



Bladder augmentation and Mitrofanoff

This leaflet explains about the cystoplasty procedure to augment or enlarge the bladder and form a Mitrofanoff (continent catheterisable channel). It also describes what to expect when your child comes to Great Ormond Street Hospital (GOSH) to have the operation.

How does the urinary system work?

The urinary system consists of the kidneys, the bladder and ureters. The kidneys filter the blood to remove waste products and form urine. The urine flows from the kidneys down through the ureters to the bladder. The ureters tunnel through the wall of the bladder at an angle to form a flap that acts as a valve.

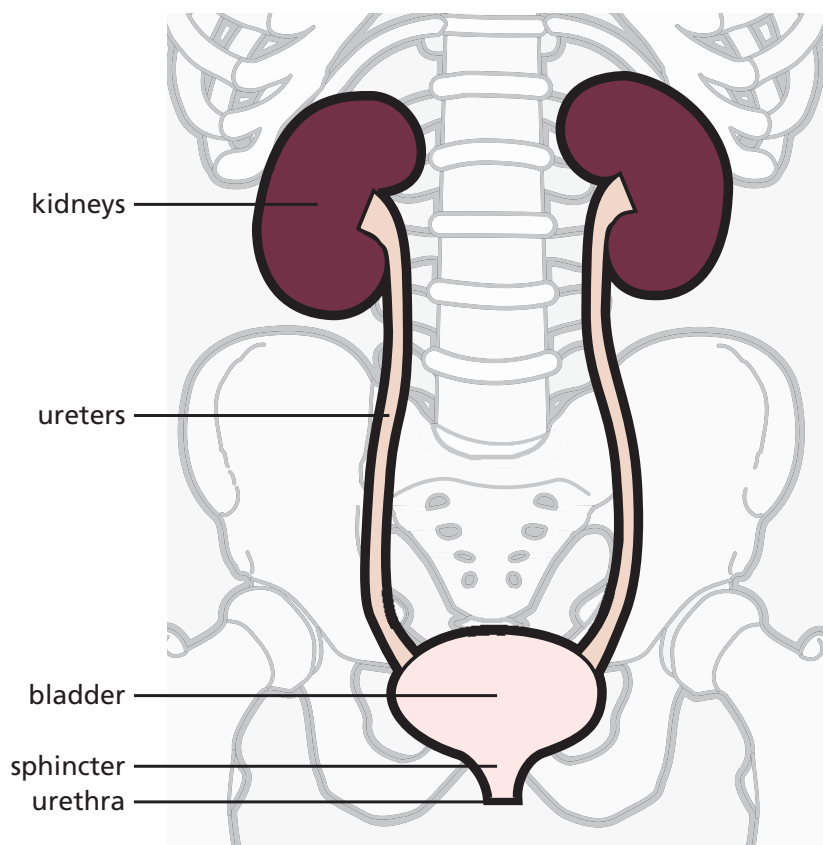
There is also a ring of muscle (sphincter) at the junction of the bladder and the urethra that stops urine leaking out in between pees. When peeing, the muscles of the bladder wall squeeze the urine out of the bladder, at the same time as the muscles in the sphincter need to relax to let the urine flow down the urethra.

The valves between the ureters and bladder prevent urine flowing backwards into the ureters, so that all the urine in the bladder is passed in one go, as the urine cannot travel anywhere else. As the urine leaves the bladder at a high pressure, the valves stop this high pressure being passed on to the kidneys.

What is bladder augmentation?

Bladder augmentation (also known as a cystoplasty) is an operation to enlarge the bladder using a piece of the body's own tissue. This is usually the large or small intestine, but the ureters or even the stomach can be used.

After the operation, the bladder will be unable to squeeze and empty normally as it does not contain sufficient muscle. If the intestines (either small or large) have been used, the tissue will also produce mucus. This means that all or some of the urine in the bladder has to be emptied with a tube called a catheter. The catheter can be passed either through the urethra or through a specially created channel called a Mitrofanoff.



What is a Mitrofanoff?

A Mitrofanoff (or continent catheterisable channel) is a tube created from the appendix or small intestine, which connects the bladder to the surface of the skin. It is tunnelled into the bladder in such a way that a 'valve' is created, which prevents urine leakage. The catheter is not left in place permanently. Instead it is passed into the bladder every three to four hours or when the bladder is full. Once the urine and mucus have been drained, the catheter is removed. Depending on your child's age and ability, he or she may be able to do this without help. Regular bladder emptying will ensure that all urine and mucus are removed, which prevents urine infections and/or bladder stones developing and ensures that your child is dry.

Why might my child need this operation?

Bladder augmentation is recommended in several situations:

- Your child's bladder is too small to cope with normal amounts of urine so he or she spends a lot of time on the toilet or has problems with wetting.
- Urine may be held in your child's bladder at a very high pressure, which can lead to leakage.
- The way the bladder is behaving may be affecting your child's kidney function.
- Prevention of urine infections.

Conditions that might require bladder augmentation include:

- Bladder and cloacal exstrophy
- Spina bifida and other spinal defects
- Posterior urethral valves
- Anorectal anomalies

More information about these conditions is available from your nurse, our website at www.gosh.nhs.uk or the Pals Office.

Are there any alternatives to bladder augmentation?

Your child may already have tried alternatives to the operation, including medicines such as oxybutinin, other minor procedures such as injection of bulking materials into the bladder neck or intermittent catheterisation. Bladder augmentation tends to be suggested when these alternatives have not been successful. Please discuss possible alternatives for your child with your doctor or nurse.

What happens before the operation?

You will receive information about how to prepare your child for the operation in your admission letter. We will also invite you to come to a pre-admission clinic. This is an outpatient appointment where you will be able to discuss the operation with the team before coming in to hospital. Your child will also have various tests and investigations during this appointment. This avoids any delays on the day of the operation.

On the day of the operation, your child should not have anything to eat or drink before the operation, for the amount of time specified in the letter. It is important to follow these instructions; otherwise your child's operation may be delayed or even cancelled.

Some children need 'bowel preparation' before the operation so that their intestines are empty. This may involve using medicine some hours before the operation or having a bowel washout. This will be explained fully during your child's pre-admission clinic appointment.

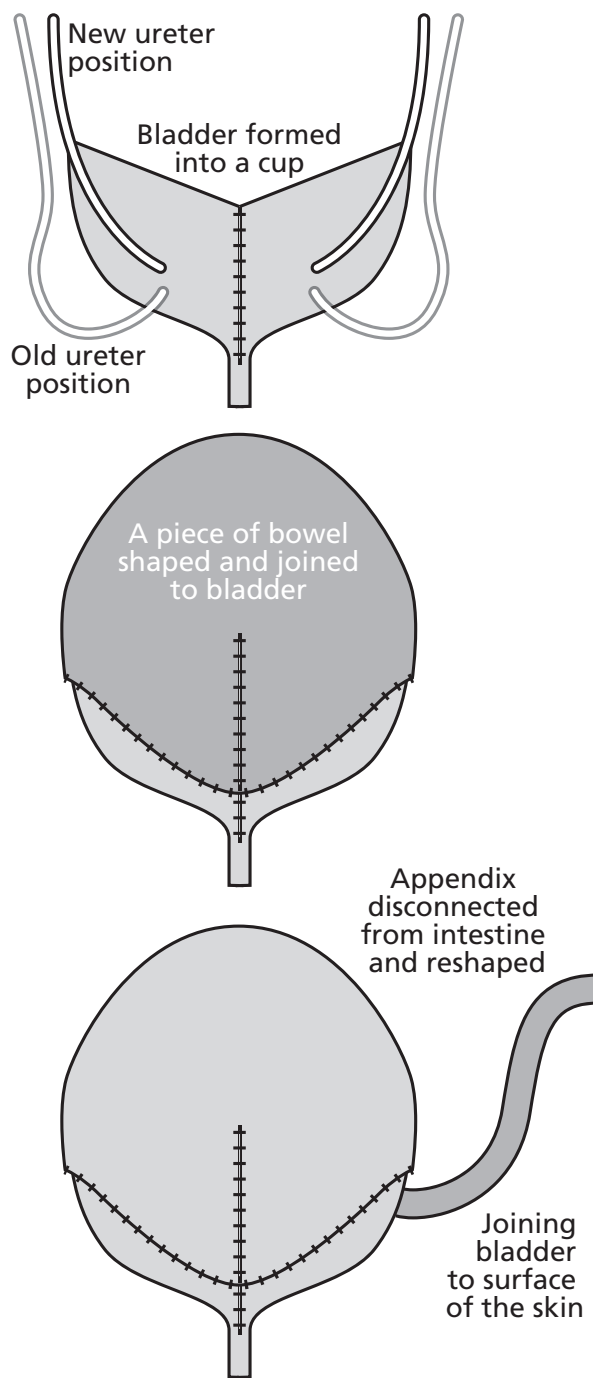
Your child's surgeon will visit you to explain about the operation in more detail, discuss any worries you might have and ask you to give your permission for the operation by signing a consent form. An anaesthetist will also visit you to explain about the anaesthetic and pain relief after the operation. If your child has any medical problems, such as allergies, please tell the doctors. Please also bring in any medicines your child is currently taking.

What does the operation involve?

The operation is carried out under general anaesthetic and lasts from three to four hours. The first stage is to open up the bladder to form a cup. The ureters are disconnected and then re-implanted so that they can drain properly (top picture).

A piece of bowel is removed and also shaped into a cup-shape and joined to the top of the bladder to close it (middle picture).

The Mitrofanoff is usually made out of the appendix. The surgeon disconnects the appendix from the large intestine while keeping its blood supply intact and opens one end to form a tube. One end of the tube is tunnelled through the bladder wall and the other is joined to a small opening in the surface of the skin (bottom picture).



Are there any risks with the operation?

Every anaesthetic carries a risk of complications but this is very small. All surgery carries a small risk of bleeding during or after the operation. In the bladder augmentation operation, there is a risk of bleeding when the surgeon removes the piece of intestine. Usually, there is only a small amount of bleeding but if there is a lot, your child may need to be given a blood transfusion. There is a chance that the Mitrofanoff could be difficult to catheterise as the opening is too narrow or the valve is too tight. This affects about one-quarter of all children with a Mitrofanoff but is easily corrected.

What happens after the operation?

Your child will come back to the ward to recover. For the first day or so, he or she will have a drip giving fluids and medications until the bowel starts to recover. Your child will also have a nasogastric (NG) tube, which goes up the nose and into the stomach (nasogastric or NG tube) to drain away any fluid from the stomach. The drip and NG tube will be removed when your child starts eating and drinking again.

Your child will also have a suprapubic catheter for a while after the operation to allow the bladder to heal. This catheter will be connected to a collection bag, so urine can drain freely from the bladder. Younger children may use double nappies instead of a collection bag, so that the catheters drain into the outermost nappy. The Mitrofanoff will have a catheter inserted into it to ensure that the tube stays open.

Your child will be in hospital for at least 10 days after the operation. Once he or she is comfortable, eating well and can move around, your child can go home. The suprapubic and Mitrofanoff catheters will remain in place for around three to four weeks after the operation. We will make sure that you can look after the catheters and have any necessary equipment ready to take home. Further information is available in our Looking after your child's suprapubic catheter leaflet.

When you get home:

- Your child will need to have regular pain relief for the first few days. Usually paracetamol will be enough to relieve any pain, but if your child needs stronger medicine, we will give you some before you go home. If when you get home you feel that your child needs more powerful pain relief medicines, you should call your family doctor (GP).
- You should encourage your child to drink plenty of fluids as this will keep the urine flowing, reduce any discomfort and minimise the risk of infection. Reducing fizzy drinks and those containing caffeine can help reduce irritation. Cranberry juice is helpful in moderate amounts as it can also reduce infections. However, if your child is taking blood-thinning medicine, cranberry juice should be avoided.
- Your child should not have a bath or shower until a scab has formed over the operation site. When a scab has formed, try to avoid long baths as this may cause the scab to soften and fall off too early.
- The operation site may be closed with Steri-strips®, which usually fall off of their own accord. If they have not fallen off within a week, you can soak them off using a wet flannel.
- The Mitrofanoff needs to be treated as a wound for the first five days back at home. After that you should wash it once a day and then pat it dry with a towel. Do not rub the Mitrofanoff as this will make it sore.
- To reduce the risk of infection, some children will be given a course of antibiotics to take at home.
- It is quite common for children to have bladder spasms after this type of operation. This is quite normal. We will give you medication to deal with the bladder spasms before you go home. Bladder spasms can show up as tummy pain or discomfort in the penis or bottom area. Constipation can make the spasms worse, so make sure that your child is eating a balanced diet and drinking plenty of fluids when you are back home. Bladder spasms rarely continue once your child is using the Mitrofanoff as the suprapubic catheter is removed at this point. If you are at all concerned about bladder spasms, please telephone the ward.
- It is also quite common to leak a small amount of urine, which may be tinged with blood, in the day after the operation but this will improve in time.

Learning how to use the Mitrofanoff

About three weeks after the operation, you and your child will need to come back into hospital for a few days to check everything is healing well, have the catheters removed and start to learn how to use the Mitrofanoff. If your child is old enough and physically able, we will teach him or her as well. You will both have a lot to learn about using the Mitrofanoff and it may feel daunting at first, but it will quickly become easier.

Catheterisation should be carried out every three to four hours or sooner if the bladder feels full. Use the largest size of catheter that can be inserted into the Mitrofanoff as this helps the bladder drain freely and quickly. There are two types of catheter used with a Mitrofanoff: plain coated catheters and hydrophilic coated catheters. Plain coated catheters need lubricating, but can be rinsed and re-used several times, and can also be left in place overnight if securely taped to your child's tummy. Hydrophilic coated catheters are pre-coated with lubricant but may need activating by adding water to the package. This type is for single use only and cannot be left in place overnight. Please discuss this further with your nurse specialist.

Your child's nurse will give you enough supplies to start using the Mitrofanoff. After this, we arrange further supplies from a home care company. Remember to order supplies in plenty of time. If you have any problems, please contact the hospital.

Instructions

1. Assemble all the equipment you will need:
 - Catheter
 - Lubricating jelly (if using a plain coated catheter)
2. Wash your hands
3. Sit or stand your child near the toilet
4. Lubricate the end of the catheter if necessary
5. Insert the catheter gently into the Mitrofanoff until you meet resistance and then give it a firm push to guide it further into the bladder
6. Allow the urine to drain freely into the toilet
7. Move the catheter about within the bladder to drain all the urine
8. When urine stops flowing, remove the catheter
9. Wash your hands

Trouble shooting

What if ...	Action
You cannot insert the catheter into the Mitrofanoff	<ul style="list-style-type: none"> ■ Try to insert a smaller size catheter ■ If you can do this, leave this catheter in place, plug the end with the spigot and call the ward for advice ■ If you cannot insert the smaller size catheter, please contact the ward urgently
Your child continues to wet in between catheterisations	<ul style="list-style-type: none"> ■ If your child has previously been dry and suddenly becomes wet again, this could should signs of infection, poor bladder emptying or a change in bladder behaviour ■ Call the ward for advice
You or your child notice blood in the urine or catheter	<ul style="list-style-type: none"> ■ A small amount of blood is normal especially when you start catheterising ■ If the amount increases or continues for a long time, please call the ward
Your child's urine becomes infected	<ul style="list-style-type: none"> ■ Signs of infection include: darker urine than usual, smelly or cloudy urine ■ Call the ward as your child may need a course of antibiotics
Your child's Mitrofanoff is red, inflamed or bleeding	<ul style="list-style-type: none"> ■ Passing the catheter can sometime cause this but it usually stops when the catheter is removed ■ If it continues, call the ward for advice
Your child's Mitrofanoff is sore and oozing	<ul style="list-style-type: none"> ■ Infections sometimes occur, usually fairly soon after the operation. Contact the ward as your child may need a course of antibiotics ■ In the long term, any weeping from the Mitrofanoff is likely to be mucus, which is quite usual. You can cover the Mitrofanoff with a small dressing or plaster if the oozing is affecting your child's clothes
Urine seems to be leaking from the Mitrofanoff	<ul style="list-style-type: none"> ■ Contact the ward as the Mitrofanoff might need checking

Long term follow up

You will have an appointment with your child's surgeon around 12 weeks after the operation. After this, your child will have an annual check up with the clinical nurse specialist and surgeon. This appointment will usually involve some tests, such as renal ultrasound, abdominal x-ray and blood samples. Occasionally, kidney function tests might be carried out at this appointment as well.

Is there a support group?

Mitrofanoff Support is an organisation supporting anyone with a Mitrofanoff. Visit their website at www.mitrofanoffsupport.co.uk.

The Bladder and Bowel Foundation can also offer advice and support. Call their helpline on 0845 345 0165 or visit their website at www.bladderandbowelfoundation.org

As many people with Spina Bifida have the operation. SHINE may be able to offer advice and support. Call them on 01733 555 988 or visit their website at www.shinecharity.org.uk.

If you have any questions, please call
020 7405 9200 and ask for the ward from
which your child was discharged.