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Family information leaflet
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Catheterisation using a Mitrofanoff

Information for families

This leaflet explains about catheterisation using a Mitrofanoff, and what to expect when your child comes to Hospital for treatment.

What is a Mitrofanoff and why might my child need one?

The Mitrofanoff procedure is an operation where a channel is made that joins the skin of the tummy wall to the bladder, through which a catheter (thin, plastic tube) can be passed to empty the bladder of urine. This channel is usually referred to as a 'Mitrofanoff', and is created in an operation under general anaesthetic. Sometimes, the 'Mitrofanoff' is made at the same time as an operation to enlarge your child's bladder.

Children with problems with bladder emptying may benefit from this procedure. This includes children with spina bifida, bladder exstrophy or bladder outflow obstruction, including posterior urethral valves or children with dysfunctional voiding. Some children may be able to pass a catheter through their urethra, but if it is not possible or it is uncomfortable for them to do this, then a 'Mitrofanoff' will help.

What happens before the operation?

Before your child comes in for the operation you will have the opportunity to meet up with members of the paediatric urology team and nurse specialists. They will give you advice about how to prepare your child for the operation and also will give you more information on what to expect following the operation and discharge from hospital.

On the day of admission to hospital, the surgeon will visit you to explain about the operation in more detail, discuss any worries and ask you to sign a consent form giving your permission for the operation. Another doctor will also visit you to explain about the anaesthetic and options for pain relief after the operation.

If your child has any medical problems, particularly allergies and constipation, please tell the doctors about these. Please also bring in any medicines your child is currently taking.

Your child may need to have his or her bowel 'emptied' before surgery which might involve them taking some medicine (or having an enema if he or she has an existing bowel problem) some time before the operation. During this bowel emptying process, your child will not be able to eat any solid food and will only be able to drink clear fluids.



Mitrofanoff procedure

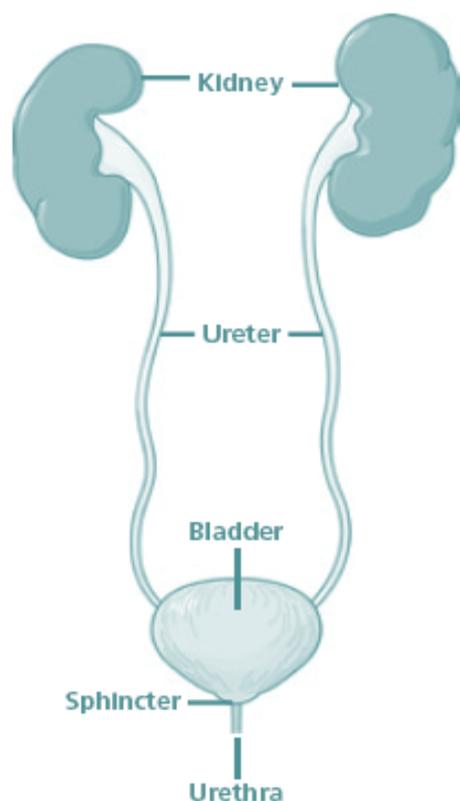


Fig 1. Normal Urinary system

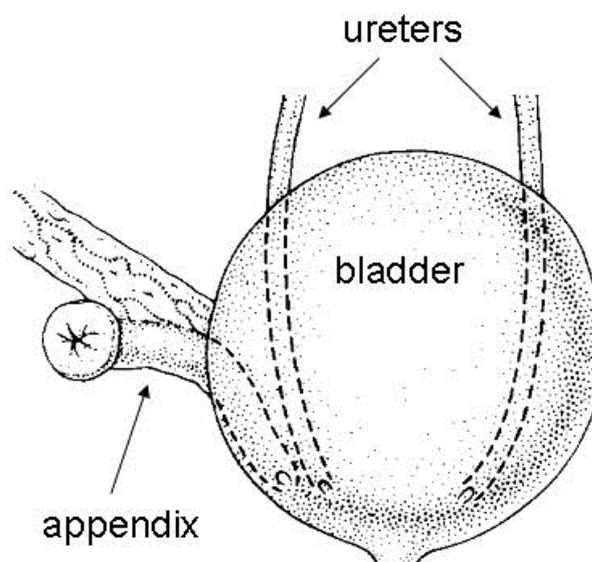


Fig 2. Bladder with Mitrofanoff

What does the operation involve?

The Mitrofanoff channel is usually made from your child's appendix. The surgeon will move the appendix from its usual position on the large intestine, and open up the tip of it to form a tube. One end will be connected to your child's bladder and the other end may be hidden in the belly button, but can also be connected to a small incision on your child's tummy wall. The surgeon will create a 'valve' where the appendix joins the bladder, which then squeezes shut as the bladder fills with urine. This will reduce the chance of urine leaking from the Mitrofanoff. If your child has already had his or her appendix removed or if it is not suitable, the surgeon may need to use a piece of the small intestine (small bowel) to create the channel.

Your child will be away from the ward for two to three hours, although it may take longer if he or she is having another procedure at the same time, such as bladder augmentation. The usual hospital stay is about five to seven days.

What will it look like?

The surgery will involve an incision being made on your child's tummy. This is usually in the mid-line between the belly button and the pubic bone and generally heals very well.

The photographs show the usual appearances of the tummy wall of a child with a Mitrofanoff after surgery. In this case, the end of the appendix has been hidden in the belly button.



Mitrofanoff procedure

Are there any risks?

All treatments carry an element of risk, but this must be balanced against the quality of life without treatment. All surgery carries a risk of bleeding during or after the operation. Every anaesthetic carries a risk of complications, but this is very small. Your child's anaesthetist is a very experienced doctor who is trained to deal with any complications. After an anaesthetic, your child may feel sick and vomit. He or she may have a headache, sore throat or feel dizzy. These side effects are usually short-lived and not severe.

In the longer term, there is a chance that the Mitrofanoff opening on the skin could narrow, making it difficult to catheterise. It is also possible for the 'valve' to stop working properly and the Mitrofanoff will then leak a little. Overall, around one-third of children with a Mitrofanoff will have one or both of these problems, and further more minor surgery may be necessary to correct them.

What happens afterwards?

Your child will come back to the ward to recover. For the first day or two, he or she will have a drip giving fluids and medication, until the bowel starts working again. The drip will be removed when your child is eating and drinking.

The surgeon will have inserted a catheter into the Mitrofanoff to keep it open while it heals. This catheter is usually left in place for three to four weeks after the operation.

Your child may also have a suprapubic catheter to drain urine from the bladder for a while after the operation. This helps the bladder and Mitrofanoff heal. During this time, the catheters will be connected to a collection bag, so urine can drain freely from the bladder.

It is quite common for children to have bladder spasms after this type of operation, and also to leak a small amount of urine, which may be tinged with blood. This is quite normal, and medication will be given to deal with the bladder spasms before your child goes home. A few days after the operation, paracetamol will be enough to deal with any remaining discomfort.

Looking after the Mitrofanoff

The Mitrofanoff needs to be treated as a wound for the first five days. Your child's nurse will show you how to care for it. After that, you should keep the Mitrofanoff clean by washing it once a day and then patting it dry with a towel. Do not rub the Mitrofanoff as this can make it sore. The Mitrofanoff can shrink a little after the operation, but this usually settles down when you start to use the catheter.

Your child should drink fluids as normal. Reducing fizzy drinks and drinks containing caffeine can help reduce any irritation. Cranberry juice is a good drink as it can also help reduce any bladder irritation and infections.

When you get home

- You should encourage your child to drink
- 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. The steri-strips usually fall off on their own. If they have not fallen off within a week, you can soak them off using a wet flannel.
- To reduce the risk of infection, some children will be given a course of antibiotics to take at home.
- The doctor will see you roughly three months after the operation and the date for this will be arranged before you go home.

Mitrofanoff procedure

Starting to use the Mitrofanoff

About three to four weeks after the operation, it will be time to start learning to use the Mitrofanoff. You may need to come back into hospital for a few days to have the catheters removed and start using the Mitrofanoff, but sometimes the nurse specialist may be able to arrange for this to happen in your own home. If your child is old enough and physically able, they will be taught to use it 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.

Your child's nurse specialist will give you enough supplies to start using the Mitrofanoff, and will usually set up arrangements for further supplies to be delivered in the community. Eventually you will take over responsibility for ordering supplies, but if you have any problems, please contact the hospital.

You will be advised how often the Mitrofanoff should be catheterised, but it is usually every three to four hours during the day and then again before going to bed. Occasionally some children have to leave a catheter in place overnight which will be attached to a special 'night bag' to collect the urine.

Instructions

1. Assemble all the equipment you will need
 - Catheter
 - Lubricating jelly (if the catheter is not pre-lubricated)
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
7. Move the catheter about within the bladder to drain all the urine – it can help if your child coughs while doing this as this tenses the bladder allowing more urine to drain
8. When urine stops flowing, remove the catheter
9. Dispose of the catheter as you have been taught
10. Wash your hands

Contact information:

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Paediatric Urology Registrars
Via hospital switchboard: 0117-927-6998

Mitrofanoff procedure

Trouble shooting

What if ...

You cannot insert the catheter into the Mitrofanoff

Action

- Try to insert a smaller size catheter
- If you can do this, leave this catheter in place and plug the end using the spigot. Contact the ward for advice
- If you still cannot insert the catheter, call the ward or your nurse specialist for advice.

Your child continues to wet in between catheterisations

- If your child has previously been dry, and suddenly becomes wet again, this could be a sign of infection, poor bladder emptying or a change in bladder behaviour. Call the ward or your nurse specialist for advice.

You or your child notice blood in the urine or catheter

- 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 or your nurse specialist for advice.

Your child's urine becomes infected

- Signs of infection include darker urine than usual, smelly or cloudy urine, tummy pains, fevers
- Call the ward or your nurse specialist for advice. They may suggest that you arrange to see your GP as your child may need a course of antibiotics.

Your child's Mitrofanoff is red, inflamed or bleeding

- Passing the catheter into the Mitrofanoff can sometimes cause this, but it usually stops when the catheter is removed
- If this continues, please contact the ward or your nurse specialist for advice.

Your child's Mitrofanoff is sore and oozing

- Infections sometimes occur, usually fairly soon after the operation. Contact the ward or your nurse specialist as your child may need a course of antibiotics
- In the long term, any weeping from the Mitrofanoff is likely to be mucous. This 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

- Contact the ward or your nurse specialist as the Mitrofanoff may need checking.

Support groups

There are no support groups specifically for children who have a Mitrofanoff, but the following organisation may be able to offer advice and support.

Association for Spina Bifida and Hydrocephalus (ASBAH) 42 Park Road Peterborough PE1 2UQ Tel 01733 555988. Website: www.asbah.org

Please contact your Regional Paediatric Nephrology/ Urology teams for further information and advice.