

The urological system and continence control issues in spina bifida

Chapter 5: Controlling urinary incontinence

Achieving control of urinary continence is the key to achieving an independent lifestyle. A wide range of interventions and resources exist to assist in the successful management of urinary incontinence. This chapter provides the clinician with an introduction to management principles, some resources and also outlines the roles of specialist clinics in the management of incontinence (for issues of faecal incontinence, see Chapter 6).

Key issues for clinicians

- Incontinence impacts on all aspects of life. Successful management of incontinence overcomes a major barrier to personal and social independence.
- Incontinence is best managed in conjunction with a specialist continence clinic.
- Most young people and adults with spina bifida will have already established incontinence management. The role of the general practitioner is largely one of review and detection of management problems. These can then be referred to a specialist clinic if indicated.
- Conservative management is the first step to incontinence management.
- Clean intermittent catheterisation is a common and important component of incontinence management. Clinicians need to familiarise themselves with this procedure.
- Incontinence management procedures need to be reviewed after a urinary tract infection.
- Persistent changes in continence patterns should be referred to a specialist clinic.
- There are surgical interventions available to assist incontinence management if conservative measures fail. These are organised through specialist clinics.
- Clinicians need to be aware of the existence of possible latex allergies when treating patients with spina bifida.

Incontinence impacts on all aspects of daily living

Incontinence can prevent people with spina bifida from achieving full participation in all aspects of life, such as work, education, personal relationships and general activities of daily living. In addition, incontinence is almost a taboo subject, viewed by many in society as a weakness and a source of shame.

Impact on self esteem

Incontinence also brings many other daily problems, such as changing beds, and clothes, washing soiled linen and clothing, constant worry over possible episodes of incontinence, embarrassment, shame at soiling in public, accusing looks from teachers, work colleagues and the general public — all leading to difficulty in coping with daily life.

These issues can lead to poor self esteem, contributing to a sense of frustration, guilt, fear and isolation, making coping even more difficult.

Continence control — the incontinence management team

There are many resources and health care providers available for achieving successful continence control and GPs can help link people with spina bifida to these specialist clinics. Not only are there specialist teams to help children, but clinics for young people and adults with spina bifida also exist (see *Chapter 9 Organisations and further resources*).

Clinicians having problems identifying nearby adult treatment centres may be able to obtain their location by contacting a paediatric treatment centre.

Overview of bladder and urinary tract management¹⁻²

Common approaches to the management of bladder and other urinary tract problems in spina bifida involve a combination of the following:

- conservative management including pharmacological agents
- surgical intervention.

All continence control needs to be managed under the direction of a urologist and continence clinic. Many adults with spina bifida are unaware of these resources, and GPs can greatly improve quality of life by referring patients to these specialist centres. The GP remains a key player in this team as the first point of contact for patients.

The following procedures are described to familiarise clinicians with common approaches to bladder management. Treatment should only be initiated under the direction of a urologist, or a spina bifida or continence clinic.

Conservative management

Conservative management of bladder problems usually involves a combination of clean intermittent catheterisation (CIC) and the use of pharmacological agents.

Establishing a routine

The key to successful incontinence control is to establish incontinence management procedures as part of every day living. When incontinence control becomes a problem, the aim is then to re-establish these routines.

Clinicians need to be aware of differences in incontinence control for those affected by spina bifida. For example, the experience of many GPs will be in children with normal bladders. Incontinence control issues in spina bifida are wider than this; incontinence occurs within the context of a neurogenic bladder, and is an ongoing issue for all ages for people with spina bifida.

Timing is the key

The key to successful control of urinary incontinence in spina bifida is bladder timing. Only a small number of people with spina bifida will be successfully bladder trained, but successful timing can be achieved in a majority of cases.

Successful bladder timing — that is, the regular emptying of the bladder — allows the person to have control and confidently participate in school, work and other areas of life.

Establishing routines and regular practice is the first step to achieving effective incontinence control. When routines become upset, this pattern can be used as a target to get habits back into line.

Intermittent catheterisation

Intermittent catheterisation of the bladder allows it to empty, in order to prevent retention, reflux and other complications, and to help control incontinence.

Practice points

In the presence of nerve damage, the person with spina bifida may have difficulty telling the difference between a full bladder and a full bowel.

Sensation from the muscle wall of overstretched bladders are weak or nonexistent.

Detrusor sphincter dyssynergia can either cause a rush of urine flow when the sphincter does open, and usually occurs at inconvenient times, or may just cause a dribble when the urinary bladder pressure rises above a certain level.

Swimming and drinking will increase the urine output.

Anxiety, shocks and excitement can precipitate episodes of incontinence.

Sensations such as abdominal 'pain' can be confused with bladder or bowel fullness sensations.

Incontinence control routines can be upset by intermittent infections, procedures, illnesses and other precipitating factors.

This simple, clean (not sterile) procedure repeated a few times a day allows control of the timing of bladder emptying.

Clean intermittent catheterisation aims to achieve continence by emptying the bladder at scheduled intervals, as well as reducing residual urine volume in order to prevent infection and bladder overstretching.

Intermittent catheterisation gives the person with spina bifida a great deal of control over incontinence, and while achieving good technique may take some practice, the effort is well worthwhile and achievable. Self catheterisation requires good hand to eye coordination.

Self catheterisation gives a young person or adult increased self esteem through increased independence. Self catheterisation also means that the person can attend school or work unassisted.

Young people may have issues with compliance with self catheterisation and the clinician may need to check that techniques are being followed. This may involve referral to a specialist incontinence management team.

Reviewing catheterisation techniques

Many young people and adults with spina bifida will have already been using intermittent catheterisation for many years. In this case, the role of GPs seeing adult patients for the first time may not be to teach intermittent

catheterisation, but to review technique, check that the appropriate catheter type is being used and refer to specialist centres as needed.

Catheterisation techniques should be especially reviewed when there is a change in continence pattern or after a urinary tract infection. Reusable catheters should be replaced with single use catheters in the presence of a urinary tract infection.

Intermittent catheterisation

Catheterisation aims to empty the bladder to protect renal function and to achieve social independence through prevention of incontinence. Catheterisation is a simple, clean method of inserting a plastic catheter several times a day to drain urine (*Tables 5, 6*).

Catheterisation and the toilet

Catheterisation is usually performed in the toilet, as using this socially acceptable place helps to normalise the process of urination. That is, the toilet is the same place used for urination as that for continent people. Toilets are always available, even if they need to be cleaned afterwards. When the catheter is correctly inserted, the person can hear the urine fall into the water and knows that the catheter has been inserted sufficiently and into the correct orifice (for women). In addition, sitting upright gives better drainage and maximises the chances of using the correct method to withdraw the catheter — that is, downwards.

Catheterisation should be performed before emptying the bowels.

The self catheterisation routine — the role of specialist clinics

Self catheterisation is a complex technique and is best taught by specialist continence clinics. These clinics can adapt teaching to suit each individual according to their special needs and gender. However, clinicians can keep copies of any instructions issued to the patient to assist in reinforcing key messages directed by the specialist clinics.

While establishing catheterisation techniques is often done with the assistance of a specialist continence team, the GP can assist by going through the patient's technique to ensure that each step is performed correctly. A checklist has been prepared to help clinicians ensure the basic technique is adequate (*Table 7*), but more detailed information and assistance is available from the specialist continence team.

General practitioners with any questions can contact the continence nurses or other health professionals of continence clinics for further assistance.

Latex allergies

Be aware that allergies to latex are more common in people with spina bifida than for the general population. Reactions can vary between mild reactions to severe anaphylactic shock. Clinicians need to remain alert to this possibility and to refer to specialist clinics for advice if the situation arises.

Case study: Betty is a 26 year old woman with incontinence.

She has overflow incontinence, and although using a CIC routine — which she has been using for many years — needs continence pads. Wheelchair bound, she has oscillated between living at home and independently, the major issue being a constant smell of urine, although she is desensitised to the smell. She lacks confidence and seems to have given up any ambition of work. Apparently very disorganised, when you talk to her about the urine smell issue she becomes distraught and angry. You encourage her to attend an adult spina bifida clinic and a continence nurse. The nurse reports that she is using inappropriate pads, wrong sized catheter, and is not catheterising frequently enough. With some planning assistance and assigning a friend who will tell her if she smells, her continence control is much improved. Establishing control involves keeping the catheterisation routine constant. Each time it is performed, it should be identical. Not only does this maximise effectiveness of the procedure, but decreases risk of urinary tract infection.

Pharmacological agents

Under the direction of a specialist, pharmacological agents can be an important adjunct to intermittent catheterisation. Common agents include anticholinergics such as propantheline bromide; musculotropics including oxybutinin, and antimuscarinics such as tolterodine.

Adverse effects

These agents can cause adverse central nervous system effects that can interfere with cognition, which may in turn complicate any deficits already present (see *Chapter 2 The impact of hydrocephalus and other CNS conditions on case management*).

These agents may also contribute to constipation, which can contribute to faecal incontinence.

Surgical intervention

Surgical intervention for the management of incontinence is an important option for people with spina bifida where other procedures, such as CIC are not feasible.

Table 5: Clean intermittent catheterisation — instructions for males³**Equipment required:**

Catheter, cleansing solution, lubricating gel, cottonwool balls or wipes.

Procedure:

1. Wash hands with soap and water.
2. Lubricate the catheter.
3. Retract foreskin if not circumcised and wash the tip of the penis using a cleansing solution.
4. 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.
5. When the urine flow has stopped, advance the catheter one more inch to ensure the bladder is fully empty.
6. Slowly remove the catheter liberally.
7. Males with foreskins should always push the foreskin back again after the procedure.
8. Put on clean pad.
9. Wash hands with soap and water after washing and packing away equipment and cleaning toilet seat.

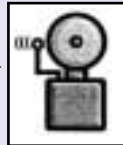
Table 6: Clean intermittent catheterisation — instructions for females^{2,4}**Equipment required:**

Catheter, clean pad and clothing, lubricating gel, washer, cottonwool swabs or wipes.

Procedure:

1. Wash hands with soap and water.
2. Lubricate catheter liberally.
3. Sit well back on the toilet.
4. Clean the vulva with 3 swabs from front to back.
5. Wipe hands.
6. With one hand, hold the labia apart and see or feel for the clitoris.
7. 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.
8. When the urine has stopped flowing, slowly pull out the catheter.
9. Wash hands and put on clean pad.
10. Wash hands with soap and water after washing and packing away equipment.

Ensure that patients using reusable clean catheters for intermittent catheterisation move to single use disposable catheters during a urinary tract infection. After the infection has resolved, patients can then start using a new, reusable catheter.



In addition, there are many urological reasons for surgical interventions, all of which impact upon the control of continence.

The decision to proceed with surgical intervention for the control of urinary incontinence in spina bifida is a highly complex area. Indications for surgical intervention of the urinary tract in spina bifida include:

- persistent high urinary storage pressure
- upper urinary tract deterioration
- gross vesicoureteric reflux
- incontinence due to intrinsic sphincter deficiency (ISD).

High bladder pressure

As discussed previously, the most common neurogenic pattern in spina bifida is an areflexic bladder with a

nonfunctional sphincter. This can lead to complications of the upper renal tract and can be a major source of morbidity and mortality. This often results in high bladder pressure due to urinary retention. High bladder pressure can result in long term urinary sphincter damage.

Surgical management of high bladder pressure may involve a variety of techniques

There is a wide range of surgical options to manage incontinence in spina bifida that can be tailored to each individual. These procedures are constantly improving and increasing in technical sophistication, emphasising the importance of patients receiving regular urological surveillance.

Overview of common surgical procedures

The following is a list of common urological procedures used in spina bifida, and their more common indications.

Vesicostomy

Vesicostomy is indicated in the presence of persistent hydronephrosis and recurrent urinary tract infection when the bladder continually fails to empty. This simple

Table 7: Checklist for reviewing self catheterisation technique

- Have copies of any patient instructions for procedures included in their medical history file to help check some of the following key issues.
- Patients may benefit from visual instruction using illustrations rather than verbal instruction if learning difficulties are present
- The routine must be kept the same each time.
- Ensure that hands are washed at each point indicated in the procedure.
- Ensure that the catheter is lubricated liberally.
- Instruct patients to be careful to prevent contamination from clothes. This may be done by folding the clothes upwards and using a peg to keep clothes fastened and away from genital area.
- The bladder must be fully drained as incomplete emptying is a common cause of urinary tract infections. To do this:
 - the full length of the catheter must be held below the level of the bladder throughout the entire procedure
 - gentle pressure is applied to the lower abdomen after the flow of urine has been stopped.
- The flow of urine is sometimes stopped if the sphincter closes on the catheter giving the impression of complete bladder emptying. This may be indicated by resistance when removing the catheter and by lower urine output than expected during drainage. In this case, repeat the procedure in 1/2–1 hour.
- Assess bowel habits: constipation may cause partial urethral obstruction.
- Associate bladder emptying to the daily routine, such as when getting up in the morning, after meal times and before going to bed.
- Also review techniques and any instructions given for cleaning catheters.

procedure which involves making a stoma from the bladder to the skin surface to allow drainage, has a low revision rate and allows normal growth and maturation. Vesicostomies are often performed as temporary procedures in children.

Urinary diversion

Urinary diversion can be used when augmentation procedures fail to work for many physical, personal and social reasons. Procedures include ileal and colon conduits and cutaneous ureterostomy.

Augmentation cystoplasty

Augmentation cystoplasty involves surgically configuring a segment of bowel to augment the bladder and correct vesicoureteric reflux. When deciding upon an augmentation cystoplasty, issues to consider include which part of the bowel to use, eg. ileum, stomach, sigmoid colon or other section. Complications can result from the mucosa of the segment of origin, such as haematuria when using gastric lining or mucus production when using sigmoid colon. Ureteric augmentation uses distended hydronephrotic ureters, if present, to augment the bladder. Other complications of augmentation can include perforation, infection, mucus production, calculi and the potential for malignancy, although this risk is small.

Catheterisable stomas

Catheterisable stomas may be useful in patients unable to perform intermittent catheterisation due to lack of dexterity or being wheelchair-bound. They also have a place when a urethra is unavailable, perhaps due to the presence of a stricture or a fistula.

The Mitrofanoff procedure is the formation of an abdominal stoma which is then connected to the bladder with a tubal structure such as the appendix. Urine is then drained by passing intermittent urinary catheters. For example, in the Mitrofanoff appendix procedure, the stoma is created from the appendix and part of the caecum with intact blood supply. The tip of the appendix is then buried through the bladder wall to create a passageway for urine. Other structures have also been used, including: gastric tissue; fallopian tubes; ureters; and other parts of the bowel.⁶

Transurethral injection

Transurethral injection therapy is used to treat intrinsic sphincter deficiency and involves the submucosal injection of a biocompatible substance such as collagen or

silicon. The efficacy of treatment depends largely upon selecting patients with suitable urodynamic patterns.³ The advantage of submucosal injection is the low morbidity, but its main disadvantage is the lack of long term data on most of the substances.

Slings

Pubovaginal slings are the treatment of choice for females with intrinsic sphincter deficiency although there is also a role for the procedure in some males. Suburethral slings use a variety of techniques and materials and many series have included long term follow up. Native tissue, such as the use of an autologous tendon, appears to be associated with less morbidity than using synthetic materials. Patients must be monitored postoperatively to ensure bladder emptying takes place and that there is no upper tract deterioration.

Artificial urinary sphincters

Artificial urinary sphincters are implanted silicon devices that close the urethra. The artificial sphincter may be placed at the bladder neck or bulbar urethra. The artificial sphincter is regarded as the main treatment option for male patients with intrinsic sphincter deficiency. Again, post-operative monitoring is essential to ensure that urinary tract complications due to the elevated bladder pressure associated with an artificial sphincter are prevented.

Circumcision

Circumcision may be indicated in males, especially when in the presence of recurrent urinary tract infections where circumcision can sometimes reduce their frequency.

Reversal of surgical procedures

Young people and adults with spina bifida may present having had a particular surgical technique for incontinence at some stage in the past but without a recent urological review. Many options are not permanent, and can be changed to suit the needs of the person at that time in their life.

In light of surgical advances there may now be further options for these patients to explore. Some of these patients may want to try alternate continence procedures and may want to have their surgery reversed. Referral to a specialist centre enables patients to explore the advantages and disadvantages of each of these procedures.

Reversal of urinary diversion (also called undiversion) may be an option in motivated patients when physical considerations allow. Patients may have had urinary diversion procedures in the past when these procedures

Case history: John is 22 years old

He is a highly motivated man who had a urinary diversion procedure when he was a toddler. He has managed with a bag for years, but is beginning to realise that he has missed out on many activities such as swimming and travelling and confides that he 'can't imagine a sexual relationship with the bag present'. He has also heard at a spina bifida meeting that his kidneys may be affected. He is amazed when you advise him that this procedure may be reversible, with him starting a clean intermittent catheterisation routine. Enthusiastic to find out more, he is eager to visit the adult spina bifida clinic.

were a more common first line treatment and may now wish to take advantage of more recently introduced augmentation procedures. Reversal of diversion allows the introduction of a clean intermittent catheterisation regimen that may be more beneficial for renal function and promotes independence. This process can offer significant benefits to a select group of patients, but motivation needs to be high as it involves considerable preoperative preparation and a high degree of postoperative compliance to ensure effective clean intermittent catheterisation

References

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