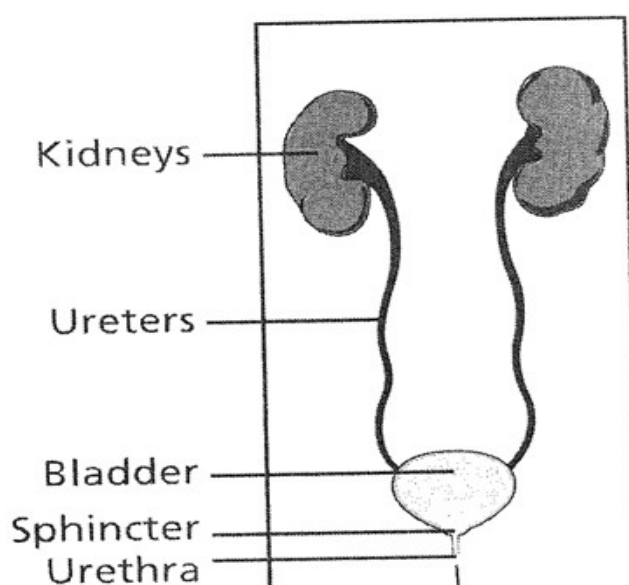


Bladder Augmentation and Mitrofanoff

This leaflet gives information for parents/carers whose child is having a Cystoplasty procedure to augment or enlarge the bladder and form a Mitrofanoff.

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 between episodes of passing urine (having a wee).

When passing urine 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 go anywhere else. As the urine leaves the bladder at a high pressure, the valves stop this high pressure being passed onto 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, 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/she may be able to do this without help. Regular bladder emptying will ensure that all the urine and mucus are removed, which prevents urine infections and/or bladder stones developing and ensures 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/she spends a lot of time on the toilet or has problems 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.

Are there any alternatives to bladder augmentation?

Your child may have already tried alternatives to the operation, including medicines such as Oxybutinin, other minor procedures such as injection of bulking materials into the bladder neck, intermittent catheterization or intravesical 'Botox' injections.

Bladder augmentation tends to be suggested when these alternatives have not been successful.

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 into 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 have nothing to eat or drink before the operation, for the amount of time specified in your letter. It is important to follow these

Bladder Augmentation and Mitrofanoff

instructions; otherwise your child's operation may be delayed or even cancelled.

Some children need 'bowel preparation' before so that their intestines are empty. This may involve using an enema some hours before the operation or having a bowel washout. This will be fully explained 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 (if not already done so in pre- assessment clinic) ask you to give permission for the operation by signing the 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 medication your child is currently taking.

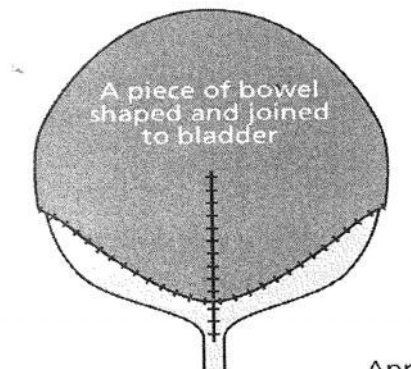
The operation

The operation is carried out under general anaesthetic and lasts around six 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.

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

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 is tunnelled through the bladder wall and the other is joined to a small opening in the surface of the skin.



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Risks and complications

Possible risks and complications for bladder augmentation and formation of Mitrofanoff include:

- Every anaesthetic carries a risk of complications but this is very small.
- Bleeding – 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 a piece of intestine. Usually there is only a small amount of bleeding but if there is a lot, your child may need a blood transfusion.
- There is a chance 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 to expect after surgery

Your child will come back to the ward to recover in one of our High Dependency beds. For the first few days, he/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 their stomach to drain away any fluid from the stomach. Your child will not be allowed to eat or drink anything until their bowel starts to recover. 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. The Mitrofanoff will have a catheter inserted into it to ensure the tube stays open.

Your child will be in hospital for a week to ten days after the operation. Once he/she is comfortable, eating and drinking well and can move around, you and your child will be allowed home. The suprapubic and Mitrofanoff catheters will remain in place for around three to four weeks after the operation. We will make sure you can look after the catheters and have any necessary equipment ready to take home.

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 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 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 paper strips (steri-strips), which usually fall off of their own accord if they have not fallen off within a week, you can soak them off with a wet flannel.

Bladder Augmentation and Mitrofanoff

- The Mitrofanoff needs to be treated as a wound for the first five days back at home. After that you should wash it once daily and pat it dry. 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 help prevent the bladder spasms before you go home. Bladder spasms can show up as a tummy pain or discomfort in the penis or bottom area. Constipation can make spasms worse, so make sure that your child is eating a balanced diet and drinking plenty of fluid when you are back at 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 contact the Children's Assessment Unit (CAU).
- It is also quite common to leak a small amount of urine, which may be tinged with blood, in the days after the operation but this will improve with time.

Learning how to use the Mitrofanoff

About three weeks after your child's operation we will start to teach you how to use the Mitrofanoff. If your child is old enough and physically able, we will teach him/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 urine drain freely and quickly. There are two types of catheter used with the 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 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.

Your nurse will give you enough supplies to start using the Mitrofanoff. After this, you will need to get further supplies from your GP or community nurse. Remember to order supplies in plenty of time so you don't run out.

Trouble shooting

| What if | Action |
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| 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 your community nurse or the Children's Assessment Unit (CAU) for advice.• If you cannot insert the smaller size catheter, please contact your community nurse or CAU urgently |

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| 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 show signs of infection, poor bladder emptying or a change in bladder behaviour. • Speak to your community nurse for advice. |
| Your child's urine becomes infected. | <ul style="list-style-type: none"> • Signs of infection include: darker urine than usual, smelly or cloudy urine • Speak to your community nurse, GP or CAU as your child may need a course of antibiotics |
| 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 seek medical advice |
| Your child's mitrofanoff is red, inflamed or bleeding. | <ul style="list-style-type: none"> • Passing the catheter can sometimes cause this but it usually stops when the catheter is removed. • If it continues, seek medical 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 your GP or CAU 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 if the oozing is affecting your child's clothes. |
| Urine seems to be leaking from the mitrofanoff. | <ul style="list-style-type: none"> • Contact your community nurse or CAU 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. 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.

Children's Assessment Unit Telephone Number is: **01603 289774**

Bladder Augmentation and Mitrofanoff

