



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

# Catheterisation using a Mitrofanoff

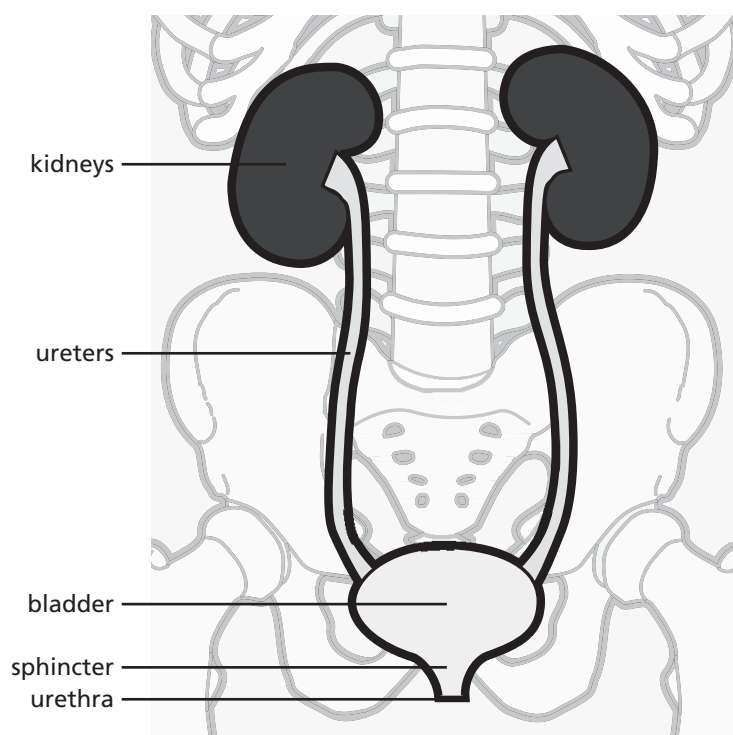
**This leaflet explains about catheterisation using a Mitrofanoff, and what to expect when your children comes to Great Ormond Street Hospital for treatment.**

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

The Mitrofanoff procedure creates a channel into the bladder through which a catheter (thin, plastic tube) can be inserted to empty the bladder of urine, instead of passing urine through the urethra. This channel – which looks like an extra tummy button – is usually referred to as a ‘Mitrofanoff’, and is created in an operation under general anaesthetic. Sometimes, this is done during an operation to enlarge your child’s bladder. Please see our leaflet *Bladder augmentation and Mitrofanoff: information for families* for more details.

Children who are incontinent (wet) may benefit from this procedure. It allows the bladder to be emptied several times a day, reducing the chance of the bladder leaking urine. It can be psychologically easier and physically less uncomfortable to insert a catheter into the Mitrofanoff rather than the urethra. It can also allow older children to lead a more normal life.

The Mitrofanoff procedure is often used for children with bladder problems due to spina bifida, bladder exstrophy or bladder obstruction (posterior urethral valves). If the bladder is abnormal, it can be difficult to empty completely which increases the risk of infection, which could lead to kidney damage.



## What happens before the operation?

Before your child comes in for the operation, you may want to come to the hospital for a pre-admission clinic. More details about this are in your admission letter.

You will already have received information about how to prepare your child for the operation in the Welcome to GOSH: a guide for parents booklet and your admission letter.



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.

In some circumstance, your child may need to have his or her bowel prepared for surgery. This means it will need to be empty of poo. Your child may need to take some medicine (or have 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 only drink clear fluids.

## **What does the operation involve?**

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 to create the channel.

The surgeon will disconnect your child's appendix from its usual position on the large intestine and open it up to form a tube. He or she will then connect one end to a small incision (cut) in your child's bladder and the other end to another small incision in your child's abdomen. The surgeon will also create a 'valve' where the tube joins the bladder, which squeezes shut as the bladder fills with

urine. This will reduce the chance of urine leaking from the Mitrofanoff.

Your child will be away from the ward for about 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 seven days.

## **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.

There is a chance the Mitrofanoff could be difficult to catheterise, as the opening is too narrow or the valve too tight. This affects about a quarter of all children with a Mitrofanoff but it is easy to correct.

## **Are there any alternatives?**

If your child has incontinence problems, they could catheterise using the urethra, although some find this difficult. Another alternative is to do nothing, and allow your child to remain wet.



## 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 to recover. The drip will be removed when your child starts eating and drinking again.

The surgeon will have inserted a catheter into the Mitrofanoff to keep it open. This should stay in place for three to four weeks after the operation.

Your child may also have a suprapubic catheter for a while after the operation, to allow the bladder and Mitrofanoff to heal. During this time, the catheter will be connected to a collection bag, so urine can drain freely from the bladder. Please see our leaflet *Looking after your child's suprapubic catheter: information for families* for more details.

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 we will give you medication to deal with the bladder spasms before you go home. A few days after the operation, paracetamol or ibuprofen 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 will make it sore.

The Mitrofanoff can shrink a little after the operation, but this usually settles down when you start to use the catheter. On rare occasions, the Mitrofanoff may need stretching while your child is under a general anaesthetic.

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 in moderation as it can also help reduce any bladder irritation and infections.

## When you get home

- You should encourage, but not force, 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 of their own accord. 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. We will arrange the date before you go home.



## Starting 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.

There are lots of different catheters available to use to catheterise the Mitrofanoff. During training, your nurse will explain each type and their advantages and disadvantages.

Your child's nurse will give you enough supplies to start using the Mitrofanoff. After this, we will arrange deliveries of supplies through a home care company. If you have any problems, please contact the hospital.

You or your child should catheterise at least every four hours during the day and before going to bed. Do not leave it for any longer as this increases the risk of infection and/or leakage.

## 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



## Trouble shooting

What if ...	Action
You cannot insert the catheter into the Mitrofanoff	<ul style="list-style-type: none"> <li>• Try to insert the smaller size catheter</li> <li>• If you can do this, leave this catheter in place and plug the end using the spiggot. Contact the ward for advice</li> <li>• If you still cannot insert the catheter, call the ward for advice.</li> </ul>
Your child continues to wet in between catheterisations	<ul style="list-style-type: none"> <li>• 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. Call the ward for advice.</li> </ul>
You or your child notice blood in the urine or catheter	<ul style="list-style-type: none"> <li>• A small amount of blood is normal especially when you start catheterising</li> <li>• If the amount increases or continues for a long time, please call the ward.</li> </ul>
Your child's urine becomes infected	<ul style="list-style-type: none"> <li>• Signs of infection include darker urine than usual, smelly or cloudy urine</li> <li>• Call the ward as your child may need a course of antibiotics.</li> </ul>
Your child's Mitrofanoff is red, inflamed or bleeding	<ul style="list-style-type: none"> <li>• Passing the catheter into the Mitrofanoff can sometimes cause this, but it usually stops when the catheter is removed</li> <li>• If this continues, please contact the ward for advice.</li> </ul>
What if ...	Action
Your child's Mitrofanoff is sore and oozing	<ul style="list-style-type: none"> <li>• Infections sometimes occur, usually fairly soon after the operation. Contact the ward as your child may need a course of antibiotics</li> <li>• 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.</li> </ul>
Urine seems to be leaking from the Mitrofanoff	<ul style="list-style-type: none"> <li>• Contact the ward as the Mitrofanoff may need checking.</li> </ul>



## Support groups

Mitrofanoff Support is an organisation supporting anyone with a Mitrofanoff. Visit their website at [www.mitrofanoffsupport.co.uk](http://www.mitrofanoffsupport.co.uk)

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](http://www.shinecharity.org.uk).

During office hours, please call the urodynamics clinical nurse specialist on 020 7405 9200 ext 5916 or 5917.

Out of hours, please call Squirrel Ward on 020 7829 8814.

## Notes

Compiled by the Department of Urology and Squirrel ward in collaboration with the Child and Family Information Group

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