

spina bifida

*A manual for young adults with spina bifida
about successfully managing your incontinence*

Passport to success



Spina Bifida Foundation of Victoria
and
The Royal Australian College of General Practitioners

February 2002

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Editorial panel

Dr Andrew Churchyard, Monash Medical Centre
Rhys Williams, Spina Bifida Foundation of Victoria
Judy Wells, Continence Nurse Royal Childrens Hospital (Melbourne)

Layout and graphic designers

Rodrick Faulkner
Mardi Saker

Illustrators

Elizabeth McLennan
Linda McLaughlan

© Spina Bifida Foundation of Victoria
PO Box 166
Parkville VIC 3052
Telephone 03 8344 7924
Website: www.sbav.org.au/foundation.htm

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A manual for young adults with spina bifida about successfully managing your incontinence.

Why is managing your continence so important?

Just as a passport allows you to enter other countries, successful continence management allows you to enter into a full and active life. A life that includes a happy sex life, good health and prevention of serious illness.

Today, most people with spina bifida live well into adulthood. Modern surgical and medical management techniques have made this possible.

Unfortunately, spina bifida never goes away. A successful lifestyle depends on you gaining the maximum amount of independence that you can. Independence to study, work, form relationships and perhaps start a family.

To achieve independence, you must be able to **manage** your spina bifida. And a difficult aspect to manage is your incontinence.

Because you have spina bifida, you should regularly attend a specialist clinic to keep well and to prevent problems from occurring. Prevention is the best way to stay well and happy.

Outline of the manual

This manual contains:

- this introduction
- tips on how to improve your organisational skills
- facts about managing bladder incontinence: question and answer checklists; managing bladder incontinence; reviewing self catheterisation techniques; urinary tract infection warning signs and case studies
- facts about managing bowel incontinence: question and answer checklists; managing bowel incontinence; diet tips and case studies
- spinal cord tethering
- hydrocephalus and shunt blockage
- sex and having a family
- staying well and preventing illness
- resources.

This manual has been written as a series of commonly asked questions and simple answers. It has a continence management planner at the end to help you organise your daily, weekly and annual routines.

You cannot do it on your own. You need to have a support team around you. There are three important team members:

- specialists at your spina bifida clinic — urologists or 'bladder' doctors, renal or kidney doctors
- your general practitioner
- continence nurse at a spina bifida clinic.

Better continence, better life: a case study

Sally is 25. She has spina bifida and a shunt for hydrocephalus. She walks with ankle foot orthoses (AFOs — a common type of splint) and uses a wheelchair for longer distances. She is on a clean intermittent catheterisation (CIC) routine for her bladder incontinence. Bowel continence is managed by very careful diet and enemas.

She says:

I loved school and though it was hard, I completed year 12 over 2 years. I didn't go to university or TAFE. Incontinence was my quiet terror word. I was never confident that I had it 100% under control so found it just too hard to take the big steps.

I did some part time work and short courses. I lost contact with good school friends as they moved on or moved away. It was so hard to talk about my incontinence. I got worse. Increasingly, I sat at home. I put on weight. I became a blob. I got a very bad urinary tract infection (UTI) which put me in hospital. Every cloud has a silver lining. I met a great urologist and continence nurse. They basically gave me confidence and forced me to confront the issue.

I went back to basics — better routines for cathing, and a minor operation called a Malone procedure to make bowel washouts more effective and easier to do. This helped me believe in myself a lot more.

What can I say? I am in the final year of a TAFE Business Information Technology diploma; I have an over- hectic social life; I have a steady boyfriend; I am a much stronger person.

MORE KNOWLEDGE IF YOU WANT IT

This manual does not cover 'what is spina bifida' in detail. The companion manual to this one, *Spina Bifida — Taking Control: Effective Continence Management in Spina Bifida* covers the medical side in detail. It has been written for doctors and nurses to help them provide better treatment. But you can find out more on the medical side by reading it. Both manuals are available on the website: www.spinabifida-incontinence.info

Ready to move on? You are taking the first step *now*.

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Tips on how to improve your organisational skills.

Most people with spina bifida have problems with organisation. Successful continence management requires very good organisation.

Good organisation is the foundation for good continence management

You know how you learn best.

Perhaps you prefer to take in information visually. If so, ask for diagrams or demonstrations with models if you have problems understanding written instructions.

If you prefer to hear in order to absorb information, use a voice recorder or a small tape cassette deck to record conversations and instructions. You can replay these later at your leisure to absorb information at your own pace.

When organising your health planner – there is a sample planner at the back of this manual – you might find it easier to transfer this to a wall chart. The planner is designed for you to record the telephone numbers of your doctors and nurses and other professionals you need to consult – a clear, easy to use ‘calendar’ for you to fill in with your various medical appointments.

Any method that improves your organisation is the one you should use!

- Be persistent and patient, and use reminders.
- Establish daily routines and stick to them.
- Do one step at a time. Break down tasks into smaller steps and master each one individually.
- The continence management planner at the back of this book will help you.

Key facts about managing bladder incontinence 1

What is the 'neurogenic' bladder?

This is where the nerves that send signals between the brain and the bladder do not work effectively. This happens to almost everybody with spina bifida.

Since the nerves do not work properly, bladder sensation is reduced and bladder emptying is affected. As a result, you may be incontinent.

For you to achieve bladder control, you need to understand a bit about the management issues related to the presence of this abnormal bladder function in spina bifida.

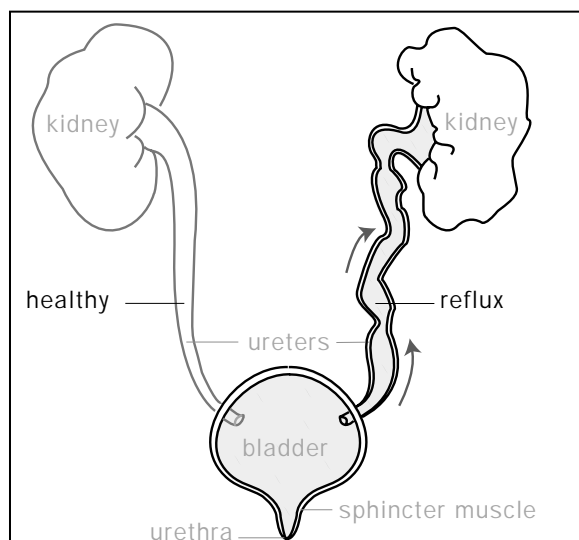
Effective bladder training depends upon the ability to feel the presence of urine in the bladder. Because of altered bladder sensation in spina bifida, you have decreased sensation. This interferes with your ability to stay dry.

What are the key characteristics of neurogenic bladder in spina bifida?

Typical characteristics are:

- not knowing when your bladder is full
- the bladder starts releasing urine when you don't want it to
- constantly 'dribbling' urine because the muscles that control the bladder are not strong enough.

Continence management is effectively working around these problems in a manner to give you maximum independence.



Contrast of healthy and neurogenic bladder in spina bifida.

Key facts about managing bladder incontinence 2

Why are people with spina bifida prone to urinary tract infections (UTI)?

In spina bifida, urine drains poorly and slowly from the bladder. Often the bladder is never completely empty, even though it leaks.

Usually, a urinary tract infection occurs because some urine stays in the bladder for too long and creates a perfect environment for the bacteria (bugs) which cause UTIs to grow.

UTIs must be managed quickly and effectively, usually with antibiotic tablets prescribed by your doctor. **Be sure to finish the course of tablets completely.**

If a UTI gets out of control, it can spread from the bladder up to the kidneys and cause a kidney infection, which is very serious. Significant, irreversible kidney damage can occur very quickly from such an infection.

Many people with spina bifida have 'bugs', which have become resistant to commonly prescribed antibiotics. This will mean a more careful examination of which bug is present (by culturing a urine sample) and the prescribing of a less common antibiotic designed to kill the bug. The antibiotic may need to be given intravenously (via a drip in your arm).

What is urinary reflux?

This is when urine which has been made in the kidney and flows down into the bladder, goes back up again, due to incorrect functioning of your urinary system.

Reflux typically causes:

- a UTI
- the kidneys to become 'urine-logged' and not work effectively.
- kidney stones.

Reflux is serious if it goes on for too long. Effective management includes seeing a urinary specialist (urologist) regularly. This specialist will test to see if reflux is occurring.

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Maintaining continence: Clean intermittent self catheterisation

Time to review your self catheterisation technique

The major bladder management technique in spina bifida today is clean intermittent catheterisation (cathing).

Every few hours the bladder is emptied through a catheter (a plastic tube) inserted into the bladder.

This keeps the bladder as empty as possible and to function as 'normally' as possible.

Keeping the bladder empty keeps you dry, prevents UTIs and prevents reflux.

The golden rules of cathing

- Establish a regular routine that suits your lifestyle.
- Empty the bladder according to your daily routine:
 - when you get up in the morning
 - after meal times
 - before going to bed.
- Always cath at the same time. This will help you to remember to cath when you are busy.
- Catheterisation should be performed before emptying the bowels
- Reusable catheters should be replaced by single-use catheters in the presence of a urinary tract infection.
- Allergies to latex (present in some gloves and catheters) are more common for you than the general population. Reactions can vary from mild skin rashes to severe anaphylactic shock. (You cannot breathe!)

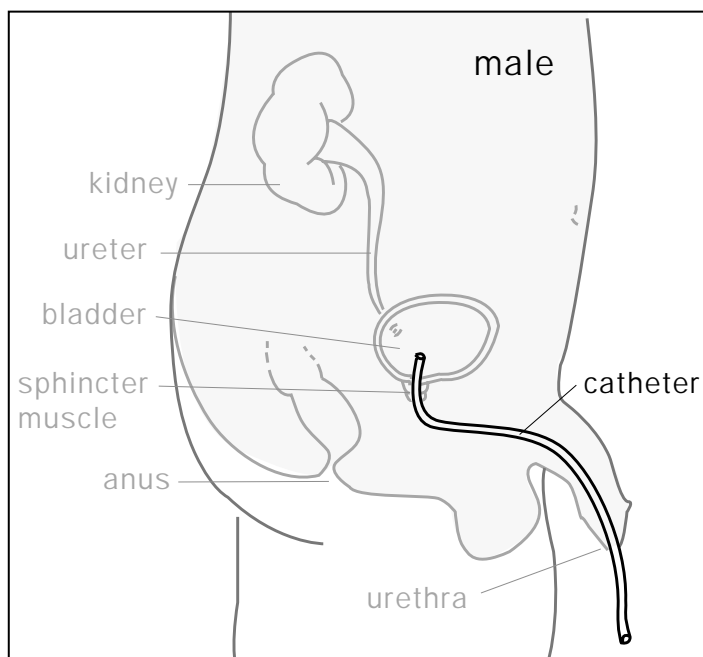
Clean intermittent catheterisation: Instructions for males

Equipment required:

- catheter
- cleansing solution
- lubricating gel
- wipes, and
- continence pads.

Procedures:

- wash hands with soap and water
- retract foreskin (if not circumcised) and wash the tip of the penis using a cleansing solution
- hold penis upright and gently insert the catheter into the urethra. If resistance is met part way, rotate the catheter or use gentle but firm pressure on the catheter until the muscle relaxes. It may also help to take some deep, slow breaths.
- when the urine flow has stopped, advance the catheter one more inch to ensure that you get the last urine drops and the bladder is totally emptied
- slowly remove the catheter
- males with foreskins should always push the foreskin back again after the procedure
- wash hands, put on clean pad
- wash up catheter and pack up.



Catheterisation for males

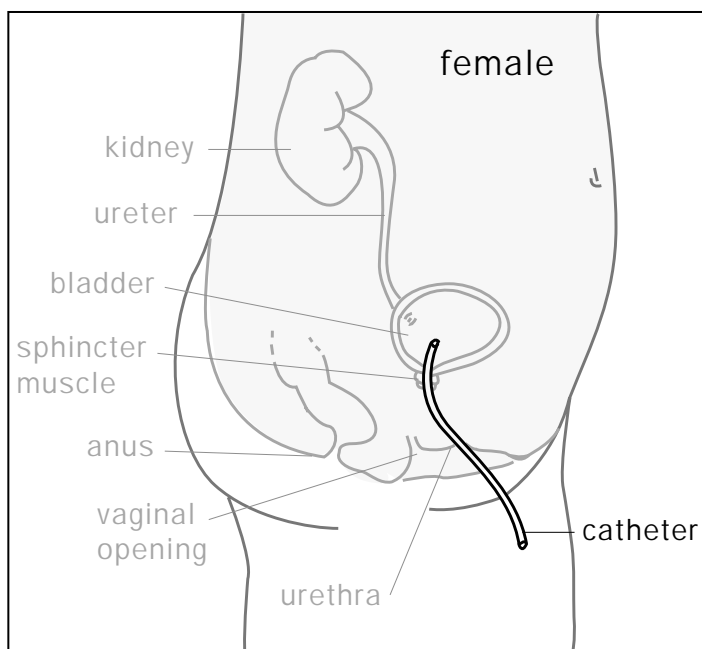
Clean intermittent catheterisation: Instruction for females

Equipment required:

- catheter
- cleansing solution
- lubricating gel
- wipes, and
- continence pads.

Procedures:

- wash hands with soap and water
- clean the vulva with three wipes from front to back
- wipe hands
- with one hand, hold the labia apart and see or feel the clitoris
- with the other hand, place the tip of the catheter behind the clitoris. Insert gently until it enters the urethra. Gently push in until the urine flow begins.
- when urine has stopped flowing, slowly pull out catheter
- wash hands, put on clean pad
- wash up catheter and pack up.



Catheterisation for females

Clean intermittent catheterisation: Instructions for males and females

Four more rules to remember:

1. The routine must be the same each time.
2. Ensure that hands are clean at each point in the procedure.
3. Be careful to prevent contamination from clothing.
4. The bladder must be fully drained, as incomplete emptying is a common cause of urinary tract infections.

Sometimes the flow of urine is stopped if the sphincter closes upon the catheter giving the impression of complete bladder emptying. This may be indicated by resistance when removing the catheter and lower urine output than expected during drainage. In this case, you will need to repeat the procedure in 1/2 to 1 hour.

Clean intermittent catheterisation: Questions and answers 1

What should I clean my catheter with?

Clean your catheter with clean soapy water, rinse it well and store it in an antibacterial solution like Milton.

What if I leak (dribble) inbetween cathing?

You need to manage it! There are many different types of continence pads, which will soak up the volume of urine you 'leak' between catheterising and will contain the smell. You need a comfortable continence pad, which holds the volume dribbled for at least 2 hours, retains odour and does not irritate the skin. See your continence nurse for help.

Why do I feel pain when I catheterise?

This can be for many reasons, some serious. It can be from a UTI, a damaged urethra where the catheter does not glide smoothly in and out, or muscle spasm, especially in the sphincter. Sometimes the sphincter will not easily open. Do not force the catheter in — try again in half an hour.

If ever blood is present, go to the doctor immediately. If pain persists for a week or more, see your doctor.



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Clean intermittent catheterisation: Questions and answers 2

What if I don't catheterise because I have had a urinary diversion procedure?

Some older people with spina bifida do not catheterise.

You have most probably had an operation called a urinary diversion when you were very young. In this operation, the ureters coming from your kidneys to your bladder were cut and tied. Urine flow was effectively diverted to a stoma (opening) on the skin of your lower stomach and into a urinary bag.

This procedure is not preferred today, because it places greater stress on your kidneys, and coping with a bag is harder to conceal and deal with in many activities.

However, if you have a stoma and a urinary continence bag, this is a very effective way of achieving bladder continence.

You must care for your stoma — to stop the skin around it ulcerating (going hard and becoming irritated). You must have a well fitting bag and change it regularly. You must regularly dipstick your urine with a nitrite stick to test for UTI.

The continence nurse or stomal therapist at your spina bifida clinic is an expert in this care, and will assist you develop and maintain a consistent and effective routine.

Some adults have their diversion operation reversed or 'undiverted', and move to a CIC routine. The ureters coming from your kidneys to your bladder are rejoined. Your urologist will assist and guide you to make the right decision in this matter.

Urinary tract infections (UTIs)

As described earlier, people with spina bifida are prone to UTIs.

You must be constantly on the alert for the warning signs and symptoms, which may indicate the presence of a UTI.

Early detection of a UTI will keep you well and out of hospital

The best person to pick up UTI early is **you**.

The commonest symptoms of a UTI are needing to go to the toilet often and pain when the urine comes out.

Because you may have reduced sensation in the pelvic region, you find it more difficult to notice these signs.

Other symptoms of UTI are:

- smelly or cloudy urine
- fever, nausea or vomiting
- sleepiness or tiredness
- loss of appetite
- headache and fever
- just feeling 'off colour'.

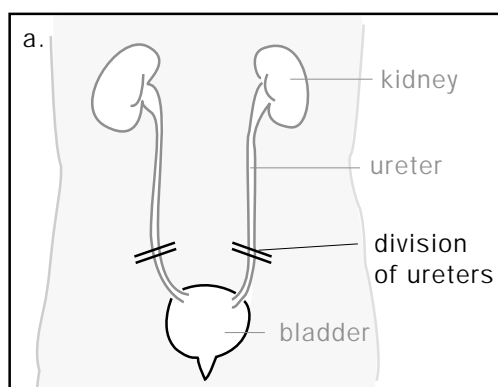
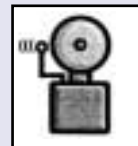
Kidney pain and spina bifida: an emergency. Do not hesitate to get expert help immediately.

Back pain in the kidney region occurs when the kidneys are infected.

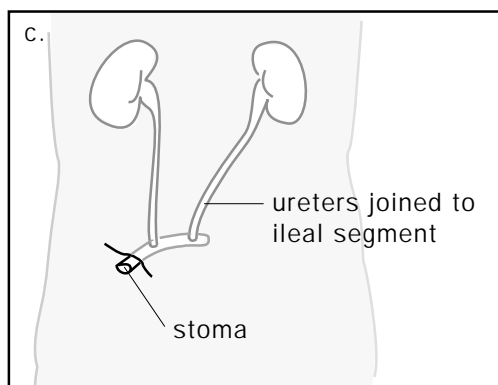
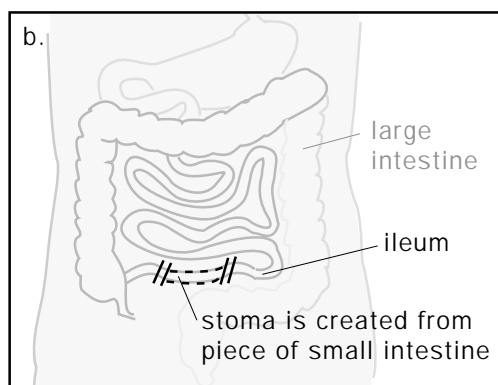
Kidney infections are very serious and can damage the kidneys

Kidney infections are always an emergency.

Always see a doctor or go to hospital immediately if you have a kidney infection.



Urinary tract diversion:
a. before,
b. ileal conduit
and
c. after diversion.



How do I manage UTI?

Prevention is the best cure

- Cranberry juice — the best kept secret in the world. This juice, readily available in supermarkets, will help prevent UTIs by keeping the urine nice and acidic and unfriendly to bugs.
- Drink lots of water, especially when it's hot. Never get thirsty. UTI bugs grow more easily if you are producing less urine. Drinking lots of water flushes the bugs out.
- Perfect cathing technique prevents UTIs. You can prevent UTIs from occurring by careful cathing.
- Detecting a UTI early is a key to good management. Early detection means immediate antibiotics and knocking over the infection before it gets out of control and into the kidneys.
- You should regularly dipstick your urine with a nitrite stick. These are relatively cheap and available from the chemist or your incontinence nurse. If the sensitive pad on the stick turns red when you dribble some sterile urine over it, a UTI is most probably starting. **Go to the doctor immediately!**

What if I get a UTI?

- UTIs must be managed quickly and effectively, usually with antibiotic tablets prescribed by your doctor.
- Be sure to finish the course of tablets completely.
- If a UTI gets out of control, it can spread from the bladder up to the kidneys and cause a kidney infection, which is very serious.
- As a result of frequent UTIs, many people with spina bifida have bugs, which have become resistant to standard antibiotics. This will mean a more careful examination of what bug is present (by culturing a urine sample), and the prescribing of a less common antibiotic to kill the bug. The antibiotic may need to be given intravenously (via a drip in your arm). This can mean a hospital stay.

How to successfully prevent UTIs yourself: a case study

Michael is a 25 year old man with spina bifida who has a history of 'run away' UTIs requiring multiple hospital admissions with kidney infections. In one year, Michael was in hospital 10 times. For Michael, the early signs of UTI included cloudy, smelly urine, fever, tiredness and nausea.

Prevention of UTIs for Michael included a referral to a specialist and urodynamic studies.

- Single-use catheters (not your usual reusable catheter) must be used when you have a UTI and until the infection has cleared.

What drugs can they help with my bladder incontinence?

- Under the direction of your specialist, medicines can be an important aid in your continence management. The most common agent is *ditropan*, which relaxes the muscles of the bladder and allows it to hold more urine. This means you will stay drier between cathing.
- These chemicals can have the side effects of dehydration and constipation, which are not desirable for reasons we have already noted.

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UTIs: The effects on your life

Case studies

Poor management

My name is Carol. When I turned 16, I didn't want to attend the children's spina bifida clinic any more. When I was very little, I had the urinary diversion procedure, which means I have a continence bag. I thought my condition had really stabilised, and I didn't need endless checkups and tests. When I left the children's hospital, I didn't have a transfer plan to adult doctors and an adult clinic. I didn't think I needed to.

I didn't know that as an adult, I had to look after my health.

In my early twenties, I had a bad run of UTIs. They kept me off work quite a bit. I went to the local doctor who prescribed antibiotics and they seemed to work. I am now 32. About a year ago, I developed a lot of kidney pains. My GP finally sent me to a kidney specialist. The pain was the signal that I was entering the final stages of kidney failure. I am now starting kidney dialysis and going on the transplant list. One kidney works about 15% and the other not at all.

I am very depressed with not being able to work and having my life ruled by dialysis. I am angry. Apparently, the urinary tract infections in my 20s had damaged my kidneys and left a lot of scar tissue. The urinary diversion caused the wrong pressures, which further hurt my kidney function. I could have had the diversion reversed. This would have meant cathing and being kinder to my kidneys.

Why didn't someone tell me that I needed to carefully manage my urinary system? Look at the mess I'm in, all unnecessary.



Effective management

My name is Sarah. I have been self catheterising since early primary school and everything has been going well. Cathing and continence pads for the inbetween periods has been my routine. It took me a long time to actually leave the children's hospital but I had a transfer plan. My 'kids' doctors found me a good 'adult' spina bifida clinic, including a urologist who still looks after me now. The 'kids' continence nurse told me just before I left: 'If you do nothing else, make sure you watch your urinary system and have regular specialist check-ups.'

I had a good urologist in my early twenties. I needed my bladder sphincter tightened. This operation also had a lot of complications, including infection, but it didn't damage my kidneys.

I am now 32. I have had a good run of late, touch wood. I had my annual check-up last month. This involves a kidney scan and some other pressure tests. The results were good. Kidneys working well; bladder volume and pressures about the same. Some overall deterioration, but no cause for alarm.

The big news for me is getting married, and yes, planning a family! Been to see all the docs in my team, to make sure my body can cope with a pregnancy. Got the go-ahead. They have found me a specialist obstetrician with lots of experience with spina bifida.

Spina bifida does not go away, but with the prospect of my own child and a good life ahead, taking good care of myself in a partnership with my medicos has paid off.



You have just looked at two totally different **continence management** scenarios. Sarah, who has taken good care of herself and been regular in consulting her urologist and other members of the spina bifida treatment team. And Carol, whose tragic situation could have been avoided, if she had sought expert advice.

Maintaining continence and preventing UTIs and kidney damage

Golden rule 1:

Regular monitoring of your urine system by **you** and your doctor is the key to staying well.

Golden rule 2:

You are the most important person in maintaining your health and happiness

Golden rule 3:

Prevention is better than cure.

How do I prevent UTIs and kidney damage?

- Cranberry juice daily.
- Drink lots of water, especially in hot weather. Never get thirsty. Drinking lots of water flushes the bugs out.
- Perfect cathing technique prevents UTIs.
- Detecting UTIs early before they get out of control and into the kidneys.
- You should regularly dipstick your urine with a nitrite stick. If the sensitive pad on the stick turns red when you dribble urine over it, a UTI is most probably starting. Go to the doctor immediately.

What tests do I need to have done once a year in adulthood?

- Urological surveillance never stops, no matter how old you are.
- You will require:
 - renal ultrasound to check for kidney condition and growth
 - renal function tests (blood tests) to check for how well your bladder and muscles are working; what volume of urine is being held and if the pressures in your system are okay.
- Refer to your health planner and make sure you record the times and dates of your regular medical appointments.
- It is essential that you go to all medical appointments and have all the tests your doctors order, **even when you feel perfectly well.**

See our continence nurse at least annually to:

- check your cathing routine
- review your products and aids — catheter type and size; pads; how to improve your routine, etc.

If you have a stoma, this should be checked by a stomal nurse at least annually.

See the example continence management planner at the end for an example of an annual cycle of good continence care.

Maintaining continence: Surgery 1

What other surgical procedures are available for improved bladder continence?

The decision to proceed with surgical intervention is a complex one, and must be tailored to suit each individual. Procedures are constantly improving so it is worth keeping up to date by asking your urologist about developments when you visit. It is also one of the reasons you must have regular urological tests.

The following is a list of common urological procedures used in spina bifida.

Vesicostomy: What is it?

The bladder is directly connected to the skin by a stoma. Urine drains directly out.

Why have it?

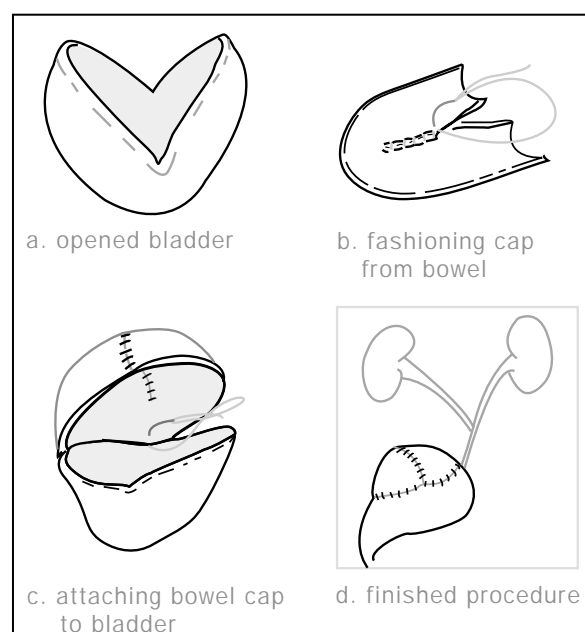
When there is poor bladder emptying with UTIs and back pressure (reflux) to the kidneys.

Augmentation cystoplasty: What is it?

The bladder is made bigger by sewing on a piece of bowel, stomach, or urinary system tissue.

Why have it?

When there is bad back pressure (reflux) to the kidneys.



Bladder augmentation

spina bifida

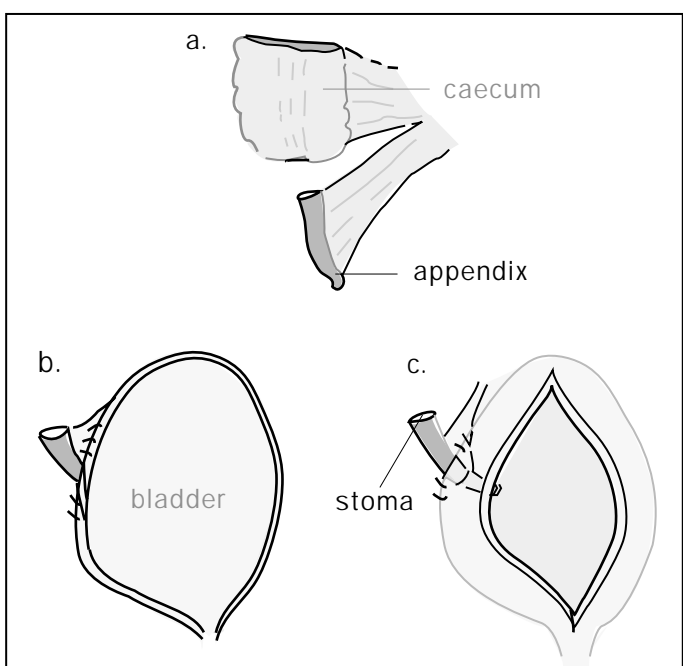
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The Mitrofanoff procedure/catheterisable stomas for the bladder: What is it?

The appendix is used to connect the bladder to the skin. The bladder can then be cathed via the stoma (hole) in the skin through the appendix.

Why have it?

When the urethra is blocked and cathing is impossible or when the person can't cath for some other reason.



Mitrofanoff procedure

Maintaining continence: Surgery 2

Transurethral injection: What is it?

The sphincter (ring of muscle) that stops urine from leaking out of the bladder is injected to tighten it up.

Why have it?

When there is leakage (incontinence) from a floppy sphincter that does not close well.

Slings: What are they?

A sling, often made of tendon, is looped under the bladder around the urethra. This operation is generally done in women.

Why have it?

When there is leakage (incontinence) from a floppy sphincter that does not close well.

Artificial urinary sphincters: What are they?

An artificial sphincter often made of silicon is inserted to help close a floppy sphincter. This procedure is usually done in men.

Why have it?

When there is leakage (incontinence) from a floppy sphincter that does not close well.

Circumcision: What is it?

The foreskin of the male penis is cut away

Why have it?

When the foreskin is 'gummed down' and causes UTIs or prevents cathing or interferes with having normal erections.

If you cannot easily pull your foreskin back over the head of your penis, see your doctor.

Bladder incontinence summary

Do I need to see my doctor?

Have you had your annual specialist check-up?

Are there any further surgery or drugs needed to improve your continence management?

If any new changes or problems occur before your next appointment, contact your doctor immediately.

How well is your catheterisation routine working?

Are your products — catheters, pads etc. up to date and suitable for your needs?

Use the attached continence management planner to record your visits and follow up.

Do I have a urinary tract infection?

Summary of key symptoms to watch for:

- smelly or cloudy urine
- fever, nausea or vomiting
- loss of appetite
- headache and fever
- just feeling 'off colour'.

Am I following good management principles for bladder incontinence?

Summary:

- regularly dipstick urine and if the stick turns red see your doctor immediately
- always drink lots of fluids
- drink cranberry juice regularly
- always follow your cathing routine and fully empty the bladder
- see your doctor immediately if there is unexplained pain or your continence changes.

Do I have symptoms of tethered cord syndrome? (see p. 18)

See a doctor immediately if you have any of the following:

- new pain
- changes to your urinary incontinence
- changes to your gait (way of walking)
- altered sensation in genital regions and during sex
- increasing muscle weakness or loss of sensation in your legs.

How do I find the best continence products and appliances for my needs?

Seek specialist advice from a continence nurse, and the Resources section on page 23.

Try as many products as possible. Trial and error is the best way to determine the most suitable products for you.

What products are available?

- drainage bags and equipment if you have had a urinary diversion
- pads (for day, night, sport, swimming etc.)
- anal plugs and bowel strapping material
- single use catheters and reusable catheters
- lubricants
- wipes
- latex free gloves
- carrying equipment
- special swimming gear and clothing.
- bedding.

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Key facts about managing bowel incontinence

This section covers bowel continence management, including constipation and other bowel problems.

You have probably discovered that achieving bowel continence has been one of your most difficult challenges.

The goal of effective bowel management is a routine that enables you to:

- avoid bowel accidents
- maintain stool consistency, and avoid constipation and diarrhoea
- achieve social continence at work and at play.

What is the cause of bowel incontinence?

As with the neurogenic bladder, bowel incontinence is caused by spina bifida related nerve damage. The nerves between the spinal cord and the bowel system have been damaged.

What are the main things that require management?

The nerve damage has caused the following:

- reduced sensation to know that your bowel is full and needs emptying, leading to bowel accidents
- reduced sensation to know when an accident has occurred
- weaker anal muscles making it more difficult for the anus to hold stools in
- bowel functioning which makes you much more prone to constipation, and if this occurs for a long time, the lower bowel becomes very stretched and even less sensitive.

The above problems will range from mild to severe in people with spina bifida. Your particular symptoms hopefully will be very mild.

What are the keys to effective bowel management?

The introduction of clean intermittent catheterisation (CIC) has made it so much easier to manage bladder incontinence in a way that supported an independent lifestyle. Nothing similar has been found for the bowel.

There is no bowel management technique which stands out like CIC does for the bladder.

How to manage bowel incontinence

The keys to effective bowel continence management are:

- understanding exactly how your bowel works and how it reacts to different food types
- how mobile you are – walker or in a wheelchair – makes a big difference. The more you exercise, the better your bowels will

function. Maintaining your mobility will protect you from constipation.

- keeping your stool at the right consistency (ie. too hard = constipation; too soft = diarrhoea) through careful diet and exercise so that your bowel is able to be managed
- effectively ‘training your bowel’ so that it is full at set times, thus making an emptying routine possible
- using the right aid to help empty the bowel — microenemas, large volume washouts, etc.
- great diet and plenty of exercise. These will keep your weight down and prevent obesity.

With a positive attitude, good organisational skills and making sure you regularly get advice from experts, you can effectively manage bowel incontinence.

If your bowel management is not ‘bomb proof’ by early adulthood, get specialist assistance from an expert. It can be difficult to talk about and really confronting, but you simply must.

Why is it so important to avoid becoming constipated?

Constipation can occur very quickly in spina bifida and makes effective continence management impossible.

Constipation increases the risk of urinary tract infections.

Many people with spina bifida have a natural tendency toward having firm stools. This is good, as firmer stools are easier to manage than loose stools. However, constipation where the stool is too hard is not good.

Constipation is often associated with bouts of diarrhoea, which is very confusing. The ‘too hard’ stools block the bowel; very soft and runny stools stuck above the constipation cannot be processed by the bowel properly, and will flow around the hard material causing a bout of diarrhoea.

Chronic constipation also stretches the bowel and leads to weakened sensation. This stretching can take years to get back to normal.

What causes constipation and diarrhoea?

The primary causes are:

- poor diet and lack of exercise
- medications, especially some used for bladder incontinence. Antibiotics – often for urinary tract infections – may cause temporary diarrhoea.

spina bifida

Passport to success

What other factors can cause a change in bowel habits?

Lifestyle factors and life events such as:

- holidays
- disruption in usual daily routines
- a change in water, such as when travelling
- illness, especially involving fever
- anxiety especially at work or school
- hospital procedures
- changes to family structure such as a new birth, separation, death of a relative or friend
- starting a new school or job.

A good diet: The key to good health and happy bowels

What diet will help achieve the right stool consistency for good bowel management?

While a healthy diet for people of all ages is a general health principle, diet can be used effectively by some people to alter stool consistency and support bowel control.

It is important to know which foods cause loose stools (diarrhoea) and which foods will promote a good firm stool.

Foods which are frequently associated with causing loose stools

- Citrus fruit, fruit juice, passionfruit, pineapple
- Corn (fresh or tinned)
- Baked beans
- Chocolate/malt/chocolate powders used to flavour milk
- Nuts/dried fruit.

If I need to soften stool consistency, what should I eat?

Eat more of:

- high fibre breads and natural whole grain cereals: eg. bran, oatmeal, rice
- fresh raw vegetables, raw fruit, sugar free juices
- fatty cuts — mince, sausage, mullet, tuna and mackerel
- matured or processed cheese, yoghurt
- whole milk
- herbs, spices, nuts, pizza, muesli bars, chocolate.

Eat less of:

- highly refined (white) breads, biscuits
- tinned fruits, juice with high sugar content
- lean cuts such as veal, chicken and whiting
- soft drinks, cordials, skim milk
- plain sugar, syrups, jellies, sweets.

If I need to harden stool consistency, what should I eat?

Eat more of:

- white bread
- cooked vegetables with low fibre such as potatoes, pumpkins, carrots
- tinned fruit in small amount
- lean meats — veal, chicken, whiting
- cottage cheese, boiled or poached eggs
- skim or low fat milk
- honey, jelly.

Eat less of:

- high fibre breads and natural whole grain cereals: eg. bran, oatmeal, muesli
- fresh fruits and vegetables, fruit juice
- fatty cuts — mince, sausage, mullet, tuna and mackerel
- whole milk, cheese, fried eggs
- cream
- herbs, spices, pizza
- minimise oil, butter and margarine.

As you can see, it is not a matter of limiting your food intake to alter stool consistency. It is a matter of selecting the right foods to suit your purpose. There is plenty of variety to choose from. You won't go hungry!

spina bifida

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Medical treatment of constipation and diarrhoea

Are there any drugs that can be used to control stool consistency?

Yes. Drugs can sometimes be used to control stool consistency, but should only be used for a limited period of time. Long term use of drugs may have a damaging effect on bowel functions.

Expert advice should be consulted before taking any drugs. Do not go to the chemist without seeing your doctor or continence nurse.



There are four types of drugs prescribed:

- laxatives (to deal with constipation)
- bulk forming agents (making your stools bigger)
- stool softeners (softening your stools)
- stool hardeners (hardening your stools).

What are the best techniques to assist with bowel emptying?

There are many techniques and methods for emptying bowels ranging from normal toileting to sophisticated surgical techniques. Most of you will have had extensive toileting experience.

Establishing a bowel emptying routine

Effective bowel management involves a system for bowel emptying at regular intervals, at least every 24 hours. For example, you could associate the timing of bowel emptying with meals, baths, and physical activities. A particular time of day can help establish predictable continence patterns.

Anal/rectal stimulation

Sometimes anal/rectal stimulation to promote bowel emptying can be achieved by wiping the anus firmly with toilet paper as soon as you sit. If the stool is not being expelled, slight pressure can be applied with the fingers to each side of the anus.

Digital stimulation involves inserting a gloved finger into the anus and massaging to stimulate a contraction to eliminate a stool.

Suppositories and microenemas

Most enemas and suppositories are special fluids squirted or placed into the anus. They assist to irrigate the bowel and wash out the stools. They assist particularly where you have reduced ability to push out the stools.

Large volume wash outs

If other methods do not work, large volume enemas also called 'colonic washouts' may be required to wash out the bowel. The amount and type of fluid is determined by the specialist clinic, and may include solutions of salty water; soap and water; or other solutions. The enema is administered by using a bowel washout kit. Make sure you get assistance from your continence nurse, and regularly review your technique at regular check-up visits.

Care must be taken not to use rubber catheters for those with latex allergies.

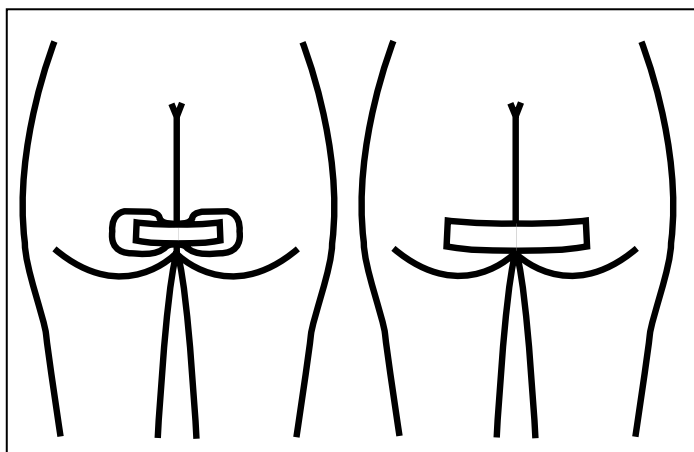


A large volume washout will clear the bowel for up to three days. The main problem is that you will probably need help to administer it. This of course means you are not as independent as you would like to be.

Are there any other procedures that may help with bowel incontinence?

Yes. Buttock strapping is a possibility. This provides a bit of extra assistance to your anus to hold in stools. However, this technique will not work when the stools are soft, or when there is diarrhoea. Strapping can be used when swimming, on special outings or even most of the time.

Try different types of tapes to ensure that they are waterproof or that no adverse reactions will occur. Typically used tapes include elastic adhesive tapes, nonallergenic tapes, waterproof adhesive and even electrician's tape.



Buttock strapping

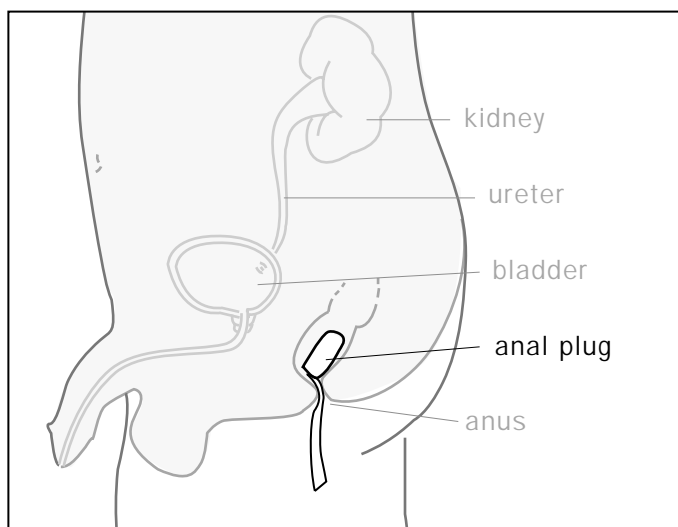
Buttock strapping procedure

- The tape is applied low on the buttocks so that it is under you when you sit down.
- Cut the appropriate length of tape.
- Look for the position of the anus.
- Attach tape to one buttock. While holding buttocks together, attach the other end of the tape to the other buttock, ensuring that the tape passes over the anus.
- If the skin is sensitive, place some nonallergenic tape on each buttock. Stronger tape can then be applied on top of this.
- If the anus is very lax, a small piece of paper, such as half a piece of toilet paper, can be folded and placed over the anus. Females should check that the tape has not slipped down into the vagina.

What is an anal plug?

Anal plugs are an important continence management tool, and can offer real independence for some. The anal plug, made from foam, is lubricated with Vaseline and inserted into the anus. After coming into contact with the moisture of the bowel, the plug expands in about 30 seconds to form a bowl-like shape that prevents leakage. The anal plug is made from slightly porous material so that air can pass through it. The plug is removed with an attached string and is changed after each toilet visit.

The anal plug can be worn safely for up to 12 hours. Combined with diet and bowel emptying procedures, anal plugs have significantly changed the lives of many.



Anal plug

What surgical procedures may assist?

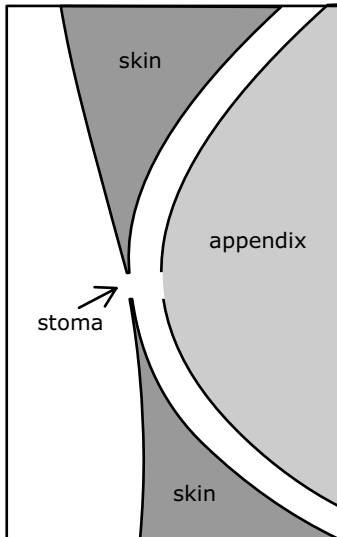
There are some options available for you to consider. Of course, you will consult a specialist in order to be advised as to the most suitable procedure for your needs. The most promising development is the **Malone** procedure which makes it much easier to administer the bowel wash out.

Malone procedure for ante grade (downward) bowel wash out

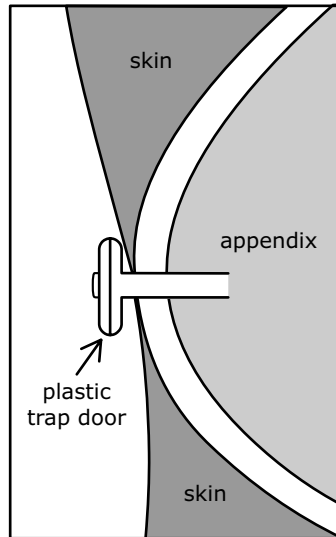
- The Malone stoma is a new surgical procedure that greatly improves the management of bowel incontinence for people with spina bifida.
- The procedure allows bowel wash outs or enemas to be done in an antegrade manner (flushing downwards) rather than in the traditional retrograde manner (flushing upwards from the anus).
- This works much more effectively and is much easier to self-administer. It supports greater self management, and therefore independence.
- In a very simple procedure, the appendix is brought to the surface of the skin and a stoma (opening on the skin) is created around the bikini line. The stoma allows access to the bowel through the appendix. The stoma has a little plastic trapdoor inserted in it that opens and closes.
- A catheter is placed into the stoma and into the bowel. A solution is injected through the catheter into the bowel. The fluid irrigates and flushes out stools in the bowel through the anus in approximately 20 minutes.
- A variety of fluids can be used (treacle and milk; saline; liquorice).
- This is much easier to do, especially for persons with limited mobility, than inserting a tube up the anus and firing a solution upwards against the force of gravity.
- Sometimes the stoma is created directly into the bowel. It has even been done through the belly button.
- The procedure is reversible, ie. if it doesn't work, the trapdoor is removed and the stoma grows over.
- Quality of life is improved. You can swim and do most other things with the device.
- The procedure is just starting to be used in spina bifida (at a range of different ages) and the results are positive.
- Be aware that it is not a magic bullet (it doesn't cure incontinence) and it won't work for everyone.
- Talk to spina bifida associations and doctors/continence nurses at spina bifida clinics for more advice and referral.

Spina bifida

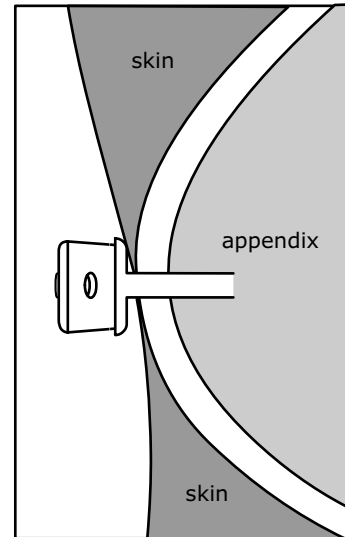
Malone Procedure



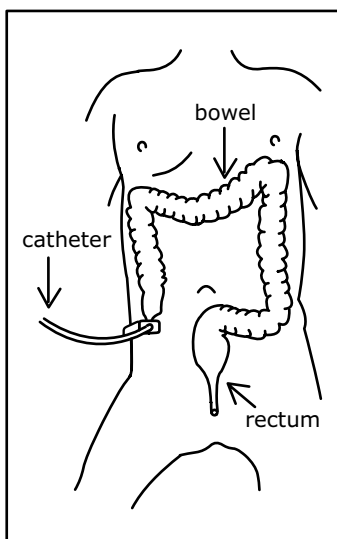
1. In a simple procedure, the appendix is brought to the surface of the skin and a stoma is created around the bikini line.



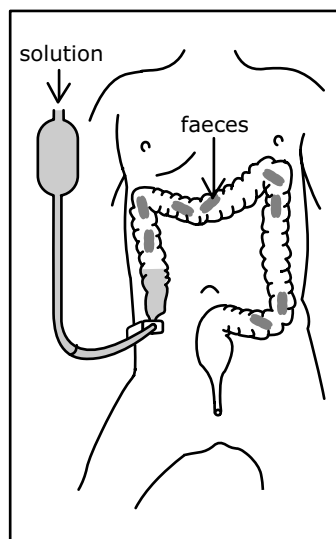
2. A little plastic trap door is inserted into the stoma allowing access to the bowel via the appendix.



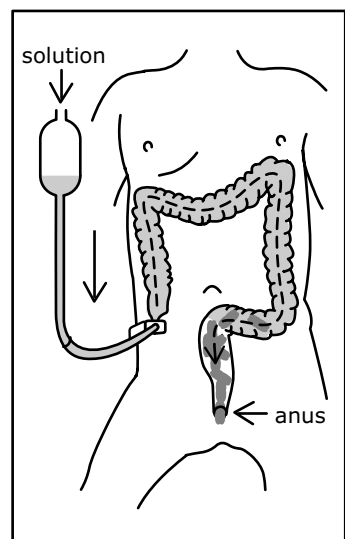
3. The plastic trap door opens and closes.



4. A catheter is placed into the stoma into the bowel.



5. A solution is injected through the catheter into the bowel.



6. The fluid irrigates and flushes out faeces in the bowel through the anus in about 20 minutes.

Bowel incontinence summary

Have I had my annual specialist check up?

Ensure that you see your urologist and continence nurse at least once every 12 months for a thorough check up and tests. This is to find out:

- how well your bowel is functioning, and how effectively your continence management routine is working
- whether you need to change your routine in any way
- whether any further surgery or drugs are needed to improve continence management
- if any changes or problems that have occurred over the last year need further investigation

- how well your enema routine and use of products is working.

Use the continence management planner at the end of this booklet to record your visits and follow up.

Am I constipated?

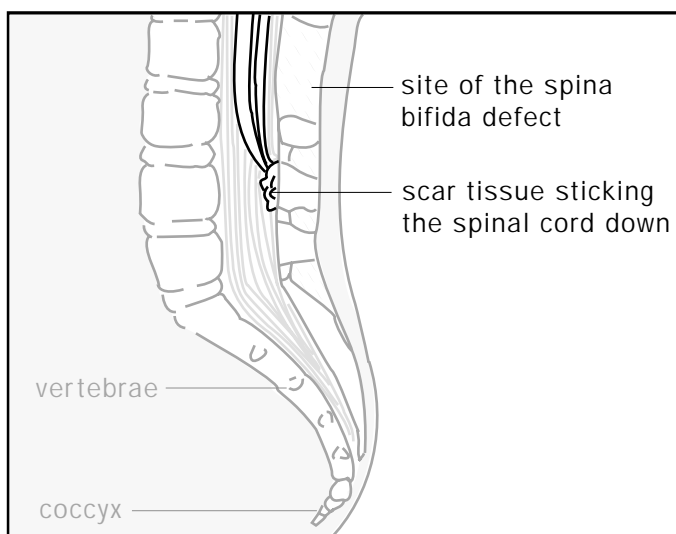
- If I have not been able to empty my bowel for two days, and my stool consistency is very hard I am constipated.
- If this occurs go to the doctor immediately for advice.
- Constipation should be attended to immediately.

spina bifida

Tethered spinal cord syndrome

What is tethered cord syndrome and how does it affect my health and continence?

In spina bifida, the end of the spinal cord is often stuck to the spinal bones and adjacent structures. This is called tethering.



Tethered cord syndrome

Stretching of the tethered spinal cord in young people and adults can occur and results in the tethered cord syndrome.

Tethered cord syndrome can occur at any age.



Stretching of a tethered cord causes further nerve damage, including to the bladder and bowel nerves.

Stretching of a tethered cord causes many serious problems including incontinence.

The following is a list of the symptoms of stretching of a tethered cord.

1. Pain

- Pain in the lower back and legs made worse by physical activity, eg. pain anywhere in the thighs or shins.
- Groin pain or pain in the genital/rectal area is common.
- Pain level stays the same when lying down.
- Straight leg raising causes no difference to pain.

- Inability to sit with legs crossed — like Buddha.
- Difficulty in bending slightly at the waist with activities such as washing up.
- Difficulty in holding light material (2.5 kg) at waist level while standing.

2. Urinary incontinence

- Worsened urinary incontinence such as the need to catheterise more often, leaking more urine between cathing, the bladder holding less urine.

3. Changes to your gait (way of walking)

- Increasing muscle weakness or loss of sensation in the legs.

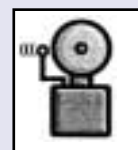
4. Altered sensation in genital region and during sex

5. Worsened bowel incontinence such as leakage.

Tethered spinal cord syndrome: diagnosis and management

How is tethered spinal cord managed?

Be aware and alert to the symptoms previously mentioned in order to maintain maximum lifestyle independence.



If you have symptoms of a tethered cord, seek medical help. Do not delay. The earlier the treatment, the less disability you will have.

A neurosurgeon will diagnose tethered cord by:

- an MRI (magnetic resonance image) picture of the spinal cord and lower brain area (an MRI is a sophisticated type of X-ray)
- careful analysis of your symptoms.

If the pain is bad or you are losing function, then surgery is necessary. The neurosurgeon will very carefully cut away the tissue which has become tethered.

Sex and spina bifida

Golden rule 1:

Many people with spina bifida have great sex lives. All should.

Golden Rule 2:

Many people with spina bifida get married and have a family of their own.

Sexual performance and spina bifida: The facts

- The nerve damage in spina bifida that affects urinary and bowel functions may also affect sexual functioning.
- Males may have normal sexual function, but this is commonly affected to some degree. Satisfactory erections are often possible, but there is no ejaculation. Other types of sexual dysfunction are also possible.
- Females are generally less affected in their sexual functioning.
- In males and females, altered genital sensation can affect – but does not prevent – arousal patterns and sexual functions.
- Orthopaedic problems, for example with lower limbs, can affect the ability to use some, but not all, sexual positions.
- Most males and females with spina bifida are fertile. Many of the issues surrounding conception in spina bifida are due to mechanical and anatomical difficulties in conceiving rather than a lack of fertility. There is access to assisted reproductive techniques. Consult your clinic about these.
- Since people with spina bifida often have latex allergies, you and your partner may need an alternative form of contraception to condoms. See your doctor for advice about forms of contraception.
- The major obstacles to a happy sex life are:
 - lack of confidence and self esteem
 - not meeting people
 - no car
 - not seeing 'sex' as being possible
 - incontinence
 - gaining independence from your parents.

All people have a right to a full sexual life. Sex and reproduction are increasingly important for young people as they reach adolescence and adulthood.

Sex and spina bifida: Important questions and positive answers

I don't want to discuss sexuality in front of my parents. I'm too embarrassed.

This is a common concern.

A supportive environment is essential.

You should feel free to ask your doctor or continence nurse for any information about your own sexual functioning when consulting them for routine assessment.

Remember, these professionals have a lot of experience in dealing with sexual issues and will understand any concerns you may have.

The best people to speak to about sexuality, relationships and achieving a meaningful sex life are adults with spina bifida who have 'been there and done that'.

When you first start to talk about sex it will be embarrassing, but after a while you will realise that it's good to do so and that it will help you help yourself!

What about the way my body is 'different' from other people's?

The issues of body image and self esteem that arise in spina bifida profoundly influence a person's sexual expression.

Remember, people with profound disabilities are capable of active sex lives.

Be reassured. Stephen Hawking the famous physicist, has overcome a great physical disability. He has fathered children.

Could my baby have spina bifida?

Yes. If you or your partner have spina bifida your risk of having a child so affected is much greater. Did you know that folate (a safe vitamin) taken by women before and during pregnancy significantly protects against spina bifida?

Genetic counselling is very important for both men and women who want to have a child. A genetic counsellor will explain the risks and the ways of protecting your baby from getting spina bifida and what screening tests can be done during the pregnancy. Your doctor can arrange for you and your partner to see a genetic counsellor before you get pregnant.

spina bifida

Sex and spina bifida: Important questions and positive answers for men

Can males with spina bifida father children?

Yes, of course. Many men with spina bifida are fathers.

Less is known about fertility in men with spina bifida than in affected women.

Men typically have problems with sexual function, which can be overcome.

Most men are fertile and can successfully father children.

What difficulties do men with spina bifida have during intercourse?

The major difficulty is achieving erections and ejaculation.

Difficulty in achieving erection is a common problem and is often easily treatable. Drugs, including Viagra, or injections often work. Physical techniques such as vacuum pumps or surgery are available. If you have difficulty with erections, you should not give up the idea of having sex until you have looked at treatment options.

Ejaculation is often impaired in men and achieving ejaculation is more difficult. Did you know that failure to ejaculate will not have any effect on the pleasure you give your partner?

There are safe methods of artificially collecting sperm which can be used to make your baby. This can be explained to you by a specialist.

Many young inexperienced guys worry that leg weakness will impair their sexual performance using the missionary position (on top). There are many other positions which can be used. Did you know that using these positions will not reduce the pleasure you give your partner?

Golden rule:

Men with spina bifida can have great sex lives and can give their partners as much pleasure as guys without disability.

Having a happy sex life: Case study

Rod is a 34 year old male with spina bifida, shunted hydrocephalus and has used a wheelchair since childhood. He has a urinary diversion and a stoma. He is continent. He has never been able to have an erection or to ejaculate. At 32, Rod formed a stable relationship with a nondisabled woman. He was given Caverject injections (an erection producing drug) and received advice about different positions which he could try during sex, as he has weak legs. He and his wife now enjoy a good sex life and are planning to commence a family.

Sex and spina bifida: Important questions and positive answers for women

Do I have a normal sexual response which is the same as for a woman without spina bifida?

Yes. Although women with spina bifida often report different vaginal sensation, this is not an obstacle to normal sexual responsiveness or your capacity to give pleasure to your partner.

Can women with spina bifida bear children?

Yes. Of course. Many women with spina bifida are mothers. Generally, fertility is not affected in women. In fact, it is important to use contraception to avoid an unplanned pregnancy.

Did you know that a study of women with spina bifida in Victoria found that although special intervention is sometimes needed, pregnancy and child birth is not tremendously difficult and does not do damage to, or worsen, mobility, continence, functioning or shunt function.

There are obstetricians (specialists who care for pregnant women and deliver babies) with experience in spina bifida who can advise and care for you. Your doctor can refer you and your partner to a specialist for advice before you become pregnant as well as for the pregnancy.

I am in a stable relationship and would like to have a child. How will spina bifida affect my pregnancy?

As described above, the course of pregnancy for you is similar to women without spina bifida except for:

- an increased risk of urinary tract infection
- the risk of pressure sores – from the extra weight you are carrying
- an increased risk rate of lower pelvic pain.

Should I have a vaginal or caesarean delivery?

The current recommendation is that you should be encouraged to deliver vaginally. It has been noted that women who have vaginal deliveries have fewer complications, faster recovery times and shorter hospital stays.

Women delivered by caesarean have a higher rate of complications, and surgery can be complicated if there is past history of urological surgery. Your specialist will recommend the best course for you to take.

Golden rule:

Women with spina bifida can have great sex lives and can give their partners as much pleasure as women without disability.

spina bifida

Passport to success

General health in spina bifida: The facts and how to stay well and happy

If you're sick, you won't be happy. Improving continence is only one part of staying well if you have spina bifida.

How can I stay well and happy?

- Look after yourself.
- Keep fit.
- Don't get fat.
- Make sure that you attend a specialist spina bifida clinic to prevent problems.
- Don't come to the clinic when you are sick. It might be too late.
- Remember, prevention is better than cure.

General health in spina bifida: Other health problems

Obesity: Getting fat

Many people with spina bifida put on weight as they get older.

Lack of mobility is a major contributing factor to the development of obesity in spina bifida.

It is crucial that you are able to manage your weight and that you do **not** get fat.

If you put on too much weight you will:

- lose mobility, including ability to transfer, and lose independence
- develop arthritis in your legs, arms and spine
- have trouble breathing
- lose your energy.

Stay physically active to keep your weight down. Sport and exercise, as well as keeping you active and slim, can be a major opportunity for social contact, peer support and meeting prospective partners. Are you aware of how many different sporting activities are possible for you?

- | | |
|-----------------|-----------------|
| • Archery | • Baseball |
| • Basketball | • Billiards |
| • Cricket | • Fencing |
| • Handball | • Lawn bowls |
| • Power lifting | • Road racing |
| • Rugby | • Shooting |
| • Swimming | • Table tennis. |

What about wheelchair dancing?

Sound like fun?

Skin care and pressure sores

Skin problems are common in spina bifida, especially when you are in a wheelchair.

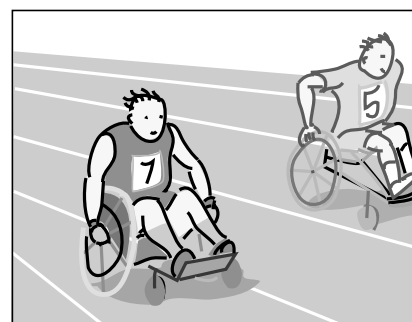
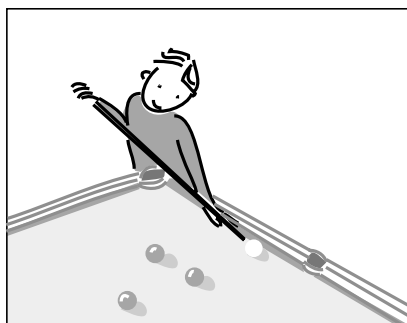
What skin problems occur and why?

The major problems are:

- poor mobility
- reduced sensation from damaged nerves
- naturally thin skin
- poor circulation
- difficulty reaching down to clip toenails and staying clean
- badly fitting shoes, aids and wheelchairs.

How can I prevent skin problems?

- Exercise and maintain mobility.
- Don't get fat.
- Move your weight regularly when sitting, and check your skin for telltale signs of a pressure sore.
- Attend your specialist clinic. They can make sure that your shoes, aids and wheelchair are OK.
- When you get a skin problem, see your doctor immediately. Never delay.



spina bifida

Passport to success

Latex allergy

Allergies to latex (common rubber) are more common in people with spina bifida than the general population. Reactions may vary from mild skin irritation to severe anaphylactic shock (where you can't breathe).

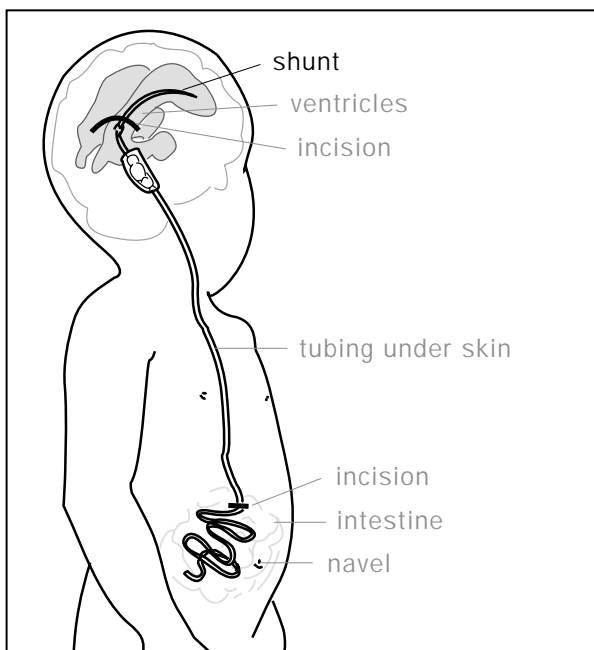
Care must be taken to avoid the use of rubber gloves and any other latex items, such as catheters and condoms. Most hospitals have a latex free operating theatre for procedures for allergic patients.

Through your spina bifida clinic, ask to have yourself tested for a latex allergy reaction so you know how badly affected you are.

Tethered spinal cord syndrome

See the special section on this important condition, page 18.

Hydrocephalus and the blocked shunt



Hydrocephalus and the V-P shunt

Many people with spina bifida have excess fluid in the chambers of the brain (hydrocephalus). Most people with hydrocephalus have a drain tube inserted when they are babies. This tube is called a V-P shunt and drains excess fluid from the brain to the abdomen. V-P shunts often block and have to be replaced. A blocked V-P shunt is a medical emergency. If the V-P shunt is not replaced, you can go blind.

Symptoms of a blocked V-P shunt are:

- headache
- nausea and vomiting
- loss of continence
- personality changes
- disorientation and memory loss
- blurred or double vision
- fits
- generally feeling unwell.

If you think you might have a blocked shunt, see your doctor urgently or go to your local hospital.

The treatment is to replace the shunt.

Social isolation and not knowing where to turn: How to overcome this

I feel isolated by having spina bifida. What can I do about the feeling of being cut off from people?

You need peer support. An excellent way to obtain this is to belong to your local spina bifida association. These excellent organisations provide contact between members by means of regular newsletters and events and will provide you with many opportunities for socialising.

Spina bifida associations are more than just social groups. They create a forum where members can offer each other mutual support and identify important common issues. Some of you may become very active in one of these organisations and find participation a very fulfilling part of your life. (See the following Resources section for contact details.)

Join your local spina bifida association now!

Peer support is one of the most important ways in which you can learn to adopt healthy behaviour and take part in various activities. If you do not already belong to your local SBA — **join now!**

The following section covers the resources available to you in your state.

STAY WELL!

STAY HEALTHY!

STAY HAPPY!



Resources

Local organisations can put you into contact with specialist centres and other resources in your area.

State based spina bifida associations

The spina bifida association in each state is a good first contact point when seeking information about support and services. The associations can assist those affected by spina bifida, their carers and those working with people with spina bifida. Membership is encouraged for all those with and affected by spina bifida.

Spina Bifida Association of NSW

c/o Northcott Society
Contact: Mike Sheargold
PO Box 4055
Parramatta NSW 2124
Telephone: 02 9890 0172
Website: www.northcott.org.au
Email: mikes@northcott.org.au

Spina Bifida and Hydrocephalus Association of SA Inc.

PO Box 272
Torrensville Plaza SA 5031
Telephone: 08 8443 5200
Fax: 08 8443 5100
Email: info@spinabifida.asn.au
Website: www.spinabifida.asn.au/

SBH Queensland

21 Tillot St (PO Box 8022)
Dutton Park QLD 4102
Telephone: 07 3844 4600
Fax: 07 3844 4601
Email: bshead@spinabifida.org
Website: www.spinabifida.org

Spina Bifida Association of Tasmania

Contact: William Brown
PO Box 450
Sandy Bay TAS 7006
Telephone: 03 6275 0987

Spina Bifida Association of Victoria

c/o Yooralla Society of Victoria
705 Geelong Rd
Brooklyn VIC 3025
(PO Box 1101, Altona Gate VIC 3025)
Telephone: 03 9362 6111 or Freecall 1800 686 533
Fax: 03 9314 9825

Email library@yooralla.com.au

Website: www.sbav.org.au

Spina Bifida Association of WA Inc.

37 Hampden Rd
Nedlands WA 6009
Telephone: 08 9389 8311
Fax: 08 9389 8331
Email: sbawa@swannet.com.au
Website: www.sbawa.asn.au

Key Australian spina bifida contact points

Australian Spina Bifida and Hydrocephalus Association Inc.

The Australian Spina Bifida and Hydrocephalus Association Inc. is an incorporated body servicing the interests of state bodies. The state based associations are the best contact point for clients, their families, carers and health workers, but the website contains useful information and links to Australian websites.

Website: www.asbha.org.au

Spina Bifida Foundation of Victoria

The Spina Bifida Foundation of Victoria was established to improve the quality of life of the spina bifida community by raising money for and developing a range of activities and services. Activities have a strong focus on promoting independence for people with spina bifida.

Spina Bifida Foundation of Victoria
PO Box 166
Parkville VIC 3052
Telephone: 03 8344 7924
Website: www.sbav.org.au/foundation.htm

Assistance for continence aids and funding

Many organisations are available to assist with obtaining continence supplies and aids.

The provision of equipment, disposables and aids for successful continence management can be expensive and many programs are available to assist affected individuals

When applying for assistance for incontinence aids, the number of organisations providing assistance and their roles can be confusing. Social workers, continence nurses and doctors all have experience in applying for the various schemes, and may be asked to help when completing application forms to ensure that no errors are made that may delay payments or applications.

spina bifida

Passport to success

Continence Aids Assistance Scheme

The Continence Aids Assistance Scheme (CAAS) is a Commonwealth Government program offering assistance to people who have permanent incontinence due to permanent disability.

The program offers an annual subsidy to approved clients to order approved continence aids listed on a schedule.

People aged 16–64 years of age with permanent incontinence from a permanent disability can apply for CAAS if they are eligible to receive a disability support pension through Centrelink, or a pension from the Department of Veterans' Affairs. CAAS also has other restrictions and eligibility criteria.

For further information, CAAS can be contacted through the company PQ Lifestyles at:

PQ Lifestyles
PO Box 2082
Milton QLD 4064
Telephone: 1300 134 260

or contact:

The Department of Health and Aged Care
Telephone: 1800 807 487

or write to:

CAAS
Department of Health and Aged Care
GPO Box 9848
Canberra ACT 2601

State based organisations

Each state has aids and equipment programs, and some have additional services available to assist with incontinence management.

Health care providers will be able to identify and refer patients to these services, especially specialist continence clinics. In addition, local spina bifida associations will also be able to identify appropriate services and agencies.

Useful websites

The following international sites contain useful information on spina bifida and hydrocephalus.

Spina Bifida Association of America
www.sbaa.org

International Federation for Hydrocephalus and Spina Bifida
www.ifglobal.org

Spina Bifida & Hydrocephalus Association of Ontario

<http://www.sbhao.on.ca/>

Other sites of interest include:

Continence Foundation of Australia
www.confound.org.au

Australian Council of Stoma Associations
www.australianstoma.org.au

Specialist spina bifida clinics

As well as adult spina bifida clinics, paediatric hospitals are listed as they can refer adult patients to suitable facilities in their local area. If there is no specific clinic listed in your area, contact your state spina bifida association for information on local specialist health care providers.

New South Wales

Adult Spina Bifida Clinic
Westmead Hospital
Department for Rehabilitative Medicine
Cnr Hawkesbury and Darcey Roads
Westmead NSW 2145
Telephone: 02 9845 7800

Spina Bifida Clinic (children)
Sydney Children's Hospital
High Street
Randwick NSW 2031
Telephone: 02 9382 1589

Spina Bifida Unit (children)
The New Children's Hospital at Westmead
Locked Bag 4001
Westmead NSW 2145
Telephone: 02 9845 2769

Northern Territory

Alice Springs — contact Spina Bifida Association of South Australia
Other places — contact SBH, Queensland

Queensland

Princess Alexandra Hospital
Spina Bifida Clinic for Adults
Cornwall St
Woolloongabba QLD 4102
Telephone: 07 3240 2641

Mater Children's Hospital (children)

Spina Bifida Clinic
Raymond Terrace
South Brisbane QLD 4101
Telephone: 07 3840 1812

Royal Children's Hospital (children)

Spina Bifida Clinic
Herston Road
Herston 4029
Telephone: 07 3636 7818

Spina Bifida Clinic Paediatrics Outpatients (children)

Gold Coast Hospital
Telephone: 07 5571 8345
Nerang Street
Southport QLD 4215

Townsville Children's Community Therapy Services (children)

Spina Bifida Clinic
Telephone: 07 4728 2681

South Australia

Spinal clinic (adult)

Royal Adelaide Hospital
North Terrace
Adelaide SA 5000
Telephone: 08 8222 4000

Spinal clinic (adult)

Queen Elizabeth Hospital
28 Woodville Road
Woodville South SA 5011
Telephone: 08 8222 6000

Continance Clinic (adult)

Repatriation General Hospital
Daws Road
Daw Park SA 5041
Telephone: 08 8275 1927

Spinal and continence (children)

Adelaide Women's and Children's Hospital
King William Road
North Adelaide SA 5006
Telephone: 08 8161 7000

Tasmania

Contact State Spina Bifida Association

Victoria

Adult Spina Bifida Service

C/- Monash Institute for Neurological Disease
Monash Medical Centre
Clayton Road
Clayton VIC 3168
Telephone: 03 9594 2240

Spina Bifida Clinic (children)

Royal Children's Hospital
Flemington Road
Parkville VIC 3052
Telephone: 03 9345 5522

Western Australia

Spinal Rehabilitation Clinic (children)

Princess Margaret Hospital for Children
Thomas Street
Subiaco WA 6008
Telephone: 08 9340 8886

Continance organisations

National Continance Helpline

The National Continance Helpline is a joint project of the Commonwealth Government and the Continance Foundation of Australia. It aims to assist people with incontinence, their families and carers, as well as health professionals. The help line can refer patients to local services. Telephone: 1800 330 066

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More help can be gained by contacting the Continence Foundation of Australia at:

Continence Foundation of Australia Ltd
AMA House
293 Royal Parade
Parkville VIC 3052
Telephone: 61 3 9347 2522
Fax: 61 3 9347 2533
Website: www.confound.org.au

Ostomy associations

The following associations may be of use to patients for stoma care. Colostomy associations can also help with other stoma besides just colostomies. If no ostomy association is listed close to your area, please contact your state spina bifida association for local ostomy health care providers and services.

Australian Capital Territory

ACT & Districts Stoma Association Inc.
2nd Floor, Department of Health Building
Cnr Moore & Alinga Streets, Canberra City 2601
PO Box 1260, Canberra City, ACT, 2601
Telephone and fax: 02 6205 1055

New South Wales

Colostomy Association. of NSW Inc.
Unit 5/7-29 Bridge Road
Stanmore NSW 2048
Telephone: 02 9565 4315

Ileostomy Association. of NSW Ltd

Block E, Ozanam Village
West St, Lewisham NSW 2049
Telephone: 02 9568 2799

Queensland

Gold Coast Ostomy Association Inc.
8 Dunkirk Close
Arundel QLD 4214
Telephone: 07 5594 7633
Website: www.ostomy.org.au

North Queensland Ostomy Association Inc.
Shop 4,
52 French Street
Pimlico QLD 2478
Telephone: 07 4775 2303
Website : www.ostomy.org.au
All correspondence and orders to:
PO Box 1017
Hyde Park
Castletown QLD 4812

Queensland Colostomy Association Inc.

22 Beaudesert Road
Moorooka QLD 4105
Telephone: 07 3848 7178
Email: colostomy@primus.com.au
Website : www.ostomy.org.au
Queensland Stoma Association Inc.
Unit 4, 'Accent Place', 10 Valente Close, Chermside 4032
PO Box 370, Chermside South, QLD, 4032
Telephone: 07 3359 7570
Emergency Telephone: 07 3359 7570
Website : www.qldstoma.asn.au

Toowoomba & South West Ostomy Association Inc.

c/o Epworth Nursing Home
Stenner Street
Toowoomba QLD 4350
Mail address: P.O. Box 7314, Toowoomba M.C., 4352
Telephone: 07 4636 9701
Website : www.ostomy.org.au

Wide Bay Ostomy Association Inc.

c/o Bundaberg Base Hospital
Bourbong Street
Bundaberg QLD 4670
Telephone: 07 4150 2074
Website : www.ostomy.org.au

South Australia

Colostomy Association of SA (C.A.S.A.)
160 South Road
Torrensview SA 5031
Telephone: 08 8354 2618

Ileostomy Association SA Inc.
1 Shipster Street
Torrensville Adelaide SA 5031
Telephone: 08 8234 2678

Tasmania

Ileostomy & Colostomy Association (TAS) Inc.
Statton Bldg, Repatriation Centre
Hampden Road
Hobart TAS 7000
PO Box 415, Sandy Bay, Tas, 7006
Telephone: 03 6223 2974

Victoria

Ileostomy Association (VIC) Inc.
Suite 322, 3rd Floor, The Block
98-100 Elizabeth Street
Melbourne, VIC 3000
Telephone: 03 9650 9040

Ostomy Association of Melbourne Inc.
Cabrini Medical Centre
Isabella Street
Malvern VIC 3144
Telephone: 03 9508 1879

Western Australia

WA Ostomy Association Inc.
15 Guildford Road
Mount Lawley WA 6050
Telephone: 08 9272 1833

Further reading for patients

Information on the following publications is available from either the Spina Bifida Association in your state, or by contacting:

Library and Information Service
Yooralla Society of Victoria
705 Geelong Road Brooklyn VIC 3025
Telephone: 03 9362 6143
Email: library@yooralla.com.au
Website: www.yooralla.com.au/library

Spina bifida and hydrocephalus explained. Spina Bifida Association of Victoria.

A booklet explaining the basics of spina bifida and hydrocephalus in plain language.

Downloadable from the website www.sbav.org.au

Spinabilities. A young person's guide to spina bifida by Lutkenhoff M, Oppenheimer SG. Woodbine house, 1997.

A young person's guide to all aspects of spina bifida including incontinence and sexuality. Excellent resource for teenagers with spina bifida.

Hoath L, Gilbert S. Oops. A common sense approach to toilet training a child who has a 'problem'.

This excellent plain language guide covers all aspects of the management of urinary and faecal incontinence. Although written for children and young people, it contains much information of use for the adult with spina bifida.

Nolan T. Fitness training diary. Royal Children's Hospital. 1996.

This resource contains information and a diary to help manage faecal incontinence and is available from the Royal Children's Hospital, Melbourne.

SAMPLE ONE YEAR CONTINENCE MANAGEMENT PLANNER

YEAR 2001

Jenny is 25. She is extremely fit and healthy, and plays A grade wheelchair tennis. She is an administration assistant in a legal firm. Her continence management routine is:

- cathing 4 times a day
- weekly dipsticking of urine with a nitrite stick to check for a UTI
- 2 hourly continence pad change
- very careful diet management, and lots of water intake
- microenema 2-3 times a week
- regular checkups.

Even though Jenny is healthy she knows that prevention is better than cure. This is her continence management planner.

SPECIALIST	NAME
My local doctor/General Practitioner (GP)	Dr. Sally Jones
My Urologist	Dr Peter Brown
My Continence Nurse/Stomal Therapist	Ms. Jeanette Petersen
My Renal (Kidney) specialist	Mr. Colin Fredericks
Spina Bifida Clinic contact details	Jenny Vagg (Coordinator)
Other - Neurologist	Dr. Susan Andrews
Other	

MY COMMENTS

MY COMMENTS

JAN	15th - Made appointments for the annual renal ultra-sound, nuclear medicine scan, blood tests - for Jan 28th. 28th - All tests done. Available in a week. Made appointment to see Dr. Peter Brown Feb 8th.	Reminders to mention to Dr. Brown Feb 8th.: 1) last UTI was 4 months ago, course of Keflex worked fine; 2) have noticed more urine overflow between catheters and less through catheter in mornings.			
FEB	8th - Dr. Brown - Good/bad news. Made appt for Feb 14. 14th - Had MRI. Get results in 2 days. 16th - MRI results - my spinal cord is a bit more tethered than the one done 3 years ago. Brain looks good though, no shunt probs. Dr. Andrews wants me to closely watch for any pain in moving around; see if worsening in bladder output. See again 6 months. Made appt for August 26.	Good: renal ultrasound and nuclear medicine scan show kidney function same as last year & pressures fine. Blood tests normal. Not happy about being wether between cath. Mentioned cord tethering and have to get an MRI and see neurosurgeon. Apparently changed cord tethering can make bladder 'weaker'.			
MAR	26th - Regular 'once over' at sb clinic. No dramas.	Jeanette reckons that I shouldn't be having any bowel accidents at all now. Has suggested that I consider Malone stoma for downward washout. Having a stoma doesn't sound too bad. I got the web address of a simple article. Note: speak to Dr Brown about it and get a referral.			
APRIL			OCT	19th - Went to continence products expo.	Saw these anal plugs. Not as gross as I thought they would be. Note: call Jeanette and see if they are available for trial and are on the CAAS [Continence Aids Assistance Scheme].
MAY			NOV		
JUNE	3rd - Bugger. Dipstick red and cloudy urine. UTI for sure. 4th - Saw doctor at 24 hour clinic. Keflex again. 11th - Finished Keflex. Bowels have been wonky all week.		DEC		
MAR			SEPT		
AUG			JULY	11th - One month since UTI and still clear.	
				23rd - Had a long chat with John [boyfriend] tonight. 26th - Saw Dr Andrews.	Went over stuff for Dr Andrews follow up on 26th. No pain; mobility about the same; definite improvement in amount of urine the bladder is holding. Just monitor! Hooray.

