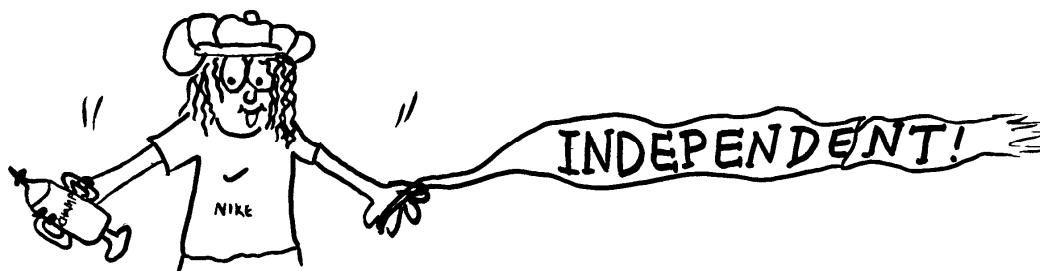




TOILETING FOR THE CHILD WITH SPINA BIFIDA



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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 Association, 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 and its treatment. 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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CONTENTS

Introduction	5
The Bladder	6
How does the urinary system work?	6
How does spina bifida affect the urinary system?	7
What are some management techniques?	9
The Bowel	11
How does the bowel system work?	11
How does spina bifida affect the bowel system?	12
What are some management techniques?	13
Handy hints for diets	15
Self Esteem and Independence	17
Compliance	18
Handy tips for schools checklist	19
Can a child with incontinence go swimming?	21
MASS (Medical Aids Subsidy Scheme)	22
Conclusion	22
Resources and References	23

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.

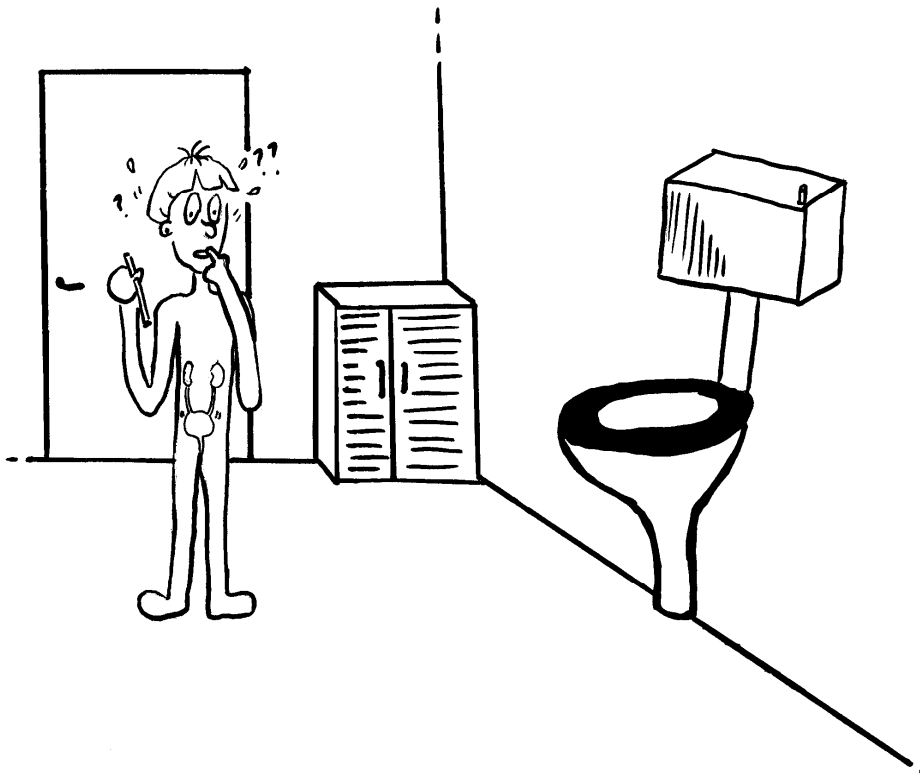
Education Advisers - Support for your school or early learning centre to help them understand and assist your child to reach their potential at school

INTRODUCTION

You may be asking many questions by now about what effect spina bifida will have on your child's bowel and bladder control, and what effects this will have on toilet training. Throughout this booklet we will discuss how the bowel and bladder work, what effect spina bifida may have on them, some ways these effects are managed, tips for school staff to know, and some handy hints for the future.

All children with spina bifida are very different, and will have very different toileting issues. This book will therefore be written as a practical guide with general information, which you can then discuss in more detail with your Specialist, G.P, Stomal Therapist or Occupational Therapist.

Remember, the more questions you ask, the more informed you will feel when discussing and deciding what the management plan for you child will be.



THE BLADDER

The urinary system is one of the most vital systems in the human body. It has two functions: to filter toxic waste and excess water from our blood to form urine, and to return salt and other important chemicals to the blood. The system, which is made up of two kidneys, two ureters, a bladder, and a urethra, keeps an even balance between water and electrolytes in the body. It is important that this balance is maintained so it is very important to a person's health that the urinary system functions properly.

How does the Urinary System Work?

The urinary system is made up of many components.

- **Kidneys** – Two complex organs that filter and process the blood within the body several times a day. They filter out the waste products no longer needed by the body, and combine them with water to form urine.
- **Ureters** – Two thin tubes that channel the urine from the kidneys to the bladder. Each ureter has a small flap of skin at the end of it which closes to prevent urine from flowing backwards up the ureters and into the kidneys.
- **Bladder** – A muscle lined storage sac for the urine. The bladder stretches to a greater volume as it fills with urine. When the bladder becomes fully expanded and cannot store any more urine, sensory receptors alert the brain, which then sends a message to the bladder muscles to contract. When the bladder contracts through controlled movements, pressure builds up and the urine pushes out through a short tube called the urethra.
- **Urethra** – A single tube that enables the passage of urine from the bladder to the outside of the body. Around the top of the urethra are circular muscles called the urinary sphincters. These are voluntary muscles and will tighten to hold the urine in, or relax to allow the urine to empty from the bladder and thus leave the body. This is what allows a person to choose when to urinate.

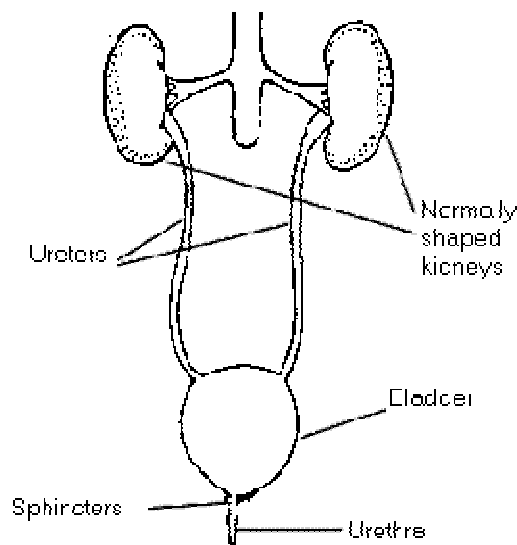


Figure 1. Normal urinary system

How does spina bifida affect the urinary system?

A person with spina bifida is usually born with an undamaged urinary system, however, over time, damage to nerves in the lower lumbar and sacral region in the spine may lead to a condition known as **neurogenic bladder**. This causes incontinence where there can be either partial or complete loss of voluntary urination. Nerve damage can result in impairment to the muscles of one or more of the following areas: the bladder, the urinary sphincter, or the flap attached to the ureter.

The neurogenic bladder can be either flaccid or spastic.

- A **flaccid bladder** is one where the muscles are limp, and cannot contract completely to force the urine out. When the flaccid bladder becomes full, excess urine spills over and flows out of the body through the urethra. Urine dribbles out continually and when excess pressure is put on the bladder such as when laughing or crying this dribbling becomes more severe. However, the bladder never empties completely and some (residual) urine always remains.
- Unlike the flaccid bladder, the **spastic bladder** does not store urine at all. The muscles that line this type of bladder are extremely sensitive and irritable. They contract and expel urine immediately after it enters the bladder. Even though the bladder is continually contracting, some urine almost always remains in the bladder.

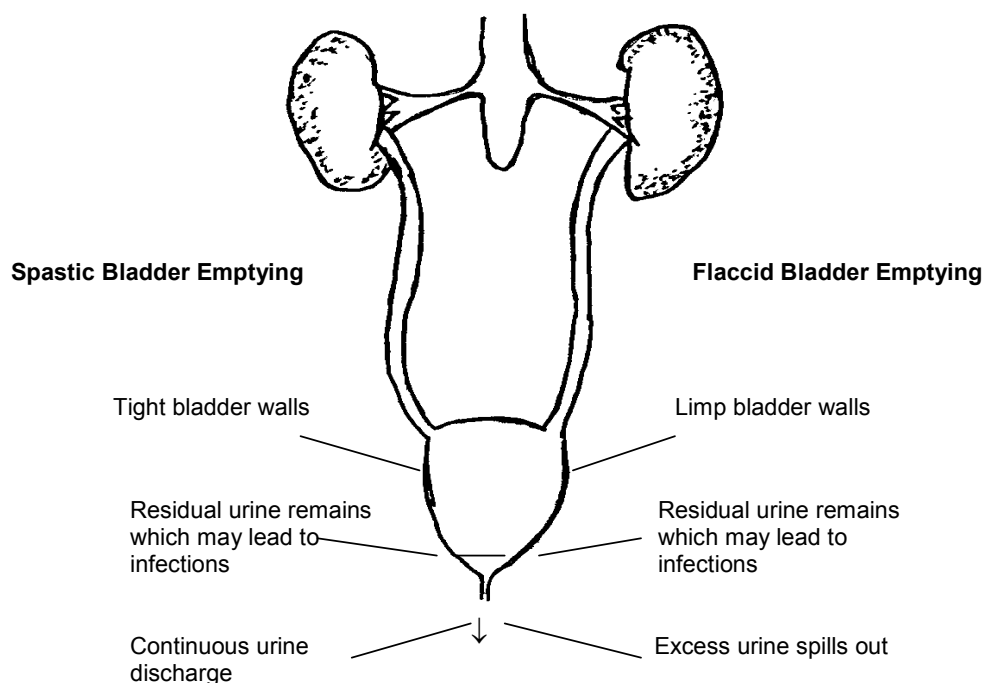
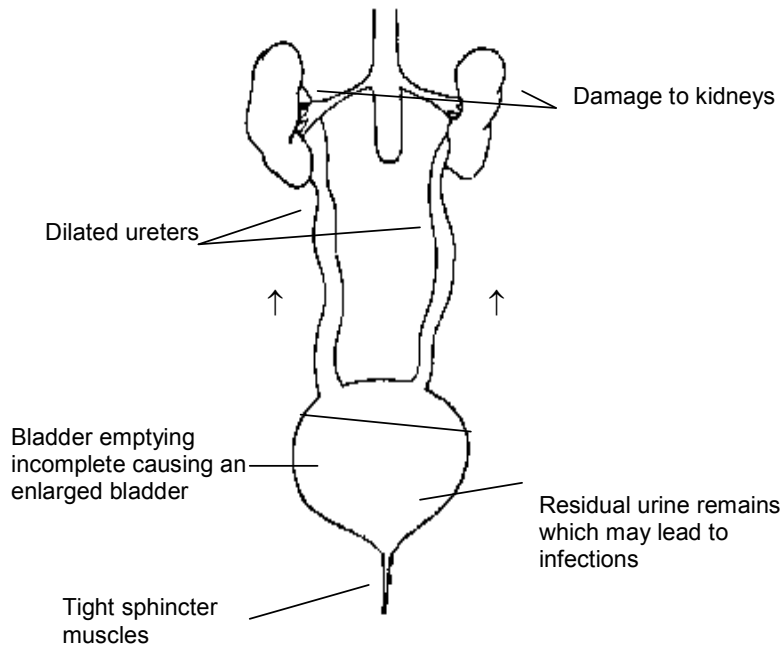


Figure 2. Urine flow of a Spastic or Flaccid Bladder with normal or low Sphincter tone

The bladder is also influenced by the control of the **urinary sphincters**. If nerve damage exists, the sphincter muscles can be either too tight or too loose. When the sphincter muscles are tight, urine becomes trapped in the bladder and is often forced back up the ureters to the kidneys (reflux). If the sphincter muscles are too loose, urine continually leaks out of the body.

Figure 3. Urine Flow of a Normal Bladder with a Spastic Sphincter



The urine, which refluxes back up to the kidneys, can be very damaging to the whole urinary system, but especially the kidneys. Normally, muscular flaps on the ureters close and once the urine flows out of the kidneys, it cannot flow back. However, the muscles that control these flaps are often damaged with spina bifida, and instead of urine following the path from the kidneys to the bladder and outside of the body, the urine can flow back up the ureters to the kidneys.

It is very important for a person's health that the bladder is completely emptied regularly. Urine that remains in the bladder provides an excellent breeding ground for bacteria, which thrive on warm, damp conditions. Repeated, severe infections in the bladder and urinary tract, over time, substantially damage the kidneys and impair their filtering capabilities.

The signs of a urinary tract infection, or as many doctors may call it, a UTI, 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

impaired function in the lower extremities should monitor the appearance of their urine carefully since they may not be able to feel the first warning signs of a urinary tract infection, such as pain while urinating.¹

Children, who have the most severe type of spina bifida (myelomeningocele), will almost always be affected by urinary incontinence. However incontinence is not limited to these children. Children with the milder types of spina bifida (occulta and meningocele) may also experience similar difficulties to varying degrees.

What are some management techniques?

There are several important aims of bladder management:

1. a reduction of reflux of urine to the kidneys,
2. a reduction of urinary tract infections and, of course,
3. social continence.

Due to the nature of the neurogenic bladder, children with spina bifida will never achieve total continence. What most children can achieve, however, is social continence. We can help children achieve social continence by teaching them techniques which will help them to stay dry throughout the day and night, and to have back-up plans for accidents. The techniques are quite discreet and only those people close to them need to know.

To become socially continent, either one, or a combination of the following strategies may be used. As you may discover, these strategies may not always work the first time, and may you need much time and patience to find the right method for **your child**. Remember, not all techniques suit all children and the same child may need different techniques at different times.

1. **Clean Intermittent Catheterisation (CIC)** is one of the main techniques used. The bladder is completely drained several times a day with a clean but non-sterile catheter. It is a relatively simple skill which children are encouraged to become independent with from an early age.
2. **Medication.** Different types of medication are prescribed for different reasons. Some medications may relax the bladder walls to allow for greater retention. Some help to dry up the bladder and some are important in clearing and reducing the occurrence of urinary tract infections. As with any medication there may be side effects. Find out what these may be when you are prescribed the medication. If you are unsure why your child is on a particular type of medication, ask!
3. **Adaptive Clothing.** Whether your child walks or uses a wheelchair, and to what degree he or she is bowel and bladder incontinent, will determine whether adapted clothing would be of benefit for your child. If adaptive clothing is required you can then decide which range of products would best suit your child's needs. Over the years, some items of clothing have been found to work better than others by parents who have 'been there... done that'. For instance, pants with velcro and straps, make dressing and undressing much easier, quicker, and allow greater independence.

4. **Incontinence Products** are available either through your local supermarket, chemist or through the MASS scheme which will be covered a little later in the booklet. Products include items such as pads, shields, nappies, and catheters.

5. **Toilet Timing.** As with many children without spina bifida, toilet management can be all in the timing. As your child grows older, your paediatrician, stomal therapist, or occupational therapist may discuss toilet timing with you as an option to maintain continence and health.

6. **Behaviour Strategies.** Toileting time is not always the most exciting time in children's lives. As a great deal of focus may be put into this private part of their lives, it is always important to remember to promote their self esteem, and encourage them by using behavioural strategies such as sticker charts and positive reinforcement.

7. **Possible Operations.** As always, there are medical procedures, which can be done, when other techniques are not sufficient. Some of these are Bladder Augmentation, Artificial Sphincters, Perineal Urethrostomy, YANG, and Mitrofanoff.

- *Bladder Augmentation* – A surgical operation where a section of the bowel (usually) is cut away and sewn onto a surgical opening in the bladder to create a large bladder with increased capacity.
- *Inserting an Artificial Urinary Sphincter* – A surgical procedure whereby a small fluid filled cuff is placed around the neck of the urethra. A pump is also inserted which when activated, releases the pressure of the cuff allowing urine to flow.
- *Perineal Urethrostomy* – A creation of an opening for the urethra in the perineum (pelvic floor) for ease of catheterisation.
- *YANG or Mitrofanoff* – Similar to a Perineal Urethrostomy, with the opening in the lower abdominal region near the belly button, allowing for easy access to the bladder directly, to allow for catheterisation.

More information on each specific operation is available and should be discussed in detail with your Urologist.

8. **Regular Check-ups.** It is important to remember that even after a child has begun their independence training, they will need to see the appropriate doctors regularly to monitor kidney and bladder function. It is through these regular check-ups that the doctors can monitor any slight changes in appearance and function, and therefore treat by prevention rather than cure.

Of course the most important thing to encourage a child to do to keep their bladder and kidneys clean and healthy, is to drink plenty of water. As always, this is easier said than done. But, persistence is important, as it may just be what their kidneys need!

THE BOWEL

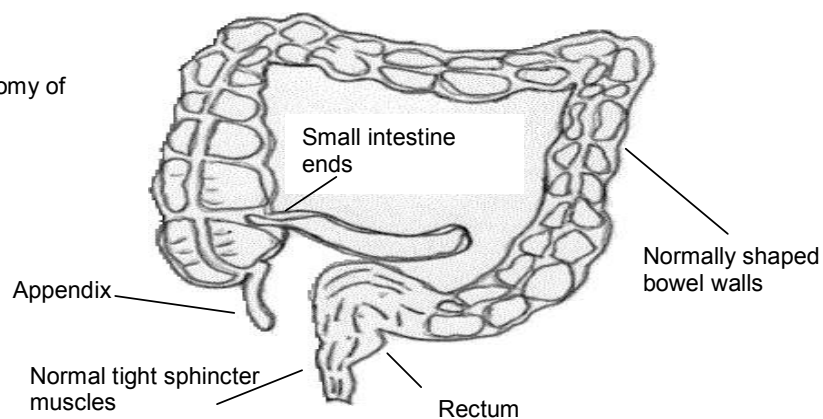
The human body is designed to rid itself of waste products, which it cannot or does not need. If we do not rid ourselves of these waste materials we can become very ill. The organs which help our body cleanse itself of waste are part of the lower digestive system, and are known as the 'bowels'.

How does the bowel system work?

The Bowel System is made up of many different components.

- **Small Intestine** – A long narrow tube in which many secretions from different organs of the body, such as the liver and pancreas, are sent to break down the products moving through it. Nutrients are absorbed and the remaining undigested materials are transported to the large intestine. Backflow of materials from the large intestine is prohibited by a muscular flap, much like urine is prohibited from going back up to the kidneys from the bladder.
- **Large Intestine** – This organ has little to do with the digestion of food. Most of the digestion here takes place in the cilia, which absorb the water and electrolytes from the remaining materials. Its main function is to form, store and expel the faeces from the body. At regular, uncontrolled intervals these materials are pushed down from the large intestine into the rectum by a series of waves of muscular contractions known as peristalsis.
- **Rectum** – The rectum is the last part of the large intestine below which the **Internal Sphincter, Anal Canal, and External Sphincter** are located. The internal sphincter muscle 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 a bowel movement is required. The bowel movement does not occur automatically at that particular time because of the external sphincter, a muscle we usually learn to control in the early years of life. When it is convenient, such as when we are sitting on the toilet, this muscle will relax, and a combination of rectal contractions and tightening of the stomach muscles, will push the faeces out of the body.

Figure 4. Normal Anatomy of the Bowel



How does spina bifida affect the bowel system?

Almost all people with spina bifida have some form of bowel incontinence. It can be very simple, or quite complex. As with most of the conditions associated with spina bifida, bowel problems are a result of damaged nerves in the lowest level of the spinal cord. Nerve damage generally affects three areas of the bowel: the two sphincter muscles, the mechanism which tells us that the rectum is full, and the muscles which aid the body in removing faecal waste.

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 a person with spina bifida often has little or no control over the external anal sphincter, faeces are often forced out of the body at an inappropriate time.

Nerve damage may affect the child's ability to realise when the rectum is full in two ways. The first is a limited sensation of what is happening in the bowel and the second is a decreased ability to send messages to the brain to empty the bowels. If the brain does not recognise when the bowel is full, and there is no control over the external sphincter, the bowels may open and empty when least expected.

Two main types of bowel incontinence are:

- The **flail anus** type. Soiling is likely to happen whenever the rectum contains faeces, as there is no external sphincter control to prevent the passing of the faeces.
- The **spastic sphincter** type. When some anal sphincter tone is retained, faeces may not be able to pass out of the rectum. Retention and a megacolon (an over-stretched piece of bowel due to a blockage such as constipation), will develop if evacuation is not regular. Due to the position of the bowel relative to the bladder, a megacolon may cause unnatural pressure on the bladder; consequently adding the instability already experienced. Further urinary incontinence difficulties, or reflux to kidneys may be experienced as a result.

Figure 5. Normal positioning of bowel and bladder

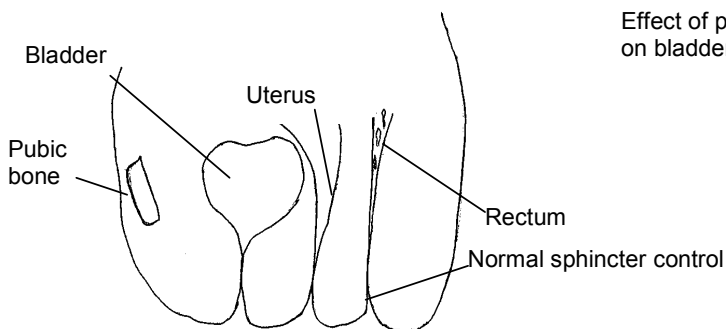
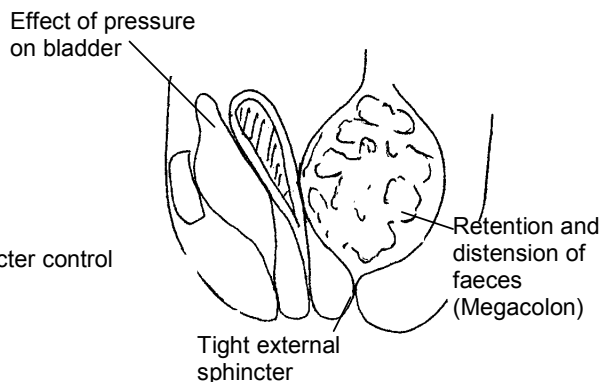


Figure 6. Spastic sphincter effect on bowel.



Weak stomach and pelvic muscles, which are commonly used to push the stool out of the body, are common amongst people with spina bifida. The combination of limited sensation in the lower digestive system and weak muscles can lead to a series of problems such as constipation, impaction, or rectal prolapse.

Being constipated can make a person feel nauseated, grouchy, and generally very sick. Constipation occurs when the stool is unable to be removed from the body and becomes hardened because the water it contains is absorbed back into the body.

What are some management techniques?

Again the important aims for bowel management is for the child to:

1. Establish regular bowel evacuations. This reduces incontinence and the risk of a megacolon developing.
2. Achieve social continence with independence and confidence in their own bowel management strategies.

As with the bladder, management of the bowel is often an ongoing issue throughout the child's life. Different combinations of strategies may be tried to achieve **the best** option for **your child**.

The following is a list of management techniques:

1. **Toilet training and timing** is similar to bladder training, where regularity is the key. It is an important part of starting a routine with your child, and will be very specific to his or her needs. It may involve different techniques such as bearing down, perhaps by laughing and coughing, to help the pushing. This should be done a certain number of times during the day and at regular times. It may also include regular enemas to ensure a clean day at school.
2. **Medications and Supplements** are often given to change the consistency of the faecal mass moving through the child's bowel. A certain consistency is required for the faeces to be pushed out whether this is done voluntarily or involuntarily. Medications and supplements may add bulk to the faeces, stimulate the bowel movements, or slow the bowel movements down. Again, the specialist will look at these depending upon the individual circumstances of the child.
3. **Adaptive clothing and Incontinence Products** are available. Anal plugs to assist with bowel continence are also available. They are often helpful in situations such as swimming lessons or day outings where social continence is a high priority. These are **not** recommended as a means of regular continence management. You should discuss these with your urologist, stomal therapist or occupational therapist before using them.
4. **Behavioural strategies**. Sitting on the toilet for long periods of time is not exciting for children who just want to play. Behavioural strategies may need to be used to distract them from the time they are there, encourage them to understand how important this is for them, and to use the time effectively. Some children

have finished off homework while on the toilet, played with a game boy, or even watched television while waiting.

5. **Possible Operations.** One current procedure is called the M.A.C.E. (Mitrofanoff Antegrade Colonic Enema). The M.A.C.E. (or A.C.E) involves the creation of a stoma (opening) for easy access into the large bowel in order to irrigate (wash out) the bowel. The appendix is often used as the duct between the opening and the bowel. More information is available on this from SBH Queensland and your hospital. Remember to ask your urologist many questions before deciding.
6. **Enemas and Bowel Washouts** will be recommended by the doctor or specialist in specific combinations and frequency. They may be used either through the M.A.C.E. (see above), or through the anus. Both techniques involve longer than usual periods of time on the toilet for the child to allow for a full clean out.
7. **Manual Evacuation (Gloving)** is often used in conjunction with pushing, to help the faeces exit through the anus, and to ensure a greater evacuation. It involves either the carer or the child manually evacuating the bowel using their finger.
8. **Diet** is a very important area for all children and should always be considered in conjunction with any other techniques. Most commonly, a diet including plenty of fibre and water is recommended. The following page contains a list of handy hints to consider regarding the diet of your child. Please speak with your doctor and dietician at your hospital when formulating new diets.
9. **Exercise.** Many children with spina bifida, due to mobility difficulties, or lack of motivation, are not as active as other children. Lack of movement in the legs and torso may cause the bowel to become sluggish, slowing down the movement of the faeces through the system. Regular exercise and increased movements are not only beneficial for the child's strength, health and size, but are also very important for helping to maintain a healthy bowel.
10. **Regular checkups** with the urologist and paediatrician will help to maintain a healthy bowel.



In the reference section, there are pictures and diagrams of several toileting aids and equipment available to look at or borrow from SBH Qld. Please call for further details on these items, or for any others not shown.

HANDY HINTS FOR DIETS

One of the most practical and important lessons you can teach a child about food is that the amount of food going in must equal the amount of energy being put out by them. If your child is putting on excessive weight, look at the amount and type of food they are eating.

Typically, many children with spina bifida are not as active as their peers. This can be due to either their physical limitations or lack of enthusiasm for sport. It is important for children with spina bifida to maintain a good weight and in turn, to maintain their mobility and strength. Remember prevention is better (and often easier) than cure.

Often the best diet for youngsters is generally to eat whatever their parents eat. This means that if you typically have a reasonably well balanced diet with minimal junk food, then this is a good place to start when creating your child's diet.²

Some ideas to think about and discuss with your doctor and dietician:

- ❑ Adding or reducing fibre in the diet will change the consistency of the child's stools. This can be done using different foods or supplements in a tablet or drink form. Remember that too much fibre can be as bad as not enough fibre.
- ❑ Adding or reducing dairy foods in the diet will also affect the activity of the bowel. Generally, the fat in dairy foods tends to slow the activity of the bowel and may eventually cause constipation.
- ❑ Adding or reducing fruit and fruit juices can change the consistency of the stools. Make sure you watch for intolerances to some fruit sugars as this may cause loose stools. The most popular fruits for loosening up stools for more regular movements are prunes, apples and pears (as well as apple and pear juice), cranberry juice, nuts, apricots, pineapples, melons, oranges and sultanas. Of course, fresh fruit with the skin on is higher in fibre than something that has been peeled or tinned, so keep the skin on your apples, pears, apricots and grapes!
- ❑ New foods should be introduced by adding small quantities to the food the child routinely eats. For example two or three peas with the mashed potato. This will let you know firstly, if they like it, and secondly, whether it will have any affect on their system.
- ❑ Vegetables are also very good for the bowel. Cabbage, corn, Brussels sprouts, cauliflower, peas, beans, carrots (uncooked especially), and celery are all good for keeping the stools a smoother consistency. (Some vegetables, such as cabbage, may cause increased wind, and consequently should be watched carefully.)
- ❑ Of course, foods with high amounts of carbohydrates such as breads, potatoes and cereals will help bulk up the amount of stool and avoid loose messy stools. They also provide lots of energy to burn, which is important for all children. Remember though to balance the input and output so children are neither over-filled and putting on weight, nor under-filled and losing energy.



Fig. 7. Healthy Diet Ideas

- Some parents recommend two types of food to help with bacteria growth in the body. The first is useful for replacing the ‘good’ bacteria in the bowel, which is lost during bowel washouts, and the second inhibits the growth of bacteria in the bladder, which lead to infections. Articles on both of these are available from SBH Queensland.
 - Many families have found, and research is being done, on the positive effects of **Yakult** on the bowel. As you may imagine, an enema will not only wash out the unwanted faeces from the bowel, but may also wash out a lot of the good bacteria as well. Yakult has been found to replace some of these good bacteria, and create a healthier bowel. However, Yakult works more on the replacing the intestinal flora in the small intestine and to a lesser extent the large intestine. It is the large intestine, which is mainly affected by the bowel washouts.
 - Research has shown that taking **cranberry juice** every day increases the ability of the bladder to defend itself against bacteria. It appears that the cranberry juice helps the bladder’s immune system by stopping the bacteria adhering to the bladder wall.

We are constantly on the look out for any more good dietary suggestions, so look for future articles in our newsletter, *Spinet*. If you happen to come across any good ideas yourself, please let us know so that we can pass them on to other parents.

- Most importantly, don’t try to rush. Finding the perfect diet can take time, and unfortunately it may also change. What seems perfect at one time may not be suitable twelve months later.

SELF ESTEEM AND INDEPENDENCE

SBH Queensland approaches independence and self-esteem holistically. The Association's staff work in conjunction with members' doctors and hospitals.

Toileting is one of many life skills, which the child will need to master, and any problems with it have a large impact on self-esteem. Therefore it is not simply treated with a short burst of intensive training. The entire process may take a long time to master successfully, many years in some cases. SBH Queensland staff regularly monitor children's progress with toilet training and particularly target skills such as regular clean intermittent self-catheterisation.³

Self esteem is a very important issue closely connected with toileting and continence. It is easily affected by the way these issues are managed. Decisions on toileting routines both at home and at school, must be made in the context of the child's self-esteem. Plans should therefore be made in conjunction with your child about his or her own toileting program. All routines should consider what is expected of the child, what happens if there is an accident, who can they talk to about this, and what back up plans can maintain privacy. A rule of thumb, to minimise embarrassment to the child and to maintain a respect for privacy, is to take a no-fuss, objective approach.

When to begin independence training will depend on what management strategies are being used. Bladder management such as catheterisation is commonly begun by preschool age, beginning with many of the background steps such as hand washing, catheter holding and removal. By this age these are usually quite easy for a child. The speed with which you progress through independence training will be determined by how quickly and easily your child is able to achieve each step. To become independent, your child must learn steps including:

- personal hygiene,
- dressing and undressing,
- transferring onto and off the toilet,
- management of any accessories required (pads, catheters, etc),
- correct sequencing of events, and
- correct timing.

Independence in the management and health of their own bowel and bladder is a big responsibility for a child of this age, and should not be rushed.

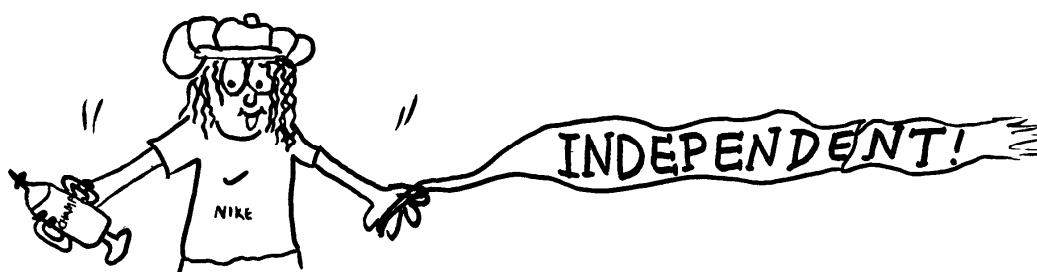
Children usually require assistance at first, and then supervision of continence management, during the first few years at school. SBH Queensland's occupational therapists can help you in this area, as well as provide information and guidance to those involved when required. Checklists, sequencing picture cards, and motivational charts are often used, depending on what appeals to each individual child. Consistency of routine between the home and school is very important for the child to gain and maintain steps to independence. Our goal of independence training is to have most children independent in bladder management by eight years of age. Depending on the technique, bowel management may or may not take longer.

It is also very important to consider the environment in which independence training is to be taught and followed through. Toilets and bathrooms must be accessible for children whether or not they use a wheelchair. For example, a sink, which is too high for the child to reach properly, compromises the hygiene steps. An occupational therapist can also assist you with the accessibility of toilets, bathrooms and all settings.

Teaching children about themselves is also an important step towards independence. This includes understanding the anatomy of the body, the effect spina bifida has on the body, and the reason it is important to follow the toileting program. This point is discussed further in the next section.

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Finally, it is important to remember that many children with spina bifida do experience many periods in hospital, or in plaster or in splints. Independence training may be halted or may even take a small step backwards during this period. Patience will be needed to work through these delays, and great encouragement and praise must be given when new skills are acquired.



COMPLIANCE

A very important thing to remember as a parent is that all children go through a stage of non-compliance at one time or another. Quite often this is related to the child wanting to feel, be, and do the same as their peers. This may range from simply becoming totally involved in an activity and forgetting to go, to being sick of toileting differently to others and to not wanting to do the routine at all any more. Whichever way this happens, the length of time this lasts will depend on how it is handled.

Being consistent and having good communication among all involved will enable you to see if problems are occurring at either home or school, and help to resolve them quickly. Praise and rewards work very well for younger children when they begin their toilet training. They must be remembered for older teenage children also who because they have become independent will not have the same amount of adult contact time as they previously did. Bargains and contracts can be used with children to help them to remember and complete their routines. One good strategy used for a child who constantly forgets the time for toileting may be to have a small beeper or alarm set on their watch to remind them.

Compliance is an important issue to address, as it not only challenges the patience of the family and school, but will also affect the health and well being of the child.

HANDY TIPS FOR SCHOOLS CHECKLIST

First and foremost, always remember that this is a child with toileting difficulties you are dealing with, not an incontinence problem that a particular child has. This simple distinction will help maintain the focus on the issues to be faced:

- Privacy
- Respect
- Continence
- Independence

To make the toileting setting more appropriate in your school, you will need to consider the following:

Tick once

- **Access to the toilet** – does the child use a wheelchair or will there be any chance a wheelchair may need to be used in the future?
- **Room** – can the child manoeuvre themselves around the toileting area independently and easily?
- **Sink, Cupboard & Bin**
 - ☐ Is the sink at a correct height for the child in a chair to reach and use independently?
 - ☐ Are there soap and paper towels handy?
 - ☐ Is there a bin for dirty nappies, pads & catheters, and a bucket or bag for washed out soiled clothing if needed?
 - ☐ Is there a lockable cupboard at the child's height in which they can keep all of their toileting needs safely and cleanly?
- **Privacy** – has this been considered?
- **Shower access**
 - ☐ Will the child require access to a shower in case of an accident?
 - ☐ Is it in an appropriate setting?
- **Equipment**
 - ☐ Have the parents provided pads, nappies, catheters, spare clothing, gloves (non-latex), wet ones, and gel (if required)?
 - ☐ Is there a change of clothes and extra pads and catheters kept in the cupboard or a bag in a specified location for emergencies?
- **Change table** – Will one be needed?
- **Routine** – Have you established how often and by whom the child is to be toileted or supervised?

- **Communication book** – Would a communication book between home and school for recording regularity, accidents, supplies needed and possible urinary tract infections be useful?

- **Contact person**

- ⇒ Is there a person the child knows to go to in times of emergencies for help?
 - ⇒ Do all the staff know who this person is?
 - ⇒ Is there a back up plan in place?

Comments _____

Further actions required _____

Our occupational therapists who have many years experience in this area can assist you by:

- Providing assistance and advice on establishing the toileting setting, for example the correct bench height, physical access, or adaptive equipment. If a new accessible toilet is to be built, the occupational therapists are happy to talk with the designer and builder about specific modifications.
- Helping to establish the toilet timing or programme routine in your school with the appropriate staff members, providing information and suggestions on independence training, checklists and motivational charts for each child.
- Providing general medical information on spina bifida and its relationship to bowel and bladder management to all staff, and
- Providing a link between hospitals and schools.

All children will be aware of their toileting problems, and may feel very self-conscious about them. They may express their negative feelings to those they interact with during toileting time. Teachers and teacher aides should feel prepared to encourage this and to discuss issues with them in a direct and responsible manner. If difficulties do continue, help should be sought through a trained counsellor.

The main thing to remember is that despite everyone’s best efforts, accidents do happen! So prepare yourself both physically and mentally.

CAN A CHILD WITH INCONTINENCE GO SWIMMING?

Yes, many children with spina bifida regularly attend swimming lessons and have found swimming an excellent way to improve both fitness and strength. However, There are a few things that you should consider before attending the pool.

- Is there likely to be an accident in the pool?

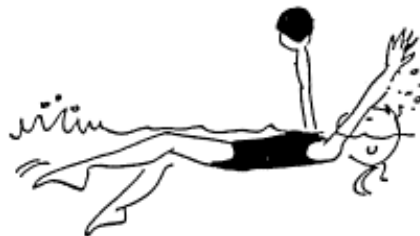
Do not assume that because your child has spina bifida or because they are bowel incontinent that they will have an accident in the pool. Arrangements can be done before hand at home in the morning, or just before entering the pool to prepare the child for an accident free day in the pool.

- Will the child be compliant?

It is very important to ask your child if he wants to participate in the swimming programme, and whether he agrees with the bowel management strategy to be used for this activity. This is particularly important for those children who may have to use temporary strategies to remain accident free in the pool.(see below)

Preparation at home simply involves the everyday routine done for an accident free day at school, such as an enema, bowel washouts, manual evacuation, or pushing. Other temporary management strategies include:

- **Anal Plugs** – These are small plugs, which are inserted much like a tampon, into the anus, and are able to stay there for several hours. Although they will keep the child completely accident free during that time, they should only be used as a temporary measure, such as during the swimming lesson, and **not** as a regular bowel management technique.
- **Taping or strapping** the buttocks together. This is really a last resort solution for a child who is unable to remain accident free during the short time they are in the pool. As taping is a specialised technique, it is important that advice is sought from the child's hospital before performing this. Taping should not be used on children who have achieved success or 'social continence' through other means, as it can be extremely damaging to their self esteem, confidence, and sense of control of their own bowel management. With taping you must also consider:
 - ☐ Who is responsible before and after swimming?
 - ☐ Will the tape cause abrasions and irritation to the skin?
 - ☐ Is this respecting the privacy and independence of the child?
 - ☐ Does he or she really want to go swimming?



MASS – MEDICAL AIDS SUBSIDY SCHEME

Previously this scheme was called the Home Medical Aids Scheme (HMAS).

The MASS scheme is operated by the Queensland Health Department to provide eligible Queenslanders, with many different types of disabilities, a range of aids to assist in living at home, and to avoid premature or inappropriate residential care or hospitalisation. For children with incontinence issues, the scheme's aim is to:

“Provide eligible Queenslanders, with permanent or stabilised incontinence, access to subsidisation for the provision of endorsed incontinent aids.”

To be eligible, the child must be a permanent resident of Queensland, and their parent's must hold:

- A Health Care Card, or receive the
- Carer Allowance (previously Child Disability Allowance)

For children who are **under five years of age**, only catheters are available through this scheme. Once children **reach five**, they are eligible for subsidies for pads, nappies, shields, and other aids through the scheme. Our occupational therapists are able to display the choices available, and provide help in choosing the best option for children. Depending on supplies, a trial pad can be sent out to make sure it suits the child's needs.

There are two things to remember when using this scheme:

- The scheme only provides a subsidy and this will usually not cover all the pads and nappies required over the same time period, and
- The choices of pads and nappies are restricted to the MASS endorsed list.

Conclusion

Although the information in this booklet is very general, we hope that you have gained further insight into spina bifida and it's effects on bowel and bladder control. If this booklet has helped you to create many questions to ask either you Paediatrician, Urologist, Stomal Therapist, or SBH Queensland, then it has achieved one of its important aims.

For further information please contact SBH Queensland.



RESOURCES

The following pages are photographs of just some of the toileting aids and equipment often recommended by our occupational therapists. Please call for further details on these, or any other aid you would like information on.



Toilet Trainer

Great for children during toilet training. Gives extra stability and confidence, as well as a step to aid in transfers.

Available through stores such as Target.

Cushie Tushie

As written about in SPINET. A cushioned toilet seat ring child size. Excellent for children who spend long amounts of time on the toilet such as for bowel washouts.

Available through Target, Toys 'R' Us, and Coles stores.



Commode

This over toilet and shower commode helps children and adults with speed and independence in the bathroom. By reducing the number of transfers required and increasing the mobility within the bathroom and bedroom, people are able to conserve energy and can achieve greater independence.



Over Toilet frame

This over toilet frame sits over the top of the normal toilet and the raised seat and grab handles help children and adults by giving extra stability and safety. It also helps with an easier standing transfer by having the level of the toilet seat raised

OTHER BOOKLETS AVAILABLE FROM SBH Queensland

Children with Spina Bifida and Hydrocephalus

Spina Bifida Occulta

Hydrocephalus: Educational and Social Implications

Visual Perception: Practical Strategies for Teachers

The Child with Spina Bifida and Sport

Swimming for Children with Spina Bifida

Folic Acid and its Role in the Prevention of Spina Bifida

Early Childhood: Learning Strategies, Social Inclusion and Social Skills Development

Adult Services Information Guide

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”.

¹ Carpick, S., **Yes You Can: A Kit for Teens** Spina Bifida Association of Canada, 1991

² Gilbert, S. and Hoath, L., **Oops: A common sense approach to toilet training a child who has a ‘problem’**, 1995, Penrith, Sydney.

³ Cheers, A., Windows, B., **The goal of catheterisation is independent children**, SBH Queensland & Mater Children’s Hospital Qld, 1999