves* of the *spinal cord* to the brain. The brain responds by sending messages back along the *spinal cord* to the bowel. These messages cause the bowel muscles to tighten (contract) while the *anal sphincter* muscles relax, opening the *sphincter* causing *stool* to empty out. This process is called a *bowel movement*.

### How Does Spina Bifida Affect Bowel Function?

The amount of bowel muscle control and sensation in each individual varies greatly depending on the level of the *lesion*. When the muscles of the bowel are weak, the waste material moves more slowly through the bowel and more water is absorbed by the body. The longer stool stays in the bowel, the harder and dryer the stool becomes. This is called constipation.

The *anal sphincter* muscles are often weak which causes bowel accidents. This is called *fecal incontinence*. Due to decreased sensation due to nerve damage, it may not be possible to “feel” the need to have a *bowel movement*. This may also result in bowel accidents.



DIGESTIVE SYSTEM

### What Can Be Done to Manage Bowel Function?

It is important to make sure your child's stool stays soft to prevent constipation. Most infants have several bowel movements per day but infants who are breast-fed tend to have softer and more frequent stools than bottle-fed infants.

It is important to work on a bowel routine early on, depending on your child's individual level of readiness.

Signs of readiness by your child to begin a bowel routine include:

- Asking about the potty or toilet
- Knowing what the toilet is for

- Showing willingness to sit on the toilet or potty for 5-10 minutes.

There are special considerations for toilet training a child with bowel *incontinence* such as establishing a regular, timed bowel emptying routine. It is also important to recognize that it will take extra time to establish a bowel routine for a child with *spina bifida* and that the training process may not work in the usual, expected way.

As part of the toilet training process, it's important to teach your child about personal hygiene and the need for privacy.

Any attempt by your child to use the toilet should be praised and never punish a child for being unable to pass *stool*.

When toilet training, the child should be positioned comfortably on the toilet so that he/she feels secure. Both feet should rest firmly on the floor or on a step-stool and knees should be slightly higher than the hips. An inexpensive child's toilet seat can provide greater stability during toileting.

If bowel movements cannot be regulated with diet, fluids and toileting alone, it may be necessary to use one or more of the following techniques, on a regular basis, to help the bowel empty completely at a predictable time:

- A diet high in fibre and lots of water intake
- Medications (e.g. laxatives, softeners, bulk formers)
- Suppositories - capsule shaped medication that is inserted into the rectum to stimulate a bowel movement
- Digital stimulation - inserting a gloved finger into the anus to stimulate a bowel movement
- Manual disimpaction - using a gloved finger to remove the *stool* from the rectum
- *Cecostomy* – a procedure where a thin tube is surgically inserted through the right side of

the abdomen and into the bowel by a doctor. The tube remains in place, enema fluid is administered through the tube every two days and all *stool* is flushed out of the bowel through the anus while sitting on the toilet.

### Why Is It Important to Avoid Constipation?

A successful bowel *continence* routine involves regular emptying of the bowel and freedom from accidents. Keeping the stool soft is the first step in developing a successful routine. If the stool is constipated it is difficult to get the bowel to empty regularly and effectively. When *constipation* occurs, the *stool* may “back-up” in the bowel. Once this happens, it is more difficult to develop a successful bowel routine.

Constipation can cause the following to occur:

- Incomplete emptying of the bowel
- Bowel blockage (*impaction*)
- Bowel incontinence
- Decreased appetite
- *Shunt* blockage (see section C)
- Further weakening of the bowel muscles due to over stretching
- Urinary incontinence and bladder infections – due to pressure on the bladder from the full bowel.

Symptoms of constipation may include:

- Bowel movements that do not seem frequent enough
- Frequent small, hard “rabbit-like” stools
- Hard, round balls of stool
- Difficulty pushing stool out
- Frequent, watery *stools*

## What Should I Do if Symptoms of Constipation Occur?

For infants, offer frequent drinks of sterilized water between regular feeds. There should be no need to sweeten the water. If needed, fibre can be added to the diet. The following strategies can be used to add fibre to the diet of infants under six months of age:

- Give the infant a bottle of 1 oz of prune puree diluted with 2 oz of sterilized water.
- At three months of age, gradually introduce vegetables and prune puree.
- pureed vegetables or fruit.

As your child gets older, the following strategies may be applied:

- Serve a diet that is high in fibre and fluids (with water is best) to prevent *constipation* and help keep stools soft and formed. Beginning this dietary habit early in life will increase the chance of it being accepted by your child.
- Choose breads and cereals made of whole wheat or bran, and fruits and vegetables as they are high in fibre. Some fruits and vegetable have more fibre than others; therefore, eating a variety of foods is the best way to ensure a balanced high fibre diet.
- Add raw bran to baked foods, cereals, casseroles, stews, sauces, meat loaves, and patties for an added fibre boost.
- Provide adequate water to accompany a high fibre diet. **Fibre without water can actually increase *constipation*. For more information about water intake, speak to your health care professional in the spina bifida service.**

- If your child develops severe *constipation* (no *bowel movement* for three to four days and your child is uncomfortable), or your child is vomiting or not eating, seek help from your nurse or doctor immediately.
- If eating a high fibre diet is new, add fibre slowly to help prevent gas, cramping and diarrhea.



## Section G:

# Muscles and Bones (The Musculo-Skeletal System)

The musculo-skeletal system includes the bones, joints, ligaments and muscles of the body. Bones give a framework to the body while muscles hold the bones in place and produce movement at the joints. Ligaments give stability to the framework and hold the bones together.

### Bones

#### Spinal Column

The *spinal column* is made up of 33 *vertebrae* which protect the *spinal cord*. The diagram below shows the bones and their names.

There are five parts to the *spinal column*:

- 7 cervical *vertebrae* (neck)
- 12 *thoracic vertebrae* (mid back)
- 5 *lumbar vertebrae* (low back)
- 5 *sacral vertebrae* (joined together to form the base of the spine)
- *Coccyx* or tail bone (made up of 4 bones joined together).

#### Pelvis

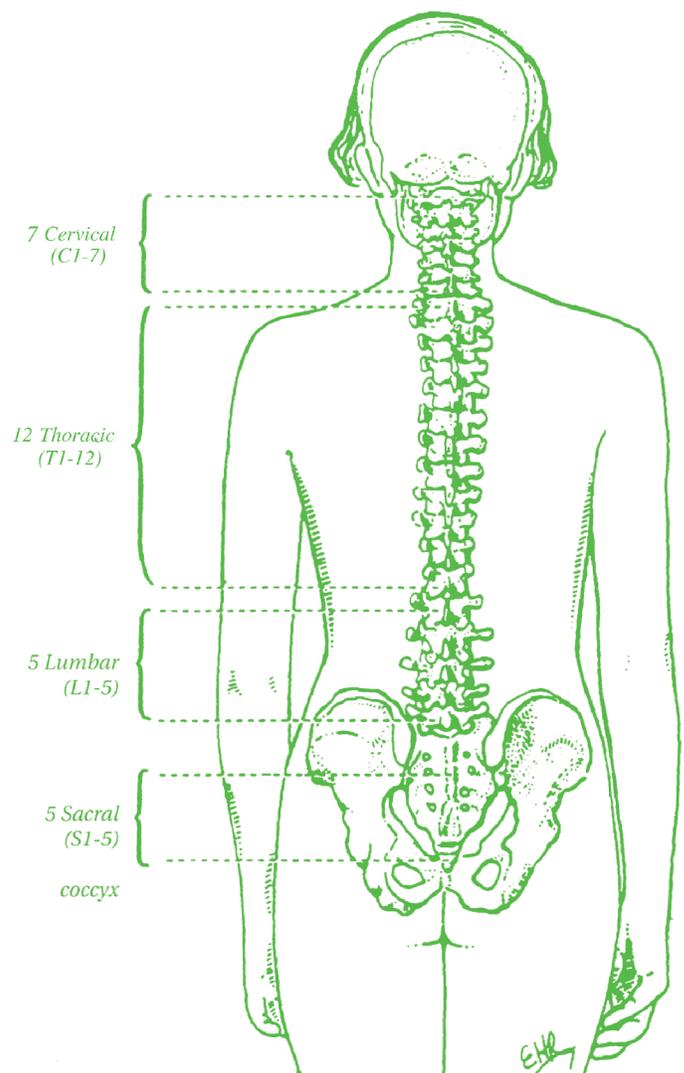
The pelvis is a basin-like structure made up of the *sacrum*, *coccyx* and hip bones. Hip bones sit inside a socket called the *acetabulum* (pronounced ass-e-tab-u-lum). The bladder, female reproductive organs and part of the bowel rest inside the pelvis and are protected by it.

#### Femur (Hip Bones)

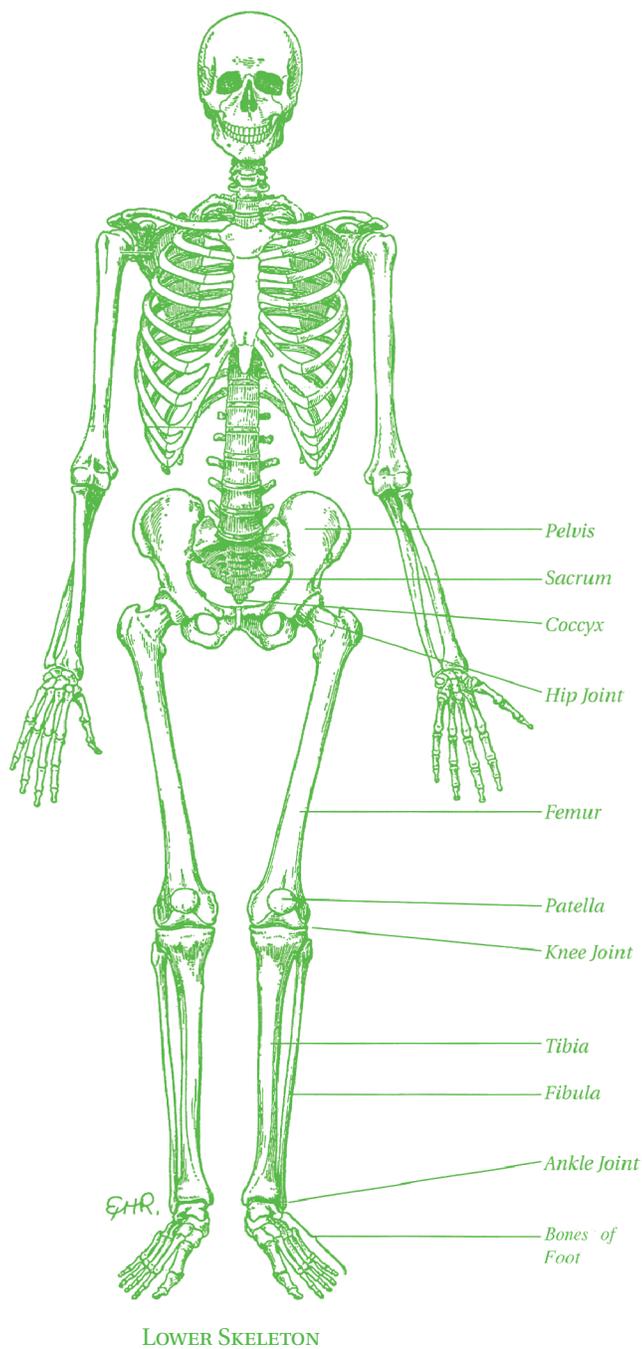
The femur is the longest bone in the body. The top or “head” rests in the *acetabulum*, (located at the side of the pelvis) forming the hip joint.

#### Tibia & Fibula (Lower Leg Bones)

The *tibia* is the strong shin bone while the *fibula* is the thin bone beside the *tibia*. The lower end of the *tibia* and *fibula* is flared out and called the *malleolus* (pronounced mal-e-o-lus).



SPINAL COLUMN



## Foot

The heel bone is called the *calcaneus* (pronounced cal-cane-e-us).

## Joints

The point at which two bones meet is called a joint. Joints are held together by ligaments and muscles and movement is produced at the joint by muscles. Spina bifida can affect the three joints described below.

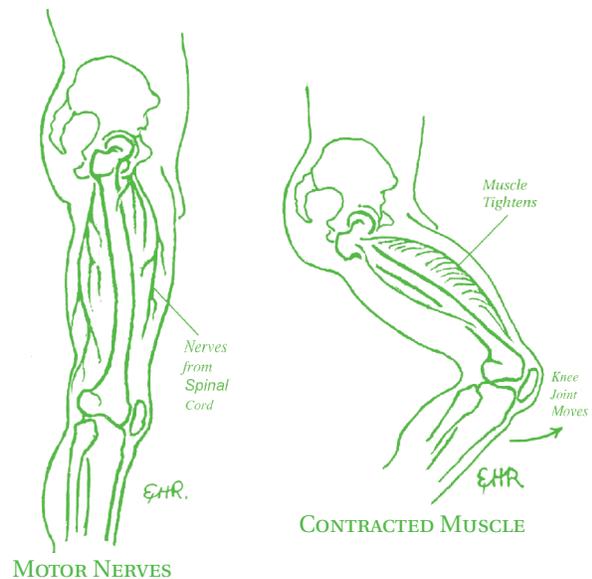
**Hip joint**—head of the *femur* and the *acetabulum* form the hip joint

**Knee joint**—top of the *tibia* and the bottom of the *femur* form the knee joint

**Ankle joint**—bottom of the *tibia* and the bottom of the *fibula* meet with the top part of the foot bones to form the ankle joint.

## How Do Muscles Move the Joints?

Muscles are attached to the bones. The brain sends messages through *nerves* along the *spinal cord* to muscles causing them to contract (tighten). When a muscle contracts it causes movement at the joint.

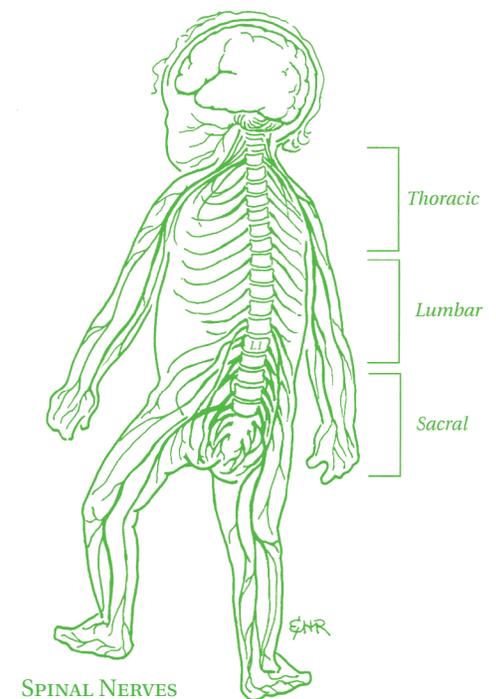


## Nerves

### How Do Nerves Work?

Messages from the brain travel along *nerves* through the *spinal cord* to a specific area of the body. For example, when a message reaches a hand, movement occurs or we may feel that something is hot or cold. The image explains the nerves and what they are called.

Spinal Nerves:	Area of the spinal cord where the nerves come from:	Spinal nerves carry messages to and from the muscle in the:
Thoracic nerves T10 - T12	The upper back	Chest, back and stomach
Upper lumbar nerves L1 - L3	The mid back	Hips and front of thighs
Low lumbar nerves L4 - L5	The lower back	Knee and front of lower leg
Sacral nerves (S1 – S3) S1 - S3	The lowest part of the spinal cord	Ankles, feet, calves, buttocks, bladder and bowel



### How Does Spina Bifida Affect Leg Muscles?

For individuals with *spina bifida*, damaged *nerves* may be unable to control the muscles properly. The position of the *lesion* on the back determines which muscles in the trunk and legs work. As a general rule, the lower the *lesion*, the more likely the muscles in the legs will work.

If the nerve leading to a particular muscle exits the *spinal cord* at or below the level of the *lesion*, there are several ways that muscles may be affected:

- The muscle does not function and therefore the joint is loose.
- The muscle functions, but is weak.
- There may be reflex activity (the muscle works only at times when it is stimulated (i.e., knee jerk, which is an uncontrolled movement)).

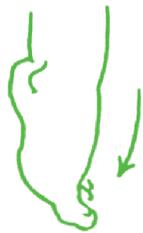
Muscles that respond to *nerves* that exit above the *lesion* will usually not be affected and there will be normal muscle activity.

### Symptoms of Muscle Conditions May Include:

- **Weakness:** When some of the muscles of the legs work and some don't work, the leg movement will be weak.
- **Paralysis:** If the *nerves* and muscles in the legs do not work, there will be no movement or feeling in the legs.
- **Contracture:** The muscle on one side of a joint may pull strongly while the other side pulls weakly or not at all. A *contracture* occurs when the strong muscles cannot be stretched back to the normal position and the joint cannot be straightened. This can occur at any joint. See the following section for information about how to help your child stay flexible.

### Examples of Contractures or Muscle Imbalances:

1) Feet:



EQUINUS



CALCANEUS



VARUS  
(FOOT TURNS IN)



VALGUS  
(FOOT TURNS OUT)

2) Knees:

- Knee will not straighten completely
- Knee will not bend fully

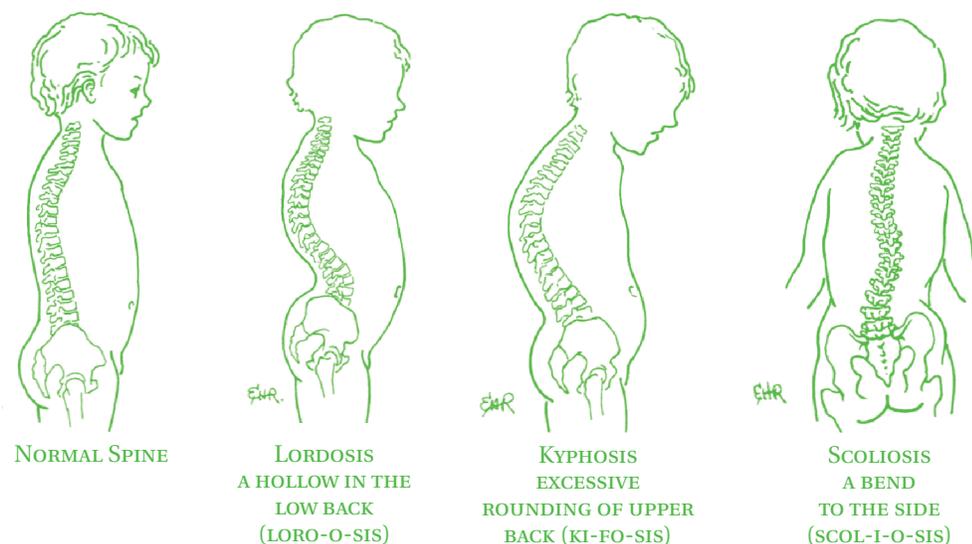
3) Hips:

- Muscles on the front of the hip may be stronger than on the back of the hip so that the leg will not rest touching the bed when you lie flat.
- Muscles on the inside of the hip may be stronger than the muscles on the outside of the hip so that it will be hard to spread the legs apart.

It is important to minimize contractures since they can interfere with standing, walking, sitting and *catheterization* as your child grows.

#### 4) Spinal curve:

Any muscle imbalance around the spine affects the position of the *vertebrae* and can produce an abnormal spinal curve. Such a curve may make it difficult for your child to sit or stand comfortably as he grows older. There are three types of abnormal spinal curves, described below.



### How Can I Help My Child Move and Stay Flexible?

The *physiotherapist* and *orthopaedic surgeon* will first assess your child, and then provide you with suggestions for helping your child to move and stay flexible. The first assessment will take place in hospital shortly after your child's birth. Your child should continue to be assessed at regular intervals and as your child grows, the spine, hips, knees and feet will be checked during appointments.

Your *physiotherapist* may provide you with stretching exercises that you can do with your child at home. Make this into a regular routine with your child. Your child may also be provided with splints or braces to hold his feet or hips in a good position.

### Club Feet

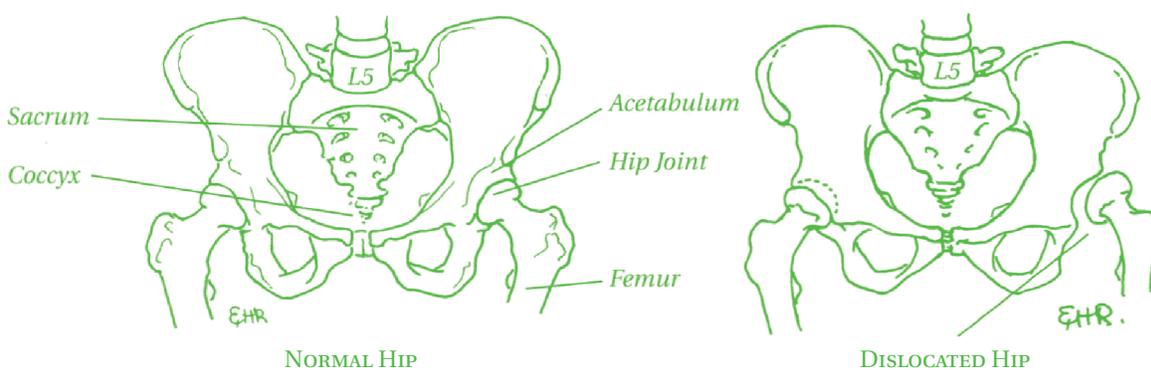
Some children with *spina bifida* are born with *club feet*, which cause the child's feet to point down and inwards. An *orthopaedic surgeon* or *physiotherapist* may put casts on your baby's feet to correct or partially correct their position. Sometimes surgery is required to correct the foot position. It is important to make sure that the feet are in a good position before your child begins to stand and walk.

#### CLUB FOOT



## Dislocated Hip

Hip dislocation occurs when the head of the *femur* or thigh bone is pulled out of its socket (*acetabulum*). Dislocation can occur if the muscles on the inside of the thigh are too tight and pull the *femur* out of the socket. It can also happen if the socket is too shallow. Your *orthopaedic surgeon* may place your child in a special harness to hold his legs apart to allow the hip joint to form.



## Walking

Many children with *spina bifida* can stand and walk to some extent. Your child's ability to walk is dependent on how well the muscles in the legs are working.

Level of spina bifida	Walking Ability
S2 - S4	<ul style="list-style-type: none"> <li>• Usually walk</li> <li>• May need shoe inserts</li> </ul>
L5 - S1	<ul style="list-style-type: none"> <li>• Usually walk with ankle foot orthoses (AFOs) or short ankle braces</li> <li>• May use crutches</li> </ul>
L4	<ul style="list-style-type: none"> <li>• Can usually walk with AFOs or knee ankle foot orthoses (KAFOs) or braces which go above the knee</li> <li>• Often uses wheelchairs for long distances as they become teens and adults but use braces some of the time to walk short distances</li> </ul>
L2 - L3	<ul style="list-style-type: none"> <li>• Usually need to use a wheelchair for long distances</li> <li>• When younger may walk with braces which go above knee and/or hip</li> </ul>
T12 - L1	<ul style="list-style-type: none"> <li>• Usually requires a wheelchair</li> <li>• When young, may walk at home or for exercise with braces which go above the hip.</li> </ul>

## What Will Happen as My Child Grows?

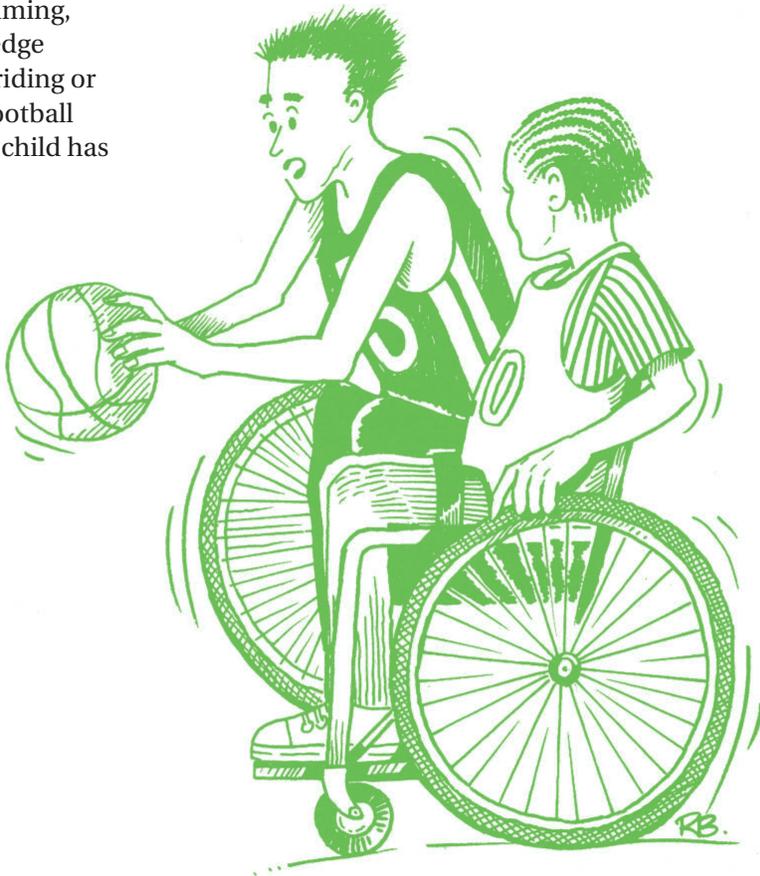
The following chart outlines typical milestones for children with and without *spina bifida*.

AGE	TYPICAL MILESTONES	CHILD WITH SPINA BIFIDA
1-2 Months	Children hold their head up on their own	If a child has difficulty holding up his head, the <i>physiotherapist</i> will give exercises to help strengthen neck muscles.
6-7 Months	Children usually sit on their own	If a child with <i>spina bifida</i> cannot sit, he will be provided with a bucket seat or a corner seat and table (see the following pages for diagrams) to allow him/her to learn to sit. The seat will free up both hands to provide an opportunity to develop hand skills for play as well as provide an opportunity to work on improving sitting balance.
8-10 Months	Children usually crawl around the house and explore their environment	Children with <i>spina bifida</i> may need a <i>caster cart</i> to help them move around the house.
12-18 Months	Children usually stand and walk	Children with <i>spina bifida</i> may use a standing <i>brace</i> to help them stand and move around the house, or may require braces for their feet.
18 Months	Children usually run and jump	If appropriate, your child may progress to using a short ankle brace or may need crutches and a walker.
3 Years	Children usually ride a tricycle and walk up and down stairs	Children with <i>spina bifida</i> may continue to use their <i>caster cart</i> or may use a wheelchair. Children with <i>spina bifida</i> may ride an adapted tricycle and/or use a wheelchair.

## Can My Child Participate in Sports and Other Physical Activities?

Children with *spina bifida* can participate in many sports and leisure activities and are encouraged to do so as part of an active, healthy and social lifestyle. Children who are actively involved in sports or other activities (such as music or theatre) tend to have higher self-esteem and a more positive outlook on life. In addition, physical activities help kids to control their weight more easily. Participating in activities also provides opportunities for social interactions with other children and adults.

Speak to your health care professional in the *spina bifida* service about the types of sports and activities that your child may enjoy. Some activities may be swimming, wheelchair basketball, baseball, sledge hockey, track and field, horseback riding or canoeing. Contact sports such as football and boxing are discouraged if your child has a *shunt* of any kind.



## Section H: Special Equipment and Mobility Aids

Assistive devices or equipment can assist your child in reaching developmental milestones that are appropriate to his or her specific age. The following lists some of the types of assistive devices that are available for children with *spina bifida*.

### Bucket Seat

This specially molded plastic seat provides your child with support to allow him/her to sit, play and develop hand skills. The *bucket seat* can be used in the high chair, stroller, caster cart or on the floor. It is important to have adequate trunk support so both hands are free for play and one hand is not required for support. This seat provides more support than the corner seat and table.



BUCKET SEAT

### Corner Seat and Table

The corner seat and table provide support for sitting. It allows your child to sit without using his/her hands for balance, enabling play and development of hand skills. The corner seat and table offer less support than a bucket seat.



CORNER SEAT AND TABLE

### Caster Cart

A *caster cart* is a three-wheeled cart that allows your child to move around inside the house or outdoors without harming his skin. This prevents skin breakdown on the legs caused by dragging the legs over rough surfaces. The bucket seat can be used in the caster cart if more trunk support is required.



CASTER CART

### Nursery Table and Chair

This large wooden table has a cutout on one side and a chair that is custom made for the exact size of your child. They can be used once your child has outgrown the corner seat and table or bucket seat to continue the development of hand skills while support is provided for the trunk.



NURSERY TABLE AND CHAIR

## Wheelchair

Around two to three years of age, children will typically want to be able to get around on their own to feel more grown up. A wheelchair will provide independence and can be used part of the day for outings or can be used all day. Your child will not be as tired when using a wheelchair compared with using braces and crutches.



WHEELCHAIR

## Bath Seats

Infant bath seats are helpful for bathing your infant safely. The *bucket seat* can also be used as a bath seat for infants and young children. For privacy, special bath or shower chairs can be ordered for older children and adults to provide support for bathing and showering. They can be purchased through a medical supply company. Your *physiotherapist* or *occupational therapist* can suggest the most appropriate seat for your child.



BATH SEAT

## Body Jackets

If your child has scoliosis, they may be prescribed a body jacket to help maintain a straight back by providing support for the trunk. They are worn under the clothing and are used all day while in a wheelchair, *parapodium* or other equipment.



BODY JACKET

## Walker/Rollator/Crutches/Canes

Some children may need walkers, rollators, crutches and canes to help them walk. These children may have weak leg muscles or tight joints. Walkers and canes provide extra support for stability and balance.



WALKER / ROLLATOR / CRUTCHES / CANES

## Transfer Board

This simple board can be used to make transferring easier from a wheelchair to bed, for example.



TRANSFER BOARD

## Braces/Splints

A *brace*, called an *orthosis*, can help your child to stand, move or walk. There are a variety of orthoses available, but each child needs to be assessed for the one most appropriate for him or her. When any of the braces become too tight and/or leave marks on the skin, your *orthotist* needs to check the fit of the braces.

Some common types of *braces* are:

### Knee Ankle Foot Orthosis (KAFO)

*KAFOs* support the knee and ankle and allow your child to stand and walk with or without crutches or a walker.

Socks must be worn under the braces to protect the skin. Regular clothing can be worn over the braces.



KNEE ANKLE FOOT ORTHOSIS: KAFO



ANKLE FOOT ORTHOSIS: AFO

### Ankle Foot Orthosis (AFO)

*AFOs* are splints which hold the feet straight for standing and walking with and without walkers or crutches.

To prevent developing any red or darkened areas on the skin, *AFOs* should be worn over wrinkle-free socks that have been turned inside out.



STANDING BRACE

### Standing brace

A standing *brace* supports your child's body and legs in a standing position and allows walking when using a walker or rollator. Some children learn to "swivel", or move forward by using a side-to-side motion without the use of a walker or rollator.

*AFOs* may or may not be used while in the standing *brace*.

### RGO (Reciprocating Gait Orthosis)

An *RGO* may be used when the standing *brace* is outgrown. The *RGO* allows your child to take steps by placing one foot in front of the other. A walker or crutches must always be used to maintain balance.



RGO  
(RECIPROCATING GAIT ORTHOSIS)

# Section I:

## Skin and Sensation

### Skin

Skin is the largest organ of the body, providing a boundary between the body and its environment. The skin's main function is protection; it keeps out anything that would harm the body such as germs or infection. Skin prevents the loss of important body substances like water. Sweat glands and blood vessels in the skin help regulate body temperature.



### Skin Sensation

*Sensory nerve endings* in the skin respond to pain, touch, heat and cold. They warn us to protect ourselves from injury. Messages, called impulses, go from these nerve endings to the *spinal cord* and the brain. For example, when a person steps on a tack, these impulses are felt as pain. At the same time, a reflex action attempts to move the foot away from the tack.

### How Does Spina Bifida Affect Sensation?

When *spina bifida* occurs, some *nerves* do not develop properly. This causes little or no feeling in some areas of the skin. The level of sensation loss is related to the level of lesion. Without sensation, your child will not feel heat, cold, pain, sharp objects, pressure, scrapes or excessive

moisture. Without the warning of discomfort or pain, your child is unaware of damage to the skin. A sore may develop quite quickly and can worsen rapidly if not attended to properly. Due to poor circulation and fragile skin in persons with *spina bifida*, healing occurs slowly.

### How Can I Protect My Child's Skin?

Teach the following skills to your child, beginning at an early age, so he/she will learn the importance of taking care of personal hygiene.

- Check skin regularly, morning and night. Teach your child how to use a hand held mirror to check those areas not easily seen with his/her eyes.
- Keep skin clean and dry. Moisture from urine, stool or sweat can damage the skin if left there too long.
- Eat nutritious foods and drink plenty of fluids to keep the body and skin healthy.



## Special Clothing Considerations

- Feet and legs should be covered when walking, crawling and swimming to prevent scrapes from rugs, rough ground, gravel, sidewalk cement, patio stones and pool sides. Socks, tights or water shoes can help protect your child's skin.
- Wear socks inside out to prevent the seam from causing pressure, which can result in sores.
- Purchase shoes large enough to prevent pressure on the top of the foot (with deep toe box), and make sure the seam at the heel does not rub and cause blisters.
- Have splints checked by your *orthotist* if they are causing marks which take longer than 30 minutes to disappear.

## Special Positioning Considerations

Your child should always sit on a well padded seat. For example, use wheelchair seat and back cushions, a cushion pad in the bathtub, a cushion (foam, inflatable or gel) for the school chair, and a padded bicycle seat. Wheelchair cushions can be removed and used when sitting on the floor or in the car.

When sitting in a wheelchair, your child should shift his body weight every hour by pushing up, leaning forward, or leaning side-to-side. It is important to change positions every few hours when lying in bed. Watch bony areas on legs and back for any sign of pressure or friction, such as red or discoloured skin.

Any red or discolored area of the skin that does not disappear in 30 minutes needs special attention. Call your *spina bifida* health care professional and do the following if you notice any of these changes to the buttocks, feet or under an area covered by a splint:

- Feet: Avoid all pressure to the foot area by leaving splints and shoes off.
- Buttocks: Avoid sitting if you notice redness or discoloration on the buttocks.
- See your *orthotist* if the redness or discoloration is caused by braces. If the irritated area appears to be caused by the wheelchair's cushion or backrest, see your wheelchair vendor or therapist for adjustments.

Consult your health care professional if the redness or discoloration persists.

If you notice an open sore or blister:

- Try to determine the cause. Review the strategies and considerations outlined above.
- Avoid all pressure to the area. If the irritated area is on the buttocks, take frequent sitting breaks.
- Try to prevent blisters from opening up as open sores can easily become infected.
- Soak open sores with warm salt water (1/2 tsp. salt in 1 cup of water) twice daily for 5 minutes and cover with a latex-free bandage to keep the area clean.
- See your health care professional if the sore persists for longer than two weeks, gets larger or deeper, if you think it may be infected, or if you're at all unsure about the sore or have questions.



## Section J: Hand Skills



### How Does Spina Bifida Affect Hand Skills?

*Spina bifida* may affect your child's hand skills. Your child may experience stiffness, weakness or lack of coordination in the arms, interfering with arm and hand function.

Children with *spina bifida* may experience the following:

- Arm and hand weakness.
- Increased stiffness or tone in arms and hands.
- Difficulty with eye-hand coordination.
- Difficulty with reach and grasp.
- Slow to develop hand preference.
- May have difficulty distinguishing left from right.



### How Can I Help My Child Develop Hand Skills?

All hand skills will develop more easily when you provide a good, supportive seat and a table or tray, to allow both hands to be free for play. Help your child develop their hand skills by doing the following activities:

- Play games which require handling small objects within the hand (e.g. hiding and handling small blocks).
- Give your child objects of different sizes, shapes, weights, and textures (e.g. clay, sand, water and finger-painting).
- Encourage eye-hand coordination by giving your child the opportunity to build block towers, stringing beads, doing puzzles, and practice songs with hand actions (e.g. "The Itsy Bitsy Spider").
- Encourage reaching for objects—out in front, side-to-side, and above the shoulder.
- Encourage your child to hold a crayon, pencil and pen. If your child is left-handed, make sure he/she has left-handed scissors.
- Provide your child with a soft-lead (2B) pencil, a pencil gripper, and a ball pen to make the task of handwriting easier.
- Encourage your child to use a computer to increase his/her skill at keyboarding, which will make homework easier.
- If your child is having difficulty with writing at school, a writing aid may be required.

## Section K: Special Considerations

### Fractures

Bones become strong through standing and weight bearing. Bones which are not used become less thick, are fragile and can *fracture* (break) more easily. Children with *spina bifida* may be unaware that they have fractured a leg due to lack of feeling. A break may be noticed only by swelling, redness, or the area may be warm to touch. Any of these signs should be reported to a health care professional.

### Seizures

Seizures may occur in children with *spina bifida* and *hydrocephalus*. Seizures may be as mild as staring spells or twitching of arms and legs, or may be as severe as uncontrolled thrashing of arms and legs with a loss of consciousness. All suspected seizures should be reported to your health professional. Medications (anti-convulsants) may be needed to control seizures. Seizures may occur when a *shunt* is not functioning properly.

If you think your child is having a severe type of *seizure* you should seek immediate medical attention and call 911.

### Eyes

Children with *spina bifida* and *hydrocephalus* may be more prone to eye problems. All children with *spina bifida* should be seen by an *ophthalmologist* (pronounced *off-thal-maol-o-jist*) (eye specialist). Children with *spina bifida* often have the following eye problems:

- *Strabismus* is characterized by the eye either turning in or turning out.
- *Nystagmus* is an involuntary, rapid, repeated movement of the eyeball in any direction.
- *Optic nerve atrophy* is damage to the *optic nerve* which can cause poor vision.

- The *ophthalmologist* may suggest glasses and/or surgery to correct these conditions.

### Hearing Sensitivity

Children with *spina bifida* and *hydrocephalus* may be very sensitive to loud noises. They may react by crying to such things as the vacuum cleaner, loud bells and fire alarms. Where possible, warn your child about anticipated loud noises and avoid unnecessary exposure to noises which cause them distress.

### Latex Allergy

*Latex* is natural rubber. A *latex allergy* is an acquired *hypersensitivity* to *latex*, a substance which is generally tolerated and considered to be harmless.

Individuals with *spina bifida* have an increased chance of developing an *allergy* to *latex*. Many individuals with *spina bifida* have been found to have this *allergy*. The risk of developing the *allergy* increases with repeated exposure to *latex*. Unfortunately, *latex* is used to make several items commonly found in the home, hospitals and most communities.

### Symptoms of a Latex Allergy May Include:

An allergic response to *latex* products could produce many familiar allergic symptoms, including:

- Watery eyes
- Sneezing
- Wheezing
- Runny nose
- Respiratory distress or anaphylaxis in extreme cases
- Hives
- Swelling and itching on contact
- Rash

## How Can I Manage My Child's Latex Allergy?

It is important for all people who have *spina bifida* to avoid *latex* products when possible. Avoiding *latex* products will minimize the risk of developing the *allergy*. Some examples may include: pacifiers, feeding nipples, erasers, craft supplies, make-up, Halloween masks, adhesives, elastic fabric (waistbands on underwear and diapers), cleaning gloves, balloons, rubber balls, rubber mats, carpet backing, condoms, medical and surgical gloves, tape and bandages.

If your child develops a latex allergy, it is important to review the following tips:

- Avoid *latex* products, especially those which are *latex*-dipped and those entering the body (examples: tropical fruits, rubber pacifiers, feeding nipples, rubber catheters and enema devices, some first aid tapes and bandages, *latex* surgical gloves, balloons and condoms). It is your right to ask if products used around your child in community settings are latex-free.
- Substitute *latex* products with those made of vinyl or silicone whenever possible.
- You may cover some products with cloth to avoid contact with skin.
- Have your child wear a Medic Alert bracelet or necklace to identify the *latex allergy*.
- Talk to your doctor or nurse about any reactions. It may be necessary to carry an *epinephrine* kit (called an Epi Pen) which is a prepared injection of *epinephrine* to be used in serious allergic reactions. Once used, it is important to seek immediate medical attention as the effect of the drug may only last 15-20 minutes.

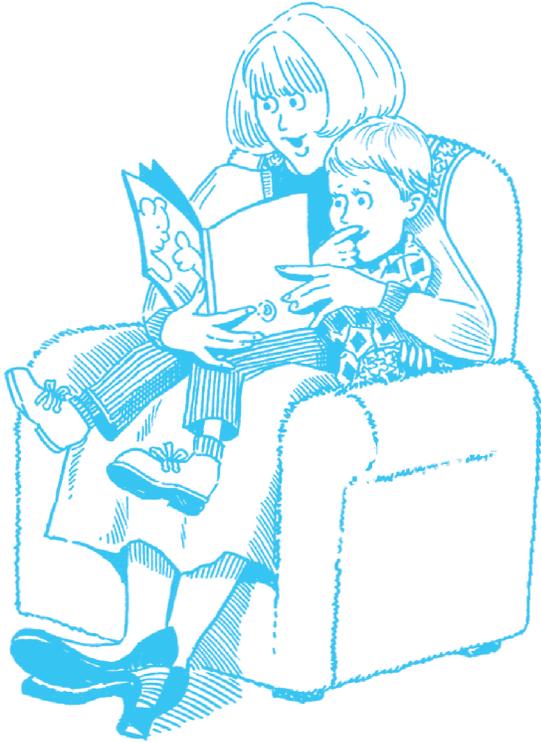
## Complementary Health Care

A growing interest in alternatives to Western or traditional medical practices is changing peoples' views and practices related to health care. Specific therapies that increase circulation may have added benefit for many people with *spina bifida*. They include: therapeutic massage, Shiatsu (application of pressure to specific points on the body), reflexology (based on reflexes in the feet) and acupuncture (penetration with needles). Other health care practices like nutritional counselling, homeopathic medicines (which stimulates the body to cure conditions), and herbology (therapy with herbal remedies) can also compliment current medical practices for people with *spina bifida*. It is important to share any complimentary health care treatment you undergo with your health care professional.

Many individuals can claim to offer natural therapeutics without the proper training or credentials. Contact only qualified professionals for complimentary health care treatments.



## Section L: Language Development



### Will Spina Bifida Affect My Child's Language Skills?

Children born with *spina bifida* and *hydrocephalus* may experience difficulty in language development. Language difficulties can emerge at different times with some children affected during infancy, preschool or school age years. If you have concerns about your child's language development, talk to a *speech-language pathologist*.

### What Areas of Language May be Affected?

Difficulties in language development can affect the use and understanding of language. Early developing areas (infancy and preschool years) that can be affected are learning to speak, using sentences, asking questions, telling stories, remembering details and problem solving.

Later developing areas (during school age years) that can be affected are:

- Auditory comprehension – understanding what is heard
- Reading comprehension – understanding what is read
- Word finding – retrieving words from memory
- Abstract thinking – understanding and connecting ideas
- Verbal reasoning – using language to work through a problem

### Under the Age of Five Years:

What to watch for:

- Is your child showing an interest in books?
- Does your child understand what you ask him/her to do? Do you need to explain things multiple times?
- Is your child naming people and objects or does he/she only use words like 'here', 'there', 'this' or 'that'?
- Is your child learning to solve problems?

Activities to try:

- Read to your child often, starting when they are born.
- Gain your child's attention before you speak or give instructions. Start by giving your child one instruction at a time.
- Talk about what you are doing and what your child is doing so as to enable your child to learn to associate the words with the objects, actions and feelings you are describing.
- Instead of giving your child what they want, encourage them to ask for it.

## School Age Years (from age six – onwards)

What to watch for:

- Is your child able to participate in conversations with adults and other children?
- Is your child able to read and understand written information (e.g. homework, books)?
- Is your child refusing or not completing his/her homework?
- Is it difficult to understand what your child is talking about?
- Is your child able to think of solutions to problems (e.g. your child cannot remember what homework he was assigned, what can he do to solve this problem?)

Activities to try:

- Gain your child's attention before giving instructions and ask him/her to repeat the instructions back to you.
- Encourage your child to ask questions if he/she doesn't understand or forgets information.
- When reading a story, talk about "Who?", "What?", "Where?", "When?" and "Why?" to help your child focus on relevant information.
- Brainstorm and discuss how to come up with solutions for problems.



## Section M: Understanding Learning

Many people with *spina bifida* and *hydrocephalus* have difficulties in specific areas of learning. Your child may or may not have difficulty with some types of learning. Some children may require educational support strategies to cope with aspects of learning that are difficult for them. It is important to recognize these needs early on in order to minimize frustration and avoid difficulties at school. Above all, your child will need your involvement and support, and that of his/her teachers. Every child is different, but the following are some common difficulties that may occur.

### What Aspects of Thinking and Learning Can be Affected?

#### Attention:

- Selective attention or the ability to focus on important information and ignore the parts that are not important for the task.
- Ability to keep attention focused on a task.
- Ability to shift attention (it might take your child longer to pull his/her focus away from what captured their attention and on to something new).

#### Language:

- Understanding of abstract language (that is, words or ideas that cannot be directly seen or experienced).
- Making connections in longer conversation and text.
- Going beyond what is clearly stated to understand ambiguity, read between the lines, and make inferences.
- Organizing what is said.

These difficulties may cause trouble with grasping concepts, following instructions, and reading comprehension. You may find that your

child can learn and remember facts, but has difficulty applying concepts or procedures to new problems.

#### Visual perceptual and spatial skills:

- Recognizing, making sense of, and remembering what is seen.
- Understanding and visualizing the positions of objects in space and in relation to each other.
- Eye-hand coordination.

These issues can cause difficulty with academic subjects that make use of visual-spatial materials (such as mathematics, geography), and trouble with written work.

#### Some types of memory:

- Working memory (holding information in short-term memory while using it to perform a task).
- Spontaneous recall (freely remembering information, without cues).
- Prospective memory (remembering to remember something in the future, like remembering to take your medication or go to an appointment).

Children who have these difficulties might have trouble remembering and following instructions, and remembering a sequence of steps in a procedure or routine.

#### Executive functioning:

- Planning and organization.
- Initiating tasks.
- Working independently.
- Completing assignments.
- Monitoring performance.
- Shifting between activities, or shifting to a new way of doing something.

Executive functioning difficulties can make it hard for your child to keep track of assignments, organize their belongings, organize their thoughts and information in written work, sequence information, think ahead and plan the steps needed to carry out a task.

### **Processing speed and motor speed**

Slower processing speed and motor functioning may cause your child to have difficulty with written work, note taking, and work completion in school.

## **Why Do These Challenges Occur?**

### **Processing difficulties result from:**

- Hydrocephalus and the effects it has on the brain
- Differences in early experiences from those of other children (e.g. physical play, social experiences). Frequent school absences, surgeries and seizures can all add to the challenge.

## **How Can I Help My Child?**

### **At home**

- Encourage and provide lots of opportunity for play that develops eye-hand skills (examples: puzzles, coloring, blocks, tracing and dot-to-dot games, beads, stickers).
- Talk with your child about what he/she is doing to promote learning of vocabulary and concepts.
- Help to develop language and reasoning skills by talking about objects and events in your child's life, how objects and words group together in categories, and how different ideas relate to each other.
- Begin by talking about concrete objects and events that are happening now,

which will be easier for your child to understand. Gradually begin to include ideas not immediately present in your child's experience.

- Help the development of problem solving skills by talking about situations as they arise and talking through how you solve the problem.
- Encourage age appropriate independence, social interaction and recreational activities; discuss situations and problems that occur during those activities and problem-solve together.

### **At school**

- Have a psychological assessment of your child's cognitive functioning done in your child's early primary years to identify areas of strength and learning difficulty.
- Communicate early with your child's school to discuss learning needs and determine the most appropriate programming and teaching strategies.
- Communicate regularly with the school and monitor your child's progress to make sure that programming remains appropriate as expectations change, and your child changes.
- Your child may need some special education support or strategies, and accommodations such as help with note taking, extra time for tests and assignments, assistance with organizing tasks. These may be documented in an individual education plan (IEP).
- Have your child's learning abilities and academic skills reassessed at transition points throughout your child's school career, such as before beginning the junior grades, middle school, secondary school, or towards the end of secondary school for future planning.

- Available resources include health care professionals in the *spina bifida* service at your child's rehabilitation centre, the Spina Bifida and Hydrocephalus Association of Ontario (SB&H), and the local school boards' Special Education Advisory Committee (SEAC).



## Section N: Independence



### Growing Up Ready

Young people and their families go through many changes as they grow up. Growing Up Ready resources were designed by Holland Bloorview to help children and youth with disabilities get ready for adult life.

**A Timetable for Growing Up**, which is a chart of activities to think about at different ages and stages, starting from birth.

**Skills for Growing Up Checklists** is a set of checklists for use with children approximately 7 years of age and older.

Growing Up Ready resources can be ordered free of charge for clients and families from Holland Bloorview Kids Rehabilitation Hospital.

### Throughout Infancy, Childhood and Adolescence

Depending on the individual and his/her abilities, independence can mean different things, including participating in one's own care with the assistance of others, or directing the care provided by others. Independence requires a large set of skills that need to develop gradually, and should be fostered beginning as early as infancy.

As parents, encourage your child to be independent as early as possible by encouraging participation in each activity to the extent of his/her ability. Many of the activities that you do with your child affect gross motor development, fine motor development, thinking, learning, and social development - all at the same time.



### Birth to 6 Months

During this period, encourage your baby to follow objects with his/her eyes. Attract your baby's attention with a colourful, noisy toy and have your baby follow it up/down and left/right.

- Encourage your baby to roll towards and grab hold of toys that are beyond his/her reach.
- Encourage your child's vocalization by mimicking the sounds he/she makes and by talking to him/her.
- Respond to what your baby does so he/she begins to learn that they have an influence over the environment.

### 7 to 12 Months

During this period, encourage sitting, with assistance if needed, to allow hands-free play with objects of different sizes, shapes and textures.

- Expand your infant's vocabulary by naming objects in their environment.
- Continue to imitate your infant's vocalization.
- Encourage your child to make choices by placing two toys within reach. Introduce a variety of toys and materials that your infant can use in different ways.

- Introduce interactive games that involve turn-taking, such as “peek-a-boo”, “pat-a-cake”, and rolling a ball.
- Encourage your infant to finger feed and hold a cup.
- Give plenty of opportunities for independent play time.

### 13 to 36 Months

During these months, encourage standing and mobility to enable your child to explore the environment.



- Teach your child to put on and remove their socks, pants and shirts. Teach the concepts: in/out, over/under, on top, behind, and large/small.
- Expand upon your child’s word use by demonstrating and modeling fuller and more complex language. Teach him/her to use words that help express their needs.
- Allow opportunities for interaction and play with other children, including other children with special needs. Begin to teach sharing and turn-taking. Allow choices and decision-making in daily activities.
- Show your child how to hold and use feeding utensils (i.e. cup, bowl, plate, spoon, fork and knife).
- Teach your child about *spina bifida* by talking during daily routines. Describe what’s going on during *catheterization*, for example.

### 3 to 5 Years

During these years, continue to encourage mobility and activities that expand your child’s environment and personal skills.

- Continue teaching and identifying vocabulary related to body parts and

his or her condition (e.g. *spina bifida*, *hydrocephalus*, *shunts*, bracing, and *latex allergy*).

- Continue to develop your child’s vocabulary necessary to express his/her feelings and needs in order to have control over their environment. For example, teach words like sad, angry, and hungry.
- Provide lots of opportunity for social experiences and interactive play. Introduce the idea of responsibility for personal routines and safety.
- Continue to teach your child about the equipment, supplies and procedures of *catheterization*. Allow your child to take part in this activity as much as possible.
- Learn to put on and take off braces.

### 6 to 10 Years

During these years, encourage your child to dress themselves, seek social opportunities, manage *braces*, and learn independent wheelchair skills (such as wheelies and managing curbs).

- Encourage the development of listening skills. Use a variety of words in everyday activities.
- Continue to teach and model abstract concepts such as same/different, left/right, more/less/equal, next to, and half.
- Provide opportunities for social and recreational activities (such as life skills programs offered at your children’s rehabilitation centre, local community centre, parks and recreation), and participation in sports groups (e.g. riding, swimming, adapted sports).
- Continue to encourage independent personal hygiene, *CIC* management and skin care while teaching when and how to ask for assistance.



- Promote an understanding of, and ability to talk about *spina bifida* and *hydrocephalus*.
- Talk to your health care professional in the spina bifida service about strategies and programs to help with your child's transition to puberty and early adolescence. See Growing Up Ready resources identified at the beginning of this section.

## 11 to 13 Years

During these years, continue to promote wheelchair skills in order to help your child achieve greater independence in the community.

- Allow for opportunities to increase upper extremity strength, endurance and fine motor *dexterity* with guidance from physical and occupational therapy.
- Provide opportunities to discuss sexual health.
- Provide opportunities for decision making (e.g.: picking chores, choosing friends, deciding what to wear, or take for lunch). See Growing Up Ready resources identified at the beginning of this section.
- Encourage your child to become an active listener and participant in problem solving. Brainstorm ways of dealing with the school bully or an embarrassing situation, for example.

- Expand opportunities for social and recreational skills while broadening your child's experiences with people, places and activities (e.g. overnight camp).
- Encourage your child to actively share responsibilities within the home, such as taking care of personal items, helping with meal preparation, and knowing personal safety. Continue to develop the concepts of time, measurement, money, and community awareness by encouraging active participation in activities such as following a recipe and clothes shopping.
- Encourage your child to practice telephone use (i.e. calling friends, taking messages).
- Talk to your child about substance use, such as alcohol and drugs, and discuss strategies for making healthy decisions.
- Talk to your health care professional in the Spina Bifida Service about strategies and programs to help with your child's transition to teen years. See Growing Up Ready resources identified at the beginning of this section.
- Encourage and support your child in actively participating in his or her own health care (i.e. ask questions during medical appointments).

## 14 to 16 Years

During these years, encourage your teen to become more independent outside of the house and gain familiarity with your community.

- Teach your adolescent how to maintain his/her wheelchair and how to identify brace fit.
- Teach your teen how to order and use accessible and public transportation when possible.
- Encourage your teen to develop problem solving, decision making and goal-setting skills.

- Encourage your teen to keep a personal contact list of friends, relatives, wheelchair vendor, and health care professionals.
- Encourage your child to keep an agenda to remember appointments and school tasks.
- Encourage your teen to go with you to the bank, open a personal account, learn how to access and manage their own personal banking (at a bank, ATM or online).



- Encourage your teen to develop practical life skills such as knowledge of traffic signs, meeting and making new friends, and money management.
- Encourage exploring life skills and social skills groups as well as overnight camp when possible and choosing activities that interest him/her.
- Talk to your child about substance use, such as alcohol and drugs, and discuss strategies for making healthy decisions.
- Talk to your health care professional in the spina bifida service about strategies and programs to help with your child's transition to young adulthood. See Growing Up Ready resources identified at the beginning of this section.

- Support your child in taking on an increasing role in his or her health and health care decisions (i.e. attending some medical appointments independently).

## 17 Years and Up

As your child approaches adulthood, it is important to promote independence in his/her own personal care, education, relationships and other areas.

- Encourage the use of public transportation and/or explore driver assessment or education classes.
- Encourage the young adult to make his/her own medical, dental, and transportation appointments whenever possible.
- Encourage and help the young adult to plan post secondary education and/or job training.
- Encourage independence in social relationships. Allow for privacy in the home.
- Provide opportunities for the young adult to earn and handle money and to become responsible for managing their own personal banking.
- Continue to encourage opportunities for participation in team sports, groups and camping.
- Talk to your child about substance use, such as alcohol and drugs, and discuss strategies for making healthy decisions.
- Encourage discussions about sexuality with close family member and professionals.
- Talk to your health care professional in the spina bifida service about strategies and programs to help with your child's transition to young adulthood. See Growing Up Ready resources identified at the beginning of this section.

## Section O: Your Child's Self-Esteem

Self-esteem reflects an individual's overall evaluation or appraisal of his/her own worth. The development of self-esteem begins at the first encounter with parents and events outside the womb and continues during infancy and throughout life. Because young people with *spina bifida* may have different experiences and capabilities than their peers, they might see themselves as being different. As a result, self-esteem may be an area in which they might need some special support.

The following suggestions are a few of the many ways you can help to promote your child's self-esteem. You may find other ways to encourage self-esteem that best suit you and your child, as you know your child best.



### How Can I Help My Child?

- Listen to what your child has to say, and acknowledge your child's concerns as real and important.
- Help your child to talk about his/her interests, and challenges, including how *spina bifida* affects their everyday life. Use resources (e.g. books, videos) from your local children's rehabilitation centre and the local *spina bifida* and hydrocephalus Association.
- Help your child work on social acceptability through managing bowel and bladder *continence* and learning effective social skills to prevent social isolation.
- Your child may encounter teasing by other children. Work with your child to develop strategies for dealing with teasing. Consult your local school board for resources.
- Encourage interests, hobbies, and activities; provide many opportunities for social experiences. Encourage friendships.
- Ensure your child's learning abilities and needs are understood, and that the most appropriate school programming is identified to allow your child to achieve to his/her full potential in school.
- Encourage your child to be independent and take on responsibilities that are within his/her capabilities. It is important to recognize and celebrate those accomplishments.

## Section P: Sexual Development and Healthy Relationships

### Puberty

Individuals with *spina bifida* may experience *puberty* earlier than their peers. These changes include early hair growth (called *adrenarche* – pronounced *ad-ren-ar-key*), or breast growth (called *thelarche* – pronounced *thee-lar-key*). It is important for parents to notify their medical team should this occur prior to age 8, as it may suggest precocious (early) puberty. Treatment options for precocious puberty may be available.

With changes to their body, adolescents – particularly those with *spina bifida* – may want and should be encouraged to have increased independence in their self-care and privacy. Parents should develop strategies to encourage that process as much as is possible.

Finally, these changes also mark changes in the sensitivity of sex organs, such as the penis in males or clitoris in females. For individuals with *spina bifida*, these changes may not occur or may occur incompletely. Adolescents may be embarrassed and uncomfortable sharing their concerns regarding their sexuality and potential for sexual functioning. An open relationship with their parents is important in order for youth to be able to explore these issues and obtain appropriate information. Options for treatment may be available.

### Sexuality

Sexuality and intimacy are important parts of every person. It is essential for parents to be open and supportive while providing education about puberty, sexual orientation, protection from sexually transmitted infections and unplanned pregnancy. Listen to your child and answer his/her questions. If needed, seek additional information from reliable sources together (e.g. local public health department, schools, your child's health care professional in the *spina bifida* service).

### Sexual Relationships

It is normal for adolescents to be interested in a sexual relationship without being aware or fully understanding all the health risks involved.

Sexually transmitted infections (STI's) include a broad range of infections that are transmitted through sexual contact. Awareness and education are the best methods of prevention. For individuals with *spina bifida*, prevention is even more important as the individual may not be aware of or experience the symptoms of STIs (such as genital sores and pain or burning) due to incomplete or abnormal sensation.

Using a condom provides a physical barrier for protection from STIs. For individuals with *spina bifida* – who are at increased risk of latex allergy – the use of latex free condoms is vital. To avoid condom failure, it is important to teach how to use, store and put on a condom.

### Sexual Orientation

Sexual orientation refers to the gender (male or female) to which an individual is attracted. Heterosexual refers to an individual being attracted to a member of the opposite sex. Homosexual refers to an individual being attracted to a member of the same sex. Bisexual refers to an individual being attracted to both genders (male and female).

In adolescence, there can be a lot of confusion as teens adjust to their sexual feelings and attractions. It is critical that teens, particularly those with *spina bifida* who are already coping with differences in their bodies, have an open and supportive environment to discuss their sexuality, including sexual orientation.

## Section Q: Family Planning

### Pregnancy

For individuals with *spina bifida*, pregnancy planning is critical to reduce the risk to the mother and/or baby's health. For a woman with *spina bifida*, medical care during pregnancy can be more complex/high risk, and consultation with experienced medical professionals is essential.

A woman with *spina bifida* (and her male and female close relatives), are at an increased risk of having a child with *spina bifida*. It is recommended that those in this high risk category increase their dietary intake of folate-rich foods and take a daily multivitamin containing 5 mg of folic acid. This should begin at least three to four months before conception and during the first trimester.

The recommendation for the increased dosage of folic acid before conception and during the first trimester applies also to the female partners of men with *spina bifida* or the female partners of men who have close relatives with *spina bifida*.



### Future Pregnancies and Folic Acid

Parents of a child with *spina bifida* who are planning a pregnancy should be aware of the important role that folic acid (a B vitamin) plays in reducing the occurrence of all forms of *spina bifida*. It is recommended that all women of child-bearing age should supplement their diet with 2 mg of folic acid daily and take it at least three months prior to conception. If you have a child with *spina bifida* or there is a family history of *spina bifida*, the dose should be increased to 5 mg per day during the child-bearing years.

Genetic counseling may be helpful to help predict the chances of having a child with *spina bifida*.

## Section R: Parenting

### A Challenging but Rewarding Journey

In the first days, weeks and months after a new baby comes home, parents cope with extra demands, new emotions, challenges and joyous experiences. During this time, parents of a child with a disability may have strong feelings about what it will mean today and in the future. They have been thrown into a confusing and unexpected world.

Joy, shock, grief, stress, exhaustion, and hope are common feelings reported by parents. As well, parents (and /or extended family members) may feel angry and start to blame themselves and others for what has happened. All of these feelings are normal and parents are often surprised by how strong feelings can be.

Feelings are real, important and useful. It is important not to deny or downplay feelings. Often mothers and fathers express their feelings differently even when they are feeling the same way.

Express your feelings to a trusted partner, friend, health care professional or counsellor. Other family members may be experiencing similar feelings and fears. By talking with others, you can help reduce the feelings of isolation for yourself and your family.

Parents of a child with special needs will gain new skills, information and confidence as they see their baby grow and develop. Parents are encouraged to seek support and information to help manage any unexpected challenges and decisions.

### Coping Strategies for Parents

As parents, you play a critical role in nurturing your child's development and independence. Your own personal needs are very important. It is important to take good care of yourself – physically, mentally and emotionally.

- Nurture your relationships with your partner, other family members and close friends. Spend time with each other and enjoy what each person brings to your life.
- You need each other's comfort and acceptance. Recognize that feeling upset, guilty, and forgetting some of the exercises and routines recommended for your child are all part of learning your new role as a parent.
- Take a break. Balance life's struggles with time off by giving yourself permission to laugh and have fun. Seek help from family members, friends and others with child-care and household chores.
- Give each member of the family time to talk, time to be away and time to experience enjoyment and fun with your new baby.
- Your child's siblings, grandparents, aunts and uncles will all have their own reactions and ways of adjusting to your new baby. Allow them their feelings and reactions. Give them the same understanding you would want. Your whole family will model how you value, enjoy and love your new baby.
- It is important to keep even young children informed and educated about your baby's special needs. This increases their understanding and reduces their fears about the unknown.
- You are not alone. Seek credible information about services, counselling, and parent support groups. Sharing stories with other parents of special needs children is a useful experience at all stages of parenthood. Talk to your local spina bifida and hydrocephalus association to get connected with other parents.
- Know that the majority of families adapt and adjust successfully, and in time view their experiences in a positive light.

## Section S: Planning for the future

### Dealing with Challenges

Every parent worries about their child's future and how their child will become self-sufficient and independent. Spina bifida brings lifelong challenges, but it is important to remember that these challenges can be managed over time – first by parents, then by the child as he/she develops independence and self-esteem. Parental attitudes and expectations play an important part in your child's future, independence and quality of life. It will take time and patience and together, you and your child can reach this goal.

Assistive devices, as well as community supports and services, may play a regular part in supporting and encouraging your child's independence.

Self-esteem developed in early childhood and reinforced by successful experiences throughout childhood and the teen years is also essential. Participation in school and the community are important factors in developing a strong, independent young person.

Developing goals and learning how and when to ask for assistance are all skills that your child can learn.

Remember, there is no one right way to help your child thrive except to love and enjoy your child. As you seek information and the support of others, do what is most practical and comfortable for you and your family. Lastly, it is important to celebrate life and your child's accomplishments...each and everyday.



**acetabulum**

hollow cavity in the pelvic bone which receives the femur; socket portion of hip joint

**adrenarche**

hair growth in early puberty

**allergy**

an acquired hyper-sensitivity to substances that are usually harmless

**anal sphincter**

circular muscle that controls the opening and closing of the anus thereby controlling bowel continence

**ankle foot orthosis (AFO)**

brace extending from below the knee to the toes to support the ankle

**apnea**

when breathing stops for more than 5-10 seconds

**Arnold-Chiari Malformation**

see Chiari II Malformation

**atrophy**

wasting, decrease in size of an organ or tissue

**aspiration**

the drawing-in of foreign bodies (food/fluids) into the lungs on inhalation

**auditory**

related to hearing

**bladder irrigation**

flushing the bladder with fluid through a catheter

**bladder augmentation**

bladder surgery to enlarge the bladder

**brace**

see orthosis

**bowel movement**

elimination of contents of rectum; “pooping“

**brain stem**

stem like part of the brain that connects the cerebral hemispheres with the spinal cord

**bucket seat**

custom molded supportive plastic seat

**C.T. Scan**

test using a computer to produce a cross-sectional view of a body part

**caster cart**

3 wheeled card to allow early management around the home

**catheter**

a small tube inserted in the urethra to completely drain urine

**catheterization (CIC)**

clean intermittent catheterization— procedure of inserting a small catheter/tube into the bladder via the urethra to completely drain urine

**calcaneus**

bone at the rear base of the foot; heel bone

**cecostomy**

a surgically inserted tube in the abdominal wall to do enemas through instead of the rectum

**cerebellum**

small part of the nervous system, situated at the back of the brain, which is concerned with coordination of movements and bodily functions

**cerebrospinal fluid (C.S.F.)**

clear fluid surrounding the brain and spinal cord which acts as a shock absorber

**Chiari II Malformation (Arnold-Chiari Malformation)**

Condition in which the lower part of the brainstem protrudes through an opening in the skull base into the upper neck

**club feet**

the feet point down and inwards

**coccyx**

tail bone

**constipation**

difficult, infrequent defecation (bowel movements); sluggish action of the bowels

**continence**

ability to control urination and bowel evacuation

**contracture**

deformity due to the shortening of soft tissue including muscle

**croup**

childhood condition characterized by a resonant barking cough, difficult breathing and/or spasm in the upper airway

**dexterity**

skill in using the hands usually requiring both fine and gross motor co-ordination

**dislocated hip**

the head of the femur is pulled out of the socket

**endocrinologist**

specialist in the study of ductless glands and their functions

# Glossary

**epinephrine**

a medication given to relieve the immediate symptoms of a severe allergic reaction. Once used, seek medical attention immediately as the effect of the drug last only 15-20 minutes

**equinus**

deformity of the foot marked by walking without touching the heel to the ground

**esophagus**

tube that connects the throat to the stomach

**fecal**

pertaining to stool/feces; “poop”

**femur**

thigh bone situated between pelvis and knee

**fibula**

the outer and smaller bone of the lower leg

**flaccid**

relaxed, flabby, having little or absent muscle tone

**fontanelle**

soft spot of a baby’s head that later is closed by the growth of the skull bone

**fracture**

broken bone

**genetics**

study of heredity

**gynecologist**

specialist in treatment of the female reproductive system

**hydromyelia**

increased fluid in the central canal of the spinal cord

**hydronephrosis**

enlargement of the kidneys

**hypersensitivity**

heightened sensitivity to a stimulus of some kind, i.e. touch, taste, hearing

**hypothalamus**

part of the brain controlling certain metabolic activities, including the secretion of hormones

**hydrocephalus**

abnormal enlargement of the ventricles in the brain due to interference with the circulation of cerebrospinal fluid

**impaction**

overloading of feces in the bowel

**incontinence**

inability to control urination and defecation; soiling oneself

**intravenous pyelogram (I.V.P)**

kidney x-ray

**knee ankle foot orthosis (KAFO)**

brace extending from upper thigh to the toes to support the knee and ankle

**kyphosis**

curvature of the back which causes a hump shape in the contour of the spine

**latex**

the sap of the rubber tree which is used to make products such as balloons, rubber catheter and enema devices, surgical gloves, condoms, some pacifiers, feeding nipples and bandages

**lesion**

site of damage or injury

**ligament**

fibrous bands that hold bones together in the region of a joint

**lordosis**

curvature of the back which causes a hollowing of the contour of the spine

**lumbar**

pertaining to the lower back

**lipomyelomeningocele**

a form of *spina bifida* where abnormal fatty tissue protrudes through a defect in the vertebrae of the lower spine

**magnetic resonance imaging (M.R.I.)**

test using magnetic field to produce an image of tissues or organs

**malleolus**

an extension of bone having the shape of a hammerhead on either side of the ankle

**meninges**

a covering of thin tissue of the brain or spinal cord

**meningocele**

a type of *spina bifida* with a protrusion of only the protective membrane of the spinal cord through an opening in the spine

**muscle tone**

the resistance of muscles to stretching

**myelomeningocele**

a type of *spina bifida* with a portion of the spinal cord and membranes protruding through an opening in the spine

# Glossary

**nerves**

bundle of fibres carrying impulses of sensation and motion between the brain and the spinal cord

**neural tube**

nerve tissue from which the spinal cord and brain develop

**neural tube defect**

damage to the neural tube during development in utero

**neurological**

pertaining to the nervous system

**neurosurgeon**

specialist in surgery of the brain and nervous system

**nurse**

a health care professional who provides general health assessments and addresses issues specifically related to: continence, skin, latex allergies, shunts, nutrition, sexuality and understanding of a disability

**nystagmus**

involuntary jerking movement of the eyes in any direction

**occulta**

mildest form of *spina bifida*

**occupational therapist**

a health care professional who addresses the issues of fine motor and perceptual motor skills, daily living skills, academic and pre-vocational concerns, seating and mobility, home and school accessibility

**ophthalmologist**

a doctor who specializes in treatment of disorders of the eye

**optic nerve**

nerve that carries impulses for sight

**oral**

pertaining to the mouth

**orthopaedic surgeon**

specialist in surgery of the bones and joints

**orthosis**

device applied to the trunk or a limb to maintain function to provide support and to prevent further deformity

**orthotist**

person who makes orthoses (splints, braces)

**parapodium**

standing brace with hip and knee joints to allow the user to sit with the brace on

**paralysis**

loss of sensation or voluntary motion

**physiotherapist**

a health care professional who addresses the issues of gross motor skills, including standing and walking abilities. Also assesses joint range and muscle strength, and provides prescription and training in the use of equipment and orthotics.

**pituitary gland**

small gland at the base of the brain secreting a number of hormones controlling many functions such as growth, reproduction

**posterior fossa**

region at the back of the skull

**precocious puberty**

early onset of body changes and development of adult sexual features

**psychologist**

a professional who assesses and provides counseling with regard to learning and school issues, behavioural, social and emotional concerns

**puberty**

a period of rapid growth and development of sexual maturity

**reciprocating gait orthosis (R.G.O.)**

a brace extending from the chest to the foot allowing alternating movement of the legs for walking

**reflux**

backward flow

**renal**

pertaining to the kidney

**sacral**

relating to the lowest part of the spine

**sacrum**

the triangular bone at the base of the spine forming part of the pelvis

**scoliosis**

curvature of the spine to one side

**seizure**

sudden episodes of eye staring, twitching or thrashing of arms and/or legs; may or may not involve loss of consciousness

**sensory nerve ending**

end of the nerve fibres which detect feelings of pain, pressure, temperature

# Glossary

**shunt**

a tube placed from a ventricle in the brain which redirects cerebrospinal fluid to be reabsorbed in another part of the body

**shunt revision**

repair or replacement of the shunt through surgery

**social worker**

a professional who provides counseling and support for personal/family issues, parenting, independence, future planning and referrals to community and social service programs

**spastic**

rigid

**spasticity**

increased tone or contractions of muscles causing stiff and awkward movements

**speech language pathologist**

a health care professional who evaluates and provides suggestions related to feeding, speech, and language skills

**sphincter**

muscle that surrounds and closes an opening

**spina bifida**

condition in which there is incomplete closure of the spinal column

**spinal column**

the vertebral bones which house the spinal nerves

**spinal cord**

part of the nervous system enclosed within the backbone or vertebrae which transmits impulses to and from the brain

**spinal fluid**

see cerebral spinal fluid

**spinal shunt**

a tube placed from the syrxinx into the abdominal cavity to drain excess fluid

**splint**

see orthoses

**stool**

feces, "poop"

**strabismus**

turning in or out of one or both eyes

**stridor**

high pitched croupy sound due to difficulty with breathing

**sunset sign or sun setting eyes**

downward positioning of the eyeballs

**syringomyelia**

abnormal fluid filled cavities in the spinal cord

**syrinx**

cavity or tube in the spinal cord or brain

**tethered cord**

attachment of the lower end of the spinal cord to the bottom of the spinal column causing over stretching of the cord

**thelarche**

beginnings of breast development during puberty

**thoracic**

pertaining to the chest or thorax

**thorax**

the chest

**tibia**

the inner and larger bone of the lower leg; shin bone

**tissue trauma**

skin breakdown

**ultrasound (U/S)**

test using inaudible sound frequencies to produce an image of a body part

**ureter**

tube that carries urine from the kidney to the bladder

**urethra**

tube which carries urine from the bladder to the outside of the body

**urinary retention**

incomplete urination

**urodynamics (UDS)**

test to measure urinary continence through measurement of bladder pressure

**urologist**

medical specialist who assesses and treats organs producing and transporting urine

**V.C.U.G.**

voiding cystourethrogram - bladder x-ray

**valgus**

deformity of a joint where the lower bone of the joint is tilted outward (away from the mid-line)

**varus**

deformity of a joint where the lower bone of the joint is tilted inward

**velum**

any veil-like structure (e.g. palate)

**ventricle**

one of the cavities of the brain

**vertebra**

bone of the spinal column







