

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.

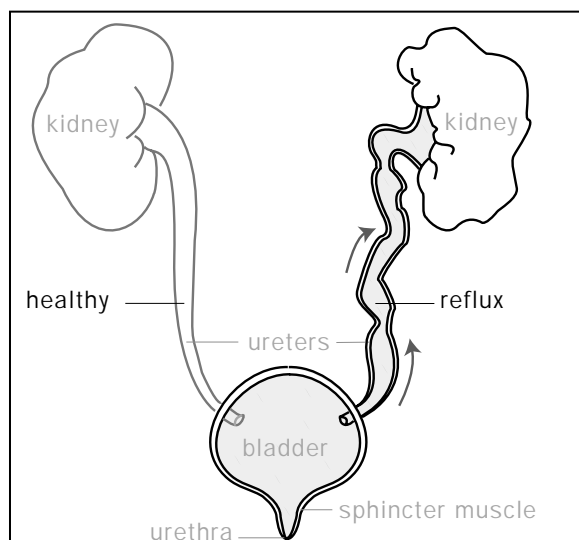
Effective bladder training depends upon the ability to feel the presence of urine in the bladder. Because of altered bladder sensation in spina bifida, you have decreased sensation. This interferes with your ability to stay dry.

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!)

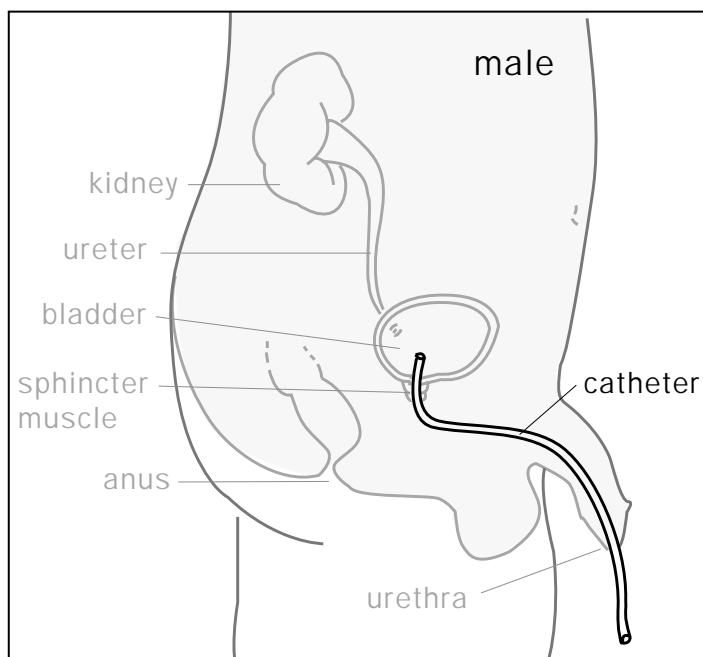
Clean intermittent catheterisation: Instructions for males

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

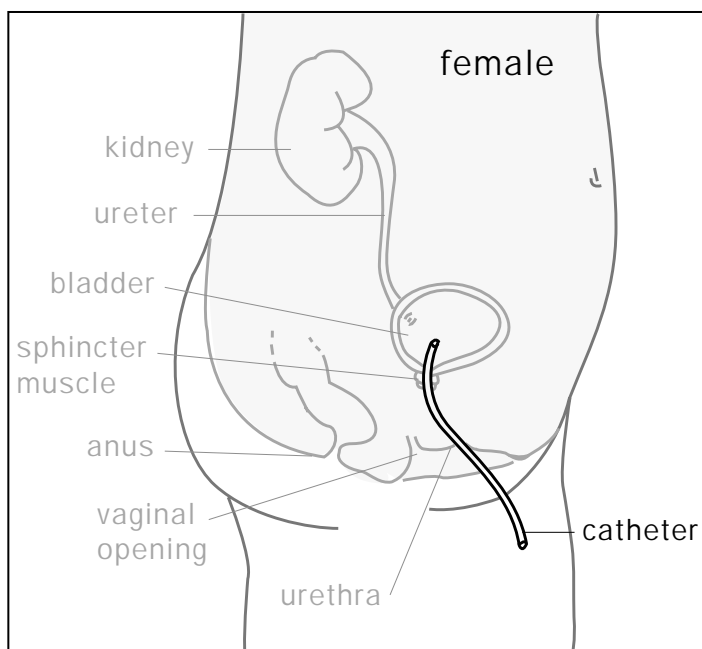
Clean intermittent catheterisation: Instruction for females

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.



spina bifida

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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'.

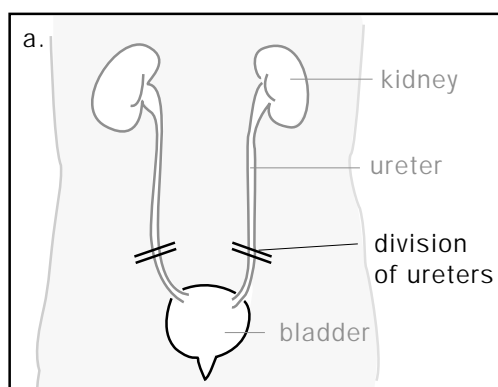
Kidney pain and spina bifida: an emergency. Do not hesitate to get expert help immediately.

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

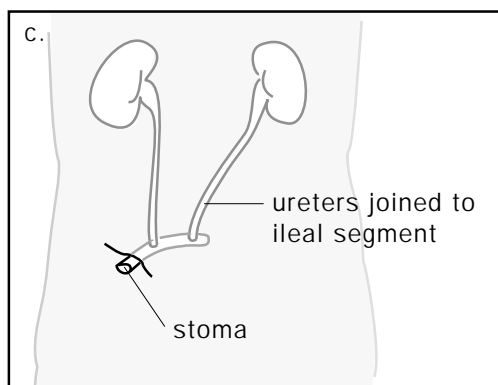
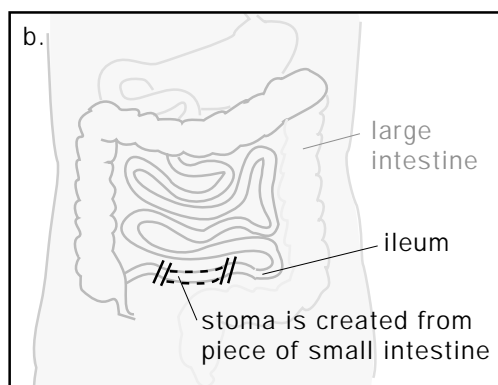
Kidney infections are very serious and can damage the kidneys

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.

spina bifida

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?

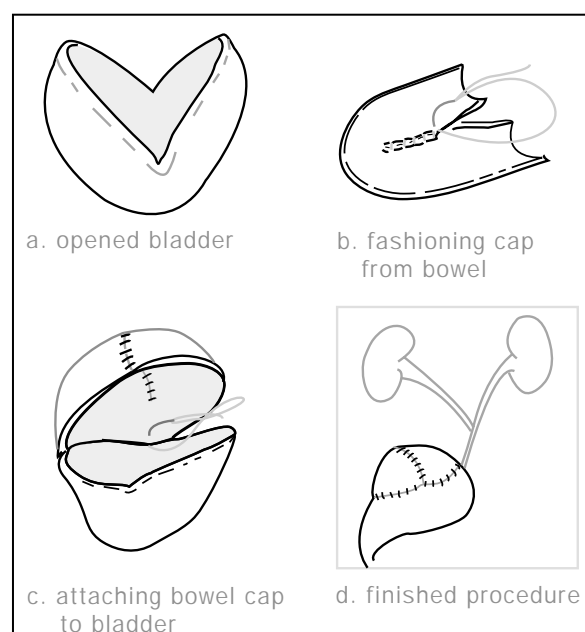
When there is poor bladder emptying with UTIs and back pressure (reflux) to the kidneys.

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

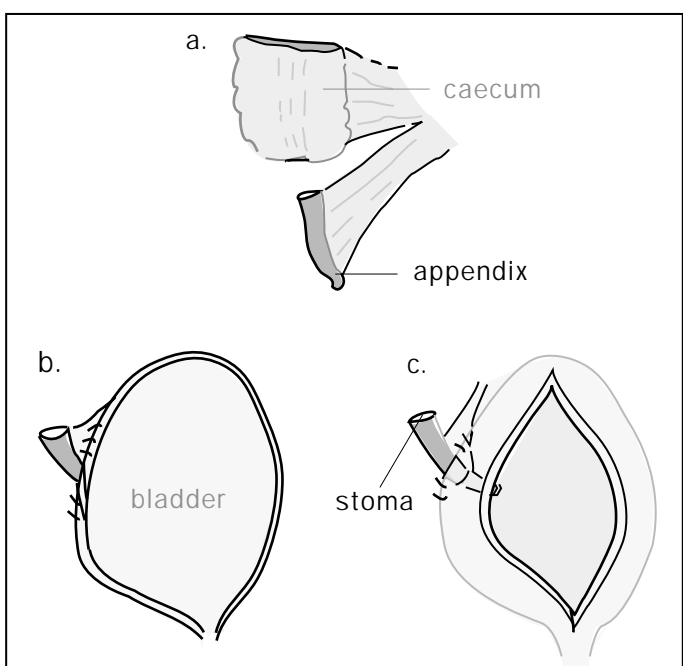
Passport to success

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.