CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS
A GENERAL INFORMATION BOOKLET

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DISCLAIMER

This booklet is designed to provide general information about the topics covered, to assist interested parties. It is compiled from information written by staff of the SBH Queensland, as well as from various publications by authors not related to the Association. Accordingly, whilst the Association believes the information is the most accurate and up-to-date available, the Association accepts no responsibility for the information from other sources. There is still much to be learnt about spina bifida, hydrocephalus, and their causes and prevention. As further developments occur, the information may prove to be incorrect or incomplete. For this reason, and because the information is of a general nature, you should always obtain specific advice about matters affecting you.

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# Table of Contents

*SBH Queensland Services* ...................................................... 2  
*INTRODUCTION* ................................................................. 3  
*FACTS ABOUT   SPINA BIFIDA AND   HYDROCEPHALUS* ................. 4  
  - SPINA BIFIDA - A NEURAL TUBE DEFECT .................................. 5  
  - TYPES OF SPINA BIFIDA .................................................. 6  
  - WHAT ARE THE CHANCES THAT MY CHILD WITH SPINA BIFIDA WILL WALK? _ 8  
  - HYDROCEPHALUS ........................................................... 9  
  - ARNOLD CHIARI MALFORMATION .......................................... 11  
  - TETHERING OF THE SPINAL CORD ....................................... 13  
  - EXPLANATION OF SOME COMMON TERMS .................................. 14  
*PHYSICAL IMPLICATIONS OF SPINA BIFIDA AND HYDROCEPHALUS* ...... 15  
  - MOBILITY ................................................................. 16  
  - CONTINENCE - BLADDER & BOWEL ....................................... 19  
  - EXPLANATION OF TERMS ................................................ 25  
  - SKIN SENSATION ......................................................... 26  
  - LATEX ALLERGY .......................................................... 28  
*DEVELOPMENTAL AND EDUCATIONAL IMPLICATIONS* ....................... 29  
  - LEARNING DIFFICULTIES .............................................. 30  
  - HANDWRITING ............................................................ 33  
  - SPORT/PHYSICAL EDUCATION ........................................... 35  
*SOCIAL IMPLICATIONS* ......................................................... 39  
  - SOCIAL DEVELOPMENT .................................................. 40  
  - IN THE PLAYGROUND .................................................... 42  
*GENETICS FOLIC ACID* .......................................................... 44  
  - GENETICS AND FOLIC ACID ............................................. 45  

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*SBH Queensland*
SBH Queensland Services

SBH Queensland
- Provides a contact point for information and services specific to spina bifida and hydrocephalus
- Empowers people with spina bifida and hydrocephalus to achieve their full potential
- Promotes the value of people with spina bifida and hydrocephalus
- Strives for excellence in the development and provision of programs to people with spina bifida and associated hydrocephalus

What SBH Queensland can offer you and your child

SBH Queensland offers a range of services for children with spina bifida and hydrocephalus aged 0 to 18 years. These services consist of:

- The library and other information resources
- Support and counselling for new parents
- Support at Royal Children’s Hospital and Mater Children’s Hospital spina bifida clinics
- Group programs such as: playgroups, mobility clinics and skill training groups
- Annual camp
- Lending of equipment for trial

Eligible children may also receive individual services from the Education and Therapy Service

Physiotherapy - Assistance with mobility, wheelchairs, anything to help your child get around

Occupational Therapy - Assisting your child to develop essential skills for school and life

Speech Pathology - Focusing on your child’s communication, speech, language and feeding abilities.

Education Advisers - Support for your school or early learning centre to help them to understand and assist your child to reach their potential at school
INTRODUCTION

In the following pages, we discuss many of the problems and difficulties associated with spina bifida and hydrocephalus.

However, it must always be kept in mind that children with these conditions are as varied as children everywhere.

Some children will face many of these difficulties, others will have very few. Some will have limited abilities, others will be very able, and have no trouble coping with all of the challenges that childhood and adolescence poses.

Take every child as an individual. All children are!
FACTS ABOUT

SPINA BIFIDA AND

HYDROCEPHALUS
SPINA BIFIDA - A NEURAL TUBE DEFECT

Spina Bifida is a Latin term meaning split spine. It is the name given to a group of birth defects which interfere with the development of the central nervous system: the brain, the spinal cord and the nerve tissues.

HOW IT STARTS

The central nervous system begins to develop from the ectoderm (the layer of cells from which the brain and spinal cord develop) in the third week following fertilisation when the embryo is only 3-5 mm long. Prior to this the ectoderm resembles a flat group of cells running down the middle of the embryo. This flat sheet begins to change, however, and folds to form a groove. (Diagram (a) and (b).) The edges of the sheet eventually come together to form a tube which later develops into the spinal cord and the brain. (Diagram (c) and (d).) This structure is called the neural tube. Once the neural tube closes it sinks into the embryo and is covered by a layer of skin. The spinal vertebrae (bony covering) then begin to form around the tube.

Normally the neural tube closes by the twenty-eighth day after fertilisation. However, if the tube fails to close properly, a neural tube defect occurs. Neural tube defects include the conditions of anencephaly, encephalocele, and spina bifida. (Reference 1)

SPINA BIFIDA

In spina bifida, at some point along the spine the posterior part of the vertebrae (the bones of the spine) are not completely joined. Babies are born with the spinal cord and covering (meninges) protruding through the opening.

Within a few days of birth, the site of the lesion on the back is operated on to ensure that it has a good skin covering. This is performed to stop infection and also for cosmetic reasons.
TYPES OF SPINA BIFIDA

**Occulta**

Outer part of vertebrae not completely joined. Spinal cord and covering (meninges) usually undamaged. Hair often at site of defect.

**Meningocele**

Outer part of vertebrae split. Spinal cord usually normal. Meninges damaged and displaced through opening.

**Myelomeningocele**

Outer part of vertebrae split. Spinal cord and meninges damaged and displaced through opening. Usually hydrocephalus.

CSF – Cerebrospinal fluid

*Diagram reproduced from "Spina Bifida and You".*
Spina Bifida Occulta

Spina Bifida Occulta literally means a hidden split in the spine. It is hidden because the deformity of the spine and any associated abnormalities are covered by skin. This is the least serious but most common type.

The split in the vertebrae is usually so small that the spinal cord does not protrude, and so little or no damage is done. The skin at the site of the lesion may be normal, or it may have some hairs growing from it; there may be a dimple in the skin, or a birthmark. Someone with spina bifida occulta may not have any problems at all, and probably wouldn't know they had this unless an x-ray of the back was taken. Occasionally problems do arise, however, and medical advice is needed.

See our booklet on Spina Bifida Occulta for more information.

Meningocele

In this type of spina bifida, the meninges (covering of the spinal cord) protrude through the opening, causing a lump or sac on the back. The spinal cord is often undamaged and there are usually no long-term problems, although once again, problems can arise. This is the least common form of spina bifida.

Myelomeningocele

This is the most common form of spina bifida and also the most severe. The sac that has protruded on the back contains fluid, blood vessels, as well as the damaged spinal cord and meninges. There is almost always some degree of paralysis. Hydrocephalus may also occur.

Spina Bifida most often occurs in the small of the back or lower down, but all three types can occur anywhere along the spine. (Reference 2)

The Effects of Spina Bifida

The effect spina bifida (myelomeningocele) has on a person's life depends on many things including the location and size of the lesion, and the degree of damage to the spinal cord and nerves.

The most common occurrence of spina bifida is in the lumbar and sacral areas. The lumbar nerves control the muscles in the hip, leg, knee and foot, and help to keep the body erect. The sacral nerves control some of the muscles in the feet, bowel and bladder. Some degree of impairment can be expected in these areas. Problems may include lack of sensation and muscle function in the lower body and legs, an inability to control urination and bowel function, joint abnormalities and deformities of the back. (Reference 3)
WHAT ARE THE CHANCES THAT MY CHILD WITH SPINA BIFIDA WILL WALK?

This depends on many factors. However, the higher up the lesion is on the spine, the more paralysis the child will probably have. The drawings below show how likely it is for the child to walk based on the level of the lesion. The shaded areas show the parts of the body affected by paralysis and loss of feeling.

<table>
<thead>
<tr>
<th>BONES OF THE BACKBONE (SPINE)</th>
<th>LEVEL OF LESION</th>
<th>PROBABLE AMOUNT OF DISABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>neck bones (cervical vertebrae)</td>
<td>probably will not walk except with very supportive equipment</td>
<td></td>
</tr>
<tr>
<td>12 back bones (thoracic vertebrae)</td>
<td>cannot control bladder or bowel</td>
<td></td>
</tr>
<tr>
<td>5 waist bones (lumbar vertebrae)</td>
<td>* * * * * * may walk using aids</td>
<td></td>
</tr>
<tr>
<td>5 joined bones at the seat (sacrum)</td>
<td>later may need wheelchair</td>
<td></td>
</tr>
<tr>
<td></td>
<td>cannot control bladder or bowel</td>
<td></td>
</tr>
<tr>
<td></td>
<td>* * * * * * may walk with little or no help</td>
<td></td>
</tr>
<tr>
<td></td>
<td>may or may not be able to control bladder or bowel</td>
<td></td>
</tr>
</tbody>
</table>
HYDROCEPHALUS

A clear, saltwater-like liquid called cerebrospinal fluid surrounds the brain. This fluid protects and hydrates the brain, carries away wastes from brain cells and contains important chemicals and nutrients. Each day the brain produces about a pint of cerebrospinal fluid which flows in a continuous circuit through the brain cavities (ventricles), and over the surface of the brain and spinal cord until it is absorbed by the body.

In approximately 90 percent of the people with myelomeningocele, the flow of cerebrospinal fluid is obstructed. A blockage at the base of the brain results in a build up of fluid in the ventricles of the brain, which then expand and push against brain tissue and the bones of the skull. In an infant the plates of the skull are not yet fused together. This enables the plates to shift and accommodate the excess cerebrospinal fluid and thus lessen the amount of damage to the brain.

In some babies born with hydrocephalus the condition is arrested if the blocked passage opens or the fluid is channelled elsewhere. If it continues to develop there is continuing pressure on the brain, which if untreated will cause brain damage.

Hydrocephalus is usually treated by insertion of a "shunt". A shunt is a device which is designed to drain excess cerebrospinal fluid from the brain and carry it to other parts of the body. A one-way valve is used, which usually sits outside the skull, but beneath the skin, somewhere behind the ear. (See diagram)

Although a shunt generally works well, it may stop working if it disconnects, becomes blocked, or it is outgrown. If this happens the cerebrospinal fluid will begin to accumulate again and a number of physical symptoms will develop. It is important to get medical attention if any of the following symptoms appear. (Reference 4)

**SYMPTOMS OF A MALFUNCTIONING SHUNT**

- HEADACHE
- VOMITING
- FEVER
- IRRITABILITY AND PERSONALITY CHANGES
- DETERIORATION IN PERFORMANCE - school work, gait, balance, and concentration
- LETHARGY AND DROWSINESS
- DIZZINESS and in more severe cases
- VISION DISTURBANCES
- SEIZURES
SHUNT SYSTEM TO DRAIN CSF INTO ABDOMEN

Catheter into ventricle

Shunt valve

Tubing to the abdomen

Brain

Cerebrospinal fluid

Diagram reproduced from "Spina Bifida and You"
CHIARI II MALFORMATION

The Chiari Type II malformation is a combination of brain anomalies – most notably a hindbrain herniation – which is only found in people with spina bifida. At the back and bottom of the brain is the cerebellum (see diagram). In the Chiari II malformation the cerebellum is small and thin and along with the brainstem – the part of the brain that joins to the spinal cord – is “squashed” into the upper part of the spinal canal. Although the brain anomalies vary from person to person, almost everyone with spina bifida (myelomeningocele) has the malformation.

The malformation shows up clearly on magnetic resonance imaging (MRI), but because only about a third of children have symptoms, the decision to perform surgery is usually based on the symptoms and their severity, not just the results of an MRI examination.

CAUSE

There have been a number of theories about the cause of the Chiari II malformation since its discovery in 1891. Although the matter is by no means settled, the currently accepted theory is that because the cerebrospinal fluid is able to leak out through the open neural tube defect during early foetal development, there is not enough pressure within the ventricular system of the developing brain for proper development. This theory also explains why most people with spina bifida are also born with hydrocephalus.
SYMPTOMS
The symptoms can vary quite markedly according to the age of the person and for ease of clarification can be divided into two groups: those symptoms in children younger than 2 years of age and those in older children and adults.

For the under 2 group, the most common and potentially fatal symptoms involve respiratory difficulties. Inspiratory stridor, a harsh high-pitched noise on breathing in, is the most noticeable sign. An inability to breathe out properly, often accompanied by cyanosis (turning blue) is also life-threatening. Choking, nasal regurgitation, prolonged feeding time and weight loss are all symptoms of Chiari Type II malformation. Other signs and symptoms are partial paralysis of the upper limbs, nystagmus (squint), weak cry, arching of the neck and lack of muscle tone (floppiness.)

For the group older than 2 years of age, the symptoms are less often a medical emergency than in the younger group. Their symptoms tend to progress more slowly and are less likely to be life threatening. The most common symptoms are weakness in the upper extremities and spasticity. The first noticeable sign may be a loss of dexterity manifesting as deteriorating handwriting and loss of self care skills. Ataxia or loss of coordination of the upper limbs and trunk is also common. Headaches in the back of the head or neck may also be present.

Symptoms in older children and adults can include difficulty swallowing, dizziness, unsteady gate, neck pain and arm weakness.

TREATMENT
The treatment for Chiari Type II malformation, if and when it is required, is invariably surgery. The neurosurgeon will want to insure that hydrocephalus or shunt problems are not the cause of the symptoms before operating for Chiari II. When he or she is satisfied that this is the case, then a decompression procedure will be performed.

The aim of this procedure is to reduce the pressure on the brainstem and other brain tissue by cutting away the bone at the bottom of the skull and top of the spinal canal. Because of the abnormal anatomy of the brain with Chiari II, the procedure can be very difficult. The success rate for the procedure is high and improving all the time.

FOETAL SURGERY AND THE CHIARI II MALFORMATION
Since the late 1990s, foetal surgery for spina bifida has been performed in 3 centres in the USA. Although a randomised control study is currently underway and the final results of it won’t be available until around 2011, preliminary data seem to indicate that the greatest benefit of this surgery may be the reduction in the severity of the hindbrain herniation.
TETHERING OF THE SPINAL CORD

Normally the spinal cord moves freely up and down within the spinal canal. However, in spina bifida, the spinal cord is almost always tethered or ‘stuck down’ at the site of the lesion, usually by scar tissue. This can cause stretching of the cord as the child grows and restriction of the blood flow within the canal.

Even though virtually everyone with spina bifida has a tethered cord, only a minority has any symptoms. For people who have no symptoms, the tethering is considered to be not significant and medical treatment for it is not required.

However, if there are symptoms, it may be necessary to have an operation to "detether" the spinal cord.

SOME OF THE SYMPTOMS ARE

♦ Increased weakness or loss of muscle function
♦ Increased muscle tone, spasticity
♦ Deterioration of walking
♦ Worsening of bladder and/or bowel function
♦ Rapidly progressing scoliosis
♦ Back or leg pain
♦ Progressive foot deformity

All of these symptoms can be from other causes, and it is important that they are investigated.
EXPLANATION OF SOME COMMON TERMS

ENCEPHALOCELE

• Local herniation of neural tissue through a defect in the skull. Often, this will involve only the brain coverings, and children will have few problems. Sometimes, the brain is also involved. Hydrocephalus may also occur.

SCOLIOSIS

• A lateral curvature of the spine, often in an S shape.

KYPHOSIS

• An exaggerated outward curvature of the spine.

KYPHOSCOLIOSIS

• A spinal deformity, in which kyphosis and scoliosis occur together. This is often how spinal deformities present in spina bifida.

CT SCAN

• An x-ray machine which revolves around the body, and takes a picture of the organs inside the body.

MRI

• Magnetic Resonance Imagery - a scanner using magnetic energy to give a clear black and white picture of the brain, and spinal cord. Does not involve radiation.
PHYSICAL IMPLICATIONS
OF SPINA BIFIDA AND
HYDROCEPHALUS

(A) MOBILITY
(B) CONTINENCE - BLADDER & BOWEL
(C) SKIN SENSATION
(D) LATEX ALLERGY
MOBILITY

The spina bifida lesion causes paralysis of varying degrees. Some children have no movement in the lower trunk or legs, while others have virtually normal movement. Most children will be somewhere in between.

Some children will walk independently, perhaps with small splints on their legs. They may have poor balance or poor endurance for long distance.

Others will walk with splints (or more supportive walking gear) and a walking frame or crutches. They will normally use a wheelchair as well.

Others will use a wheelchair most or all of the time.

ACCESS

All children need adequate access to their kindy/preschool/school setting.

This means access to classroom, play area, toilets, tuckshop etc. Often extra room is needed to manoeuvre within the classroom.

Some children can quite easily crawl or bottom up and down steps. Whether this is appropriate depends on the age of the child, where the steps are, how the child feels etc.

TRANSFERS/LIFTING

Lifting of school-aged children should be kept to a minimum. Most children with spina bifida, who use a wheelchair, can learn to transfer themselves (with or without assistance) from the wheelchair to floor and back, wheelchair to other seats and back, etc. This should be encouraged as much as possible. Advice on this should be sought from parents, or from a therapist.

FLOOR MOBILITY

It is important that small children who use a wheelchair should not spend all their time in the wheelchair, when other children are playing or working on the floor. Being down on the floor encourages social inclusion, as well as involvement in the same activities as other children.

For some small children, other equipment such as a castor cart, which is down at ground level, may be appropriate for outdoor play.
SEATING
Many children with spina bifida need special consideration of their seating.

Many children who walk may need a smaller chair or table, because of short stature. Some may need a footrest so feet are supported and not dangling. This assists balance. Correct desk height assists fine motor skills.

Many children who use a wheelchair can and should sit in a normal classroom chair at preschool/school. This makes them more a part of the group. If it is more appropriate to sit in the wheelchair, a special desk may be needed so the wheelchair fits under easily.

WALKING
How well and how much a child walks, depends on many factors besides how much movement he/she has. Motivation is a big factor. Some children love to walk, and walk well with the appropriate gear. For others, it is a real chore.

There are many benefits of walking:
1. Improves fitness
2. Helps prevent deformities e.g. keeps hips and knees straight, feet flat
3. Improves strength of bones through weight bearing and exercise
4. Improves upper limb strength
   - Needed by all for wheelchair use, transfers, etc. as well as walking
5. Improves bladder and bowel function
   - Gravity and exercise help with these
6. Improves circulation and helps prevent pressure problems of skin
7. More normal visual input
   - Sometimes the child looks at the world from the same level as everyone else when standing
8. Social interaction
   - E.g. when standing at a table or workbench
   - But a wheelchair is much better if children are out running around
9. Accessibility
   - Being able to access high benches, cupboards etc.
   - But a wheelchair is much better for travelling long distances
WALKING/USE OF WALKING GEAR IN A PRE-SCHOOL OR SCHOOL SETTING

This must be agreed between parents and the school - with advice from a physiotherapist where appropriate.

It must be practical and fit in with the school's needs and the child's educational needs.

Obviously, it is good to achieve regular walking at school if that is possible.

WHEELCHAIR

Many children get their wheelchairs at approximately 3 years of age, so they are usually quite proficient in them by the time they go to school.

They can usually negotiate:

- Ramps - if not too steep.
- Rough ground
- Small lips - gutters are very difficult for a small child but they may learn these, as they grow older.

BENEFITS OF WHEELCHAIR

- Speed
- Requires less energy and therefore reduces fatigue.
- Allows the child to keep up with others.

It is often helpful if early rules re wheelchair use are set in a school situation; e.g. other children are not to help more than necessary. They often love to push the wheelchair, or to fetch and carry for the child.

There are two issues:

1. Independence. A child should be expected to do as much as he/she can for himself.

2. Safety. A young child pushing a wheelchair can often cause an unsafe situation.

SUMMARY

There are many issues that may be relevant in regard to mobility. Consider which ones are relevant to your situation. Parents are the experts on their children. Ask them for advice. Ask the children themselves what they can do. Don't assume they cannot do something without checking it out.
CONTINENCE - BLADDER & BOWEL

THE BLADDER
The urinary system is one of the most vital in the human body. It has two functions: to filter waste and excess water from our blood to form urine and to return salt and other important chemicals to the blood. It is of extreme importance to your health that the urinary system functions properly.

HOW THE URINARY SYSTEM WORKS
The urinary system consists of a pair of kidneys, two ureters, a bladder, two urinary sphincters, and a urethra. The kidneys are made of special filtering tissue through which all of the body's blood passes several times a day. They strain the useful material from the blood and send excess water and waste material down two thin tubes (ureters) to the bladder. Each ureter has a flap of skin at the end which acts as a valve to prevent urine from flowing back up the ureters into the kidneys.

The bladder is a muscle-lined sac. The muscle, called the detrusor, remains relaxed creating a low pressure reservoir for the urine until urination occurs. A 12 year-old’s bladder capacity is about 300 – 400 ml. A 3 – 4 year old’s is about half of this. The outlet from the bladder to the outside world is a small tube called the urethra. It is longer in boys than girls, because it passes through the penis. The urethra is surrounded by two small circular muscles called sphincters, which remain contracted until urination. One of these operates involuntarily, and the other voluntarily, i.e. we can control it.

When the bladder is full sensory receptors tell the brain via the nerves in the spinal cord that you need to empty your bladder. When you are ready to go to the toilet, the brain sends messages via the nerve pathways to the bladder muscle and sphincter. It coordinates the contracting of the bladder muscle with the relaxation of the sphincter muscle. This discharges the urine from the body.

HOW SPINA BIFIDA AFFECTS THE URINARY SYSTEM
A person with spina bifida is usually born with an undamaged urinary system but with an interrupted nerve supply between it and the brain. This condition is called neurogenic or neuropathic bladder.

Nerve damage can result in impairment to either or both of the bladder muscle and the urinary sphincters. The bladder muscle can be such that it cannot contract (i.e. it is always relaxed) or overactive and the sphincters (especially, the voluntarily controlled one) uncontrollable and either too relaxed or too tight. It is rare for the bladder muscle to be flaccid and the sphincter muscle too tight.
There are basically three scenarios.

1. A bladder with a muscle which cannot contract combined with a sphincter which is too relaxed. This is the most common scenario for people with spina bifida. The result is constant dribbling of urine, but not always complete emptying of the bladder.
2. An overactive bladder with a sphincter which is too relaxed. This also results in unpredictable discharge of urine and incomplete bladder emptying.
3. An overactive bladder with a sphincter which does not relax. This is a dangerous situation because the bladder contracts and because the urine cannot get past the tight sphincter, it is forced back up the ureters past the small valve at the bottom of the ureters and into the kidneys. Urine in the kidneys can cause serious kidney infections leading to kidney damage.

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**NORMAL EMPTYING OF BLADDER**

**BLADDER EMPTYING INCOMPLETELY**

- DILATED URETERS
- ENLARGED BLADDER
- DAMAGED KIDNEYS

**NORMAL URETERS & KIDNEYS**
It is very important for health that the bladder is completely emptied regularly. Urine that remains in the bladder provides an excellent breeding ground for bacteria which thrive in warm, damp conditions.

The signs of a urinary tract infection are cloudy or discoloured urine, fever, chills and shakes, headache, fatigue, nausea, pain and an increased frequency and need to urinate. A person with spina bifida who has paralysis in the lower extremities should monitor the appearance of their urine carefully since they may not be able to feel the first warning sign of a urinary tract infection - pain while urinating. (Reference 6)

Urinary incontinence will usually affect those children who have the most serious type of spina bifida (myelomeningocele). It may also affect, though not usually, those children with the less serious types of spina bifida (occult spinal dysraphism and meningocle).

**HOW URINARY INCONTINENCE IS MANAGED**

1. Almost always - clean intermittent catheterisation
2. Medication to relax the bladder muscle
3. A toilet timing and training program. The key is regularity.
4. Continence products eg pads and shields.
5. Surgical procedures eg bladder augmentation, insertion of an artificial sphincter, the creation of a perineal urethrostomy

NB A combination of the above suggestions is usually required for successful urinary continence management.

The key to a healthy urinary system is **FREQUENT COMPLETE EMPTYING.**

**CLEAN INTERMITTENT CATHETERISATION (CIC)**
Clean intermittent catheterisation is the process in which the bladder is drained several times a day (usually every 4 hours during waking hours) with a catheter using a clean but non-sterile technique.

Clean intermittent catheterisation helps the urinary system by facilitating complete bladder emptying, reducing the number of urinary tract infections, reducing constant urinary leakage and protecting the kidneys from damage.

Training in independent clean intermittent catheterisation is usually started when a child is at kindy or preschool and most children are basically independent by 8 years of age (Grade 3).

Children should still see their urologist or paediatrician regularly to monitor kidney and bladder function.
THE BOWEL
The human body is designed to rid itself of waste products. If we do not rid ourselves of waste material we can become very ill. The organs which help our body cleanse itself of waste are part of the lower digestive system and are often called the 'bowels'.

HOW THE BOWEL SYSTEM WORKS
The bowel consists of the small intestine, the large intestine, the rectum, internal and external anal sphincters and the anal canal. The large intestine (the colon) stores the waste material in liquid form and moves it along towards the rectum by a series of waves and contractions known as peristalsis. While the faeces is in the colon, excess water is removed from it until it forms the consistency of a stool. The internal anal sphincter located below the rectum, opens automatically when it senses that there are faeces in the rectum. Nerves located in the anal canal send a message to the brain that we need to have a bowel movement. When it is convenient the brain tells the external sphincter to relax and the rectum and stomach muscles to contract. The faeces is then discharged from the body. We usually learn to control this process between the ages of one and three.

HOW SPINA BIFIDA AFFECTS THE BOWEL
Almost all people born with spina bifida have bowel problems. As with most of the conditions associated with spina bifida, bowel problems are a result of damaged nerves at the bottom of the spinal cord. Nerve damage generally affects three areas of the bowel: the external anal sphincter; the sensory mechanism which tells the brain that the rectum is full; and the muscles which move the faeces along the colon and out of the body.

In a normally operating bowel the external sphincter will contract when the rectum is full and hold the faeces in the anal canal. However, because there is little or no control over the external anal sphincter for a person with spina bifida, faeces can be discharged or flow from the body unexpectedly.

The interrupted nerve supply to the colon also means that the liquid faeces does not progress as quickly through the colon as it normally would. The longer time spent in the colon leads to more water than usual being extracted from the faeces, turning it into a very hard consistency and leading to constipation.

Even though a person is constipated, the liquid faeces at the top of the colon can work its way past the large dry faecal mass and leak out. This ‘overflow diarrhoea’ makes it appear that the person is not constipated at all. This type of diarrhoea is common for people with spina bifida and when it happens, the person should be checked for constipation.

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HOW BOWEL CONTINENCE IS MANAGED

1. A high fibre diet with plenty of water and fluids
2. Medication to soften the stools
3. A toilet timing and training program. The key is regularity.
4. Enemas eg bowel washout with Microlax
5. Manual evacuation (gloving)
6. Exercise
7. Surgical procedures such as the Mitrofanoff Antegrade Colonic Enema (MACE) which enables an enema to be given from above the faeces.

The overall aims of bowel management programmes are:

1. Overall good health
2. Confidence in the reliability of one’s bowel management strategies
3. Dignity and full social integration
BOWEL AND BLADDER CONTINENCE IN THE SCHOOL SITUATION

The child with spina bifida will probably have some problem with continence and will therefore need:

1. Suitable toilet facilities:
2. Wheelchair accessible (if necessary)
3. Sink, cupboard and bin in toilet
4. A clean toilet area
5. Privacy
6. Aide time for supervision and or assistance with catheterisation.
7. Extra time for toileting
8. An established toilet routine
9. To deal with accidents
10. Change clothes
11. Clean wheelchair
12. Wash out soiled clothes
13. To be told they have had an accident, as children are not always aware of the situation.
14. To inform the teacher if there is a change of continence management procedures.
15. To drink regularly to minimise urinary tract infections.

The system that is in place should always maintain the dignity of the child.
EXPLANATION OF TERMS

BLADDER AUGMENTATION
A surgical procedure in which the bladder is cut open and a section of bowel is removed and sewn onto the opening to create a bladder with increased capacity. The procedure also stops the bladder from being overactive.

PERINEAL URETHROSTOMY
The creation of an opening for the urethra in the perineum to make catheterising easier.

ARTIFICIAL URINARY SPHINCTER
The artificial urinary sphincter is a device which can be inserted to give control over the flow of urine through the urethra. It comprises a small fluid filled cuff which is placed around the neck of the urethra and a pump which when activated opens the cuff allowing urine to flow.

MACE (or ACE)
The surgical procedure creates a stoma (opening) near the navel for easy access into the colon to wash it out from above. The appendix is often used as the tube between the stoma and the bowel. An enema solution is run through the stoma into the colon once each day or two days to wash out the faeces.

MEGACOLON
An overly stretched piece of bowel resulting from constipation.
SKIN SENSATION

As a general rule, if a child has some loss of movement, there will be loss of skin sensation too.

For example, a child who has no movement from mid-trunk level will generally have no feeling from that level downwards. He cannot feel anything inside (e.g. the need to go to the toilet) or outside (e.g. when something touches his leg).

For lower lesions, it is not so straightforward. A child may be able to walk fairly well, seem only to lack some movement in the foot, but loss of sensation will usually be in some areas of feet, right up the leg, and also the buttocks.

POSSIBLE PROBLEMS
If a child is not aware of being hurt, he will not move away from danger.

1. BURNS
   Examples:
   - Sunburn on legs/feet (especially if shoes/socks are usually worn)
   - Wheelchair left in hot sun Child transferring back into a hot wheelchair may burn buttocks, legs and feet.
   - Hot drinks/chips held on lap
   - Hot car/bus seat
   N.B. Because of poor circulation and poor nerve supply, the skin is often not strong and will burn more easily than normal.

   How to Prevent:
   - Wear shoes/socks
   - Wear long pants
   - Awareness by child and carers.
   - Check for hot surfaces

2. SCRAPES
   Examples
   - Child crawling on rough ground (especially pool surrounds) may scrape knees, ankles and toes.
   - During transfers from floor to wheelchair, child may scrape body and legs on footplates.
   - During transfers from wheelchair to chair, child may scrape buttocks (this can be a big problem if it happens repeatedly).
   N.B. Any scrape/scratch may take longer to heal than in another child.

   How to Prevent
   - Wear shoes and socks
   - Wear long pants
   - Wear kneepads
   - Good transferring techniques
   - Awareness by child and carers
3. PRESSURE AREAS
These are red areas of skin, caused by prolonged pressure on one area. Any red area that disappears within 30 minutes is no problem, but one, which persists from day to day, needs attention.

Typical areas are:
- Buttocks/sacrum from prolonged sitting in wheelchair
- Heels/ankles from ill-fitting or incorrectly applied splints

These can develop into very nasty sores, if not treated early and effectively. They can in some cases, take months or years to heal. Treatment must always involve removing the pressure.

How to Prevent:
- Regular bottom lifts for wheelchair users
- Sheepskin or pressure-relief cushion on wheelchair
- Care with surface that a child is sitting on, and nothing in back pockets of pants, etc.
- Regular checking of heels/ankles, etc. for red areas from splints
- Beware of problems like sand getting into splints - (abrasive effect)
LATEX ALLERGY

Latex allergy in children with spina bifida has recently become a serious concern. Reports from the American Food and Drug Administration indicate that between 18% and 40% of children with spina bifida are allergic to latex.

Children with spina bifida experience multiple surgical procedures, diagnostic tests, ongoing bowel and bladder continence programmes and frequent laboratory specimen collection. Since the precautions introduced in the mid 1980’s to combat HIV infection in medical settings, these children have undergone frequent and significant exposure to latex. This increased exposure is thought to be responsible for the increase in number and severity of allergic reactions to latex among this group.

WHAT ARE THE SYMPTOMS

The symptoms experienced by children with spina bifida can vary from mild skin irritation to a life threatening reaction (anaphylaxis). Some common symptoms are:

- Skin rash
- Hives, welts, swelling, redness
- Eye irritation
- Sneezing or coughing
- Wheezing
- Itching
- Difficulty breathing
- Chest pain or tightness
- Throat tightness
- Fainting or unconsciousness

WHAT IS LATEX

Latex is the milky sap from the rubber tree Hevea brasiliensis. It is contained in some rubber products.

WHAT IS MADE OF LATEX

Latex can be found in health care settings as well as in everyday items, such as balloons, latex gloves and condoms. For more information, see the SBH Queensland brochure on Natural Rubber Latex which contains a list of common items which contain latex and latex free alternatives.

WHAT TO DO FOR AN ALLERGIC REACTION

1. Remove the object causing the allergic reaction immediately.
2. Rinse the affected area of skin with copious amounts of water.
3. If the child has trouble breathing or experiences chest tightness, call for emergency help immediately.
4. Caregivers and school and medical staff should find out if children they are involved with are allergic to latex.
5. The child should wear a Medic Alert bracelet.
DEVELOPMENTAL AND EDUCATIONAL IMPLICATIONS

(A) LEARNING DIFFICULTIES
(B) HANDWRITING
(C) SPORT/PE
LEARNING DIFFICULTIES

The following information is taken from the booklet *Educating the Student with Spina Bifida and Hydrocephalus* published by the Spina Bifida Foundation of Victoria.

- John does not remember today what he appeared to know last week.
- Susie talks a lot but is often off the point. She does not listen effectively and the other students find this irritating.
- Toby seems interested and starts tasks willingly, but rarely completes anything. His writing is awful.
- Peter works well when the teacher or aide sit beside him but he gets distracted and produces little if left to work on his own.
- Melissa forgets due dates for work requirements.
- Sean finds it difficult to grasp fundamental mathematical and spatial concepts.
- George can learn effectively but this often takes longer than his peers.

The above statements often apply to students with SBH. Although they may sound like difficulties that can affect any student every once in a while, it must be realised that for SBH students these problems are pathological in origin and need to be addressed accordingly.

The problems can be grouped under the following headings: attention, language, memory and learning, visuo-motor integration skills, planning and organisational skills. What follows is a short description of how they manifest and some recommended strategies for educators when confronted with them. Remember that though most students with SBH will exhibit similar learning difficulties, the range and their severity in individuals will vary widely.

**ATTENTION**

Most SBH students appear interested and motivated to learn. However they are easily distracted and find it difficult to sustain attention until the completion of work. Some have difficulty identifying the most salient aspect of a task and focusing their attention. Instead they tend to get distracted to less relevant aspects.

Students with attention problems usually function best when:

- the work environment is quiet, well organised and clearly structured;
- a single activity is set and competing distractions are minimised;
- high demand working periods are brief and interspersed with more relaxing activities;
- instructions are clear and step by step and repeated when required;
- adult assistance is available to redirect the student after lapses in concentration.

**LANGUAGE**

Students with SBH are often described as sociable and talkative with good vocabulary skills. However, they may have difficulty monitoring what they say for logic, relevance or appropriateness. This poor comprehension may be difficult to identify when associated with articulate presentation. Some ‘over talk’, perhaps to compensate for their limited mobility or to conceal their inability to do what is asked, may be evident.

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Teachers can help by:
- encouraging the student to use language for communication of meaning rather than only to manipulate others or to conceal areas of difficulties;
- insisting that the student maintains a shared topic of conversation and redirecting them if they wander;
- routinely checking the student's understanding of the language they are using (for example, by asking the student to paraphrase what is said to them, particularly instructions).

**MEMORY AND LEARNING**
Immediate memory for auditory/verbal information may be intact, i.e. the student has an age appropriate capacity to remember instructions or explanations immediately after they are given. However, there is a rapid loss of information over time and difficulty in retrieving the appropriate bit of information from long term memory when it is needed. Visual memory is weak and concepts grasped last week are later lost. Students with SBH can learn effectively however often take longer to learn and struggle with abstract concepts, for example, mathematics. During bad periods they may appear lazy or 'inert' and simply cannot function at the level they are capable of.

Students with memory learning deficit are helped by:
- reducing the amount of information presented at one time and allowing extra opportunity for rehearsal;
- emphasising key points in a logical sequence - information is remembered most effectively when it is processed in an organised and logical way. Extraneous information should be minimised;
- reinforcing conceptual learning through practical activities related to the student's interests and life experience.

**VISUO-MOTOR INTEGRATION SKILLS**
Most students with SBH have difficulty with tasks requiring eye-hand coordination and motor planning skills. They may have difficulty with accurately interpreting what they see in terms of shape, size, space, and distance and then correctly matching their movements (gross or fine). Some students may experience confusion differentiating between left and right. Complaints about slow and untidy handwriting are common and written tasks are often not fully completed.

Assistance can be given by:
- allowing extra time for written work or assignments;
- providing alternatives, for example using an audio tape for creating writing activities;
- encouraging early and frequent use of a word processor for the presentation of written work;
- providing activities which allow the above skills to be practised.

**PLANNING AND ORGANISATIONAL SKILLS**
Most students with SBH find it hard to organise themselves, plan ahead and think flexibly. In addition, some may experience difficulty in understanding the passage of time or understand when matters are urgent. They may be unable to generate strategies for solving problems or to alter their approach if the first attempt is unsuccessful. They seem lost when confronted by a novel or multi-staged task and their work output falls off when they are expected to work independently.
Teachers can help by:
- breaking down complex tasks (eg. assignments, projects) into smaller steps, helping the student generate a plan of approach before they commence, reviewing progress after each component step has been completed and, in brief, providing signposts to guide the student's progress;
- encouraging organised work habits, eg. set homework times, the use of a diary, focusing on time management, use of written of pictorial check lists, use of colour coding to assist planning;
- encouraging the student to check and proofread their work.

The levels of educational achievement of students with SBH are in a wide range, from completion of university and vocational training programs to non-completion of secondary schooling. Whatever the potential of individual students, through awareness of the specific learning difficulties listed above and consistent strategies to intervene where necessary, educators will assist them reach their full potential.

The above is a general outline of how a child with spina bifida and/or hydrocephalus may present. The degree to which a child has any or all these problems varies a great deal. Unless the problems are severe, they do not prevent the child from actively participating in the classroom. Specific strategies and interventions may need to be put in place to allow for maximum educational outcomes.

Active participation and social interaction in educational settings, clubs, youth groups, etc, is important as the disabled child like any other child wants and needs to be accepted as a friend.

FURTHER INFORMATION AND ASSISTANCE
For additional information on the specific learning difficulties associated with SBH and for detailed teaching strategies for primary and secondary levels, you are referred to the following resources:


Education advisers employed by SBH Queensland
Spina Bifida is often considered as a condition which primarily affects the lower half of the body. It is, however, frequently associated with Hydrocephalus which may affect a child's ability to concentrate and learn. Similarly, through compression and stretching of the lower lobes of the brain (Arnold Chiari Malformation), coordination and dexterity of the arms and hands may also be affected.

This is usually not so apparent at birth, and real difficulties may not arise until a child is of a Pre-school age, or in fact not at all.

Initially, it may involve difficulties with small toys like Lego and trouble doing up buttons and zips in dressing. The child may not be keen to sit and play with fine motor toys or experiment with drawing or cutting activities. This kind of aversion to fine motor activity may indicate not only a dislike for but also a difficulty in handwriting, later on at school.

Handwriting, however, is much more than a fine motor activity and other factors need to be considered when looking at this skill development. These include:

- **VISUAL ACUITY**  
  (how clearly can the child see)

- **VISUAL MOTOR INTEGRATION**  
  (eye-hand coordination)

- **SEATING POSTURE**

- **WRITING TECHNIQUE**  
  (pencil grasp/pressure)

- **ESTABLISHMENT OF HAND DOMINANCE**

- **INTEREST AND MOTIVATION**

It is important to remember that the ultimate aim is for writing to be functionally useful both for the work required in primary school but more importantly for the volume of work provided in high school, and ultimately as a daily skill.

If it is determined that handwriting is not functional then an alternative means of written expression may need to be considered. It is reasonable, though, to assume that the child be allowed more time to develop the basic skills of handwriting before any recommendation for keyboards is made.
KEYBOARDS

Primarily, lightweight electronic typewriters are used as a means of increasing a child's "output" with increased speed and reduced effort. They should not be used as a full time alternative to handwriting but a way of tapping into a child's creative expressive language, or in producing written work where writing is not essential to the task e.g. Maths.

Typewriters are also still preferable as an initial tool for the training of keyboard skills, even in this day of computers, because:

- They can be specially/only for the child; no queuing for access
- An immediate input/immediate output is provided
- They are lightweight and portable
- Families can also purchase one
- They have limited functions thereby, decreasing confusion
SPORT/PHYSICAL EDUCATION

All children should be involved in sport at school, right from the start.

Involvement in sport will:

- Improve fitness;
- Improve balance and co-ordination;
- Give opportunity for social interaction;
- Increase self-esteem;
- And it’s fun!

When planning a sport or PE program, there are several factors which need to be considered:

1. Physical ability:
   - Does the child use a wheelchair, or does the child use aids to walk? Can the child run?
   At times, a child who can walk but with some difficulty, is more difficult to cater for than one who uses a wheelchair. If the child has a wheelchair but seldom uses it, perhaps a PE or sports session is the time to use it.
   - Ability to transfer in and out of wheelchair.
   - Mobility on the floor.
   - Fitness/endurance.

2. Motivation

3. Upper limb strength and co-ordination

4. Eye-hand co-ordination, visual-perceptual problems, etc.

5. Cognitive level (understanding of rules, remembering commands, etc.)

Most children can be involved in a wide variety of physical games/sports, with or without modification.

As a general rule, assume a child can join in the activity, then try to work out what modifications, if any are needed.
Modifications may take the form of:
(i) Modifying the whole activity slightly
(ii) Modifying the rules for the child
(iii) Modifying equipment used, etc.

Ask the child what he/she can do! A child often has excellent ideas on how he/she can participate as fully as possible.

Ask the rest of the class! Other children are often very inventive. Also, they will usually have more understanding of the disability, and accept modifications to an activity more readily, if they have been involved in the process.

Remember, the game must be challenging and rewarding for all the players. Don't make it too easy for the rest of the group!

While children should be fully involved with the rest of the class in all sports or activities wherever possible, this is not always possible or practical.

It may be desirable at some time to give a child an alternate program, perhaps with just a few other children, to practice specific skills, so that he/she can then rejoin the group with an improved skill level. Some examples may be simple throwing and catching, or dribbling and goal shooting in basketball.
POSSIBLE MODIFICATIONS

1. Running in softball/cricket etc.
   Allow the child to cover only half the distance (reach a middle point) to be safe. They can finish the distance at their own pace.

2. Allow a child who can stand and walk, but with poor balance, to sit or lean against a solid object, for striking activities.

3. Allow use of a batting tee, in striking activities.

4. If needed, a smaller or lighter bat may be appropriate. A larger ball will simplify catching/striking activities.

5. In team ball games, e.g. captain ball, have one less child on the team, to allow for the extra time the child with spina bifida may take.

6. Use of a multi-coloured ball with help a child who has difficulty with visual tracking.

7. A bounced ball is easier to follow and therefore catch, than a ball which is thrown direct.

8. In running races, a disabled child should not finish last every time. Allow a child to run (or wheel) with the rest of the group, but with an earlier start or a shorter distance to cover. (The finish line should be the same). In this way, the child should usually finish in the main group.

9. Use the "buddy system". The "buddy" - often it is a good idea for the "Buddy" to be a different person each time - can help as needed. Sometimes it may be someone to hold the hand of a runner with poor balance.

10. Rule changes may be made to simplify any game. The rules may be different for different children.

11. Prevent the more able players dominating play totally by restricting their role e.g. the "no-return -pass".

12. Restrict certain players to a specific position on court.

13. "Safe-ball" rule:
    In passing games, defending players may not infringe within 2 metres of the disabled child with the ball. Time and distance limits apply as usual.

14. In net games, keep the net height standard, but give some individual practice at clearing the net.
OTHER TIPS

1. Give simple, clear instructions. These may sometimes need to be given individually to a child with spina bifida to ensure they’ve been understood.

2. Highly inflated tyres make a wheelchair much easier to push/manoeuvre.

3. A hard, smooth surface is much easier to wheel on than a soft surface. If there is someone in a wheelchair in the group, have you chosen the best possible location for the activity? If the only option is a rough, grassed area, the child in a wheelchair may need to be pushed.

WHERE TO GET HELP

1. Ask your AVT (PI) (Advisory Visiting Teacher with the Education Department).


3. Willing and Able and PE and Sport for Young People with Disabilities - Aussie Sports

4. The Child with Spina Bifida and Sport available from this Association

5. Sporting Wheelies - Phone (07) 3252 5242

They cater for anyone with a physical disability, not just those in wheelchairs.

They can offer:

- Information on wheelchair equivalents for many events;

- Information and advice on how to adapt a PE or sports program;

- Sometimes, a school visit can be arranged to give further assistance with a modified program. This depends on the area.

6. SBH Queensland. We have many resources and can also provide individual advice.

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SOCIAL

IMPLICATIONS

(A) SOCIAL DEVELOPMENT

(B) IN THE PLAYGROUND
The following is based on information supplied by the Hydrocephalus Association of America.

Positive social interactions are an important part of life. The social skills critical for social inclusion are numerous and for most our social learning is done automatically by seeing, copying and conditioning - we learn social skills incidentally, without formal instruction. However, many children with spina bifida and hydrocephalus have learning difficulties that make it difficult, or almost impossible, to pick up the verbal and non-verbal cues necessary for the acquisition of social skills.

Some of the most common problem areas are:

- Talking over differences without getting angry
- Persistence when facing frustration
- Refusing requests politely
- Taking turns while talking
- Understanding social rules
- Demanding immediate attention
- Waiting when necessary

Difficulty perceiving non-verbal cues can create serious social problems. Children with learning difficulties often misjudge distance and spatial relationships. They get too close to other people, or they stay back too far. Getting too close will cause others to back off and find an excuse to escape. Staying back too far makes eye contact difficult, puts them out of reach of voice range and is likely to cause others to ignore them.

These children may also have difficulty picking up other social cues, such as those from clothing, for example. Someone dressed in a suit and carrying a briefcase tells us, “I am an authority”. If a child doesn't pick up such cues, they might not figure out who is the authority, boss, teacher, or even the 'boss kid'. And, as a child, if you can't spot the leaders you may end up imitating the school 'nerd' with the high probability that you will then be socially scorned or ignored.

Children who have a problem with non-verbal cues also often have difficulty perceiving intonation. For example, consider the youngster who hears that a party is being planned and goes up to ask if they can come. The 'child' responds, “Yeah, SURE, I REALLY want YOU”. If the child shows up at the party, it is sure to be a heartbreaking experience. The child has heard the WORDS (“I want you”), but not the TONE (“I would rather die than have you at my party”). Errors such as these can be incredibly painful for children who are not attuned to such nuances as tone, rhythm or pitch.
Other important non-verbal cues are posture and facial expression. **If a child can't read faces very well, they will likely interpret things incorrectly.** These children may perceive only two kinds of facial expressions, 'happy' and 'mad', and perhaps 'sad'. This understanding is not enough to get along in the world. They need to perceive such subtleties as "quizzical", "reflective", and others, and are expected to learn them incidentally.

It is known that many youngsters with spina bifida and hydrocephalus may be slower in acquiring physical skills. With time, remediation and early intervention however, many of these skills are obtained. **But what about social skills?** If the child lags behind, will they eventually catch up on these skills on their own, or is intervention important at an early level? **Intervention is vital because even if the child does catch up on their own, it will probably happen over time and some skills may always be missing.** If undeveloped, social skills may come later but by then a youngster may be exhausted, reclusive or self-defeating in interactions with others, having had so many rejections that they refuse to continue to extend themselves socially.

We do not need to wait for this self-defeating behaviour to happen if we realise that many of these social skills can be taught. **These skills can be often be broken down into component parts and taught in stages.**

By recognising and addressing the issue of social skills development, children with learning difficulties can make a move from potential social isolation to social inclusion and participation.
IN THE PLAYGROUND

When there is a child with a disability in your school, having that child fully involved in the classroom program is only half the story.

It is also the school's (and that means the whole school) responsibility to try to ensure that the child is as fully involved as is possible in playground activities as well, i.e. at lunchtime and playtime.

A child who, from Grade 1, has less opportunity to talk and play with schoolmates in the playground will have more difficulty developing appropriate social skills. With inadequate social skills, the problem obviously grows.

Play is important!

WHAT TO DO

(1) **Access** - If access to the appropriate play area is difficult, can the teacher-on-duty take responsibility to escort the child to that play area? Or can older students be rostered to do this? Can a more accessible area be made available to that Grade?

(2) **Encouraging/facilitating appropriate play** - Sometimes it may be possible for a teacher-on-duty to suggest or encourage games in which the child with a disability can join in. This is not to limit the other children, but to encourage games which they can all enjoy.

Try to **tune in to whatever games are popular now**. It may only take a small modification to make it suitable for all the children.

**Ask the children for ideas** - both the child with the disability and his classmates. They will often have the best ideas about what games will work, or how to modify them.

These are just a few ideas to start with. Remember that the teachers in the schools are the ones who see the myriad of games which children play. **YOU** probably have lots of good ideas!

* Cubbyhouses - usually of bushes in the school ground. Can it be made accessible?
* Imaginative play - each child making believe he is someone/something/somewhere else.
* Walking tiggy - instead of running to chase each other, a different type of gait is set (so not as fast moving). Alternatively you may add extra rules about using lines or markings on the ground to limit the pace or area of the game.
* Ball games - e.g. handball (i) against brick wall so a missed ball does not take so long to retrieve and (ii) having a designated catcher, to retrieve missed balls. There are usually kids watching a game, so it is often easy to find a willing catcher. (Be careful not to give **too much** assistance).
* Modified ball games - e.g. grip ball
* Sevenies - ball games against a wall
* Piggy-in-the-middle type games
* Simon says

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**SBH Queensland**
* Traffic lights
  
  *Green* - one step forward
  *Red* - one step back
  *Orange* - don't move
  If you do the wrong thing you are out.

If the classmates are playing active games, then the child with a disability should too, whenever possible.

When this isn't practical, a sedentary activity such as *Where’s Wally?* Books or board games may be good lunchtime activities.

It is sad to hear of children, especially young children, spending lunchtime in the library, even if it is their choice. It only magnifies the social isolation, so they feel even more uncomfortable trying to join in, in the playground.
GENETICS

FOLIC ACID
GENETICS AND FOLIC ACID

Spina bifida is a congenital defect of the spine. It involves a failure of the vertebrae and spinal cord to develop properly and occurs within the first month of pregnancy. It is one of a number of defects collectively called neural tube defects.

The cause of spina bifida is not well understood. A combination of genetic and environmental factors seem to be involved and there are a variety of things which are known to give parents an increased risk of having a child with a neural tube defect.

The incidence of spina bifida in Australia is approximately 1 in 3000 live births. One pregnancy in 500 involves a neural tube defect. However, if a woman or her partner has a close family history of neural tube defects, the risk of having an affected child is greatly increased.

FOLIC ACID
One factor, which is known to influence the risk of having a child with spina bifida, is the amount of folic acid in the mother’s diet.

Folic acid is a water-soluble vitamin, found in many fruits (particularly avocado, grapefruit and oranges), green vegetables and legumes.

It has been found that a diet rich in folic acid, or the taking of folic acid supplements in the month before, and the first three months of pregnancy, can significantly reduce the incidence of neural tube defects.

For more information on this subject, please contact SBH Queensland.
REFERENCES

The referenced sections are based largely on information taken from the publications listed below.

* 1,3,4,6.  Yes You Can, A Kit for Teens  
Published by the Spina Bifida Association of Canada

* 2  Spina Bifida and You  
Published by the Association for Spina Bifida and Hydrocephalus as part of the Young ASBAH series.

OTHER BOOKLETS AVAILABLE FROM SBH QUEENSLAND

Folic Acid and its Role in the Prevention of Spina Bifida
The Child with Spina Bifida and Sport
Swimming for Children with Spina Bifida
Toileting for the Child with Spina Bifida
Handwriting for the Child with Spina Bifida and Hydrocephalus
Home Modifications
Early Childhood: Learning Strategies, Social Inclusion and Social Skills Development
Children with Hydrocephalus
Visual Perception: Practical Strategies for Teachers
Information Guide for Adults
Spina Bifida Occulta

THANK YOU

Our thanks go to the Spina Bifida Association of Canada, for their kind permission to use and reproduce information from the book "Yes You Can".