

Feedback

We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

Freephone (City Hospital campus): 0800 052 1195

Freephone (QMC campus): 0800 183 0204

From a mobile or abroad: 0115 924 9924 ext 65412 or 62301



Minicom: 0800 183 0204

E-mail: pals@nuh.nhs.uk

Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614,
Nottingham NG7 1BR

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Caring for your child's Mitrofanoff

A guide for parents and carers

This document can be provided in different languages and formats. For more information please contact:

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Introduction

This booklet has been prepared to help parents and carers understand this treatment and to offer advice regarding the management of your child's Mitrofanoff.

Notes

Why does your child need a Mitrofanoff?

There are various reasons why you and your child may choose to have a Mitrofanoff. It may allow some older children with mobility difficulties to have more independence. And for the small group of children who struggle with urethral catheterisation this would be an alternative method to empty their bladder.

What is a Mitrofanoff?

The Mitrofanoff procedure creates a channel, through which a catheter can be inserted to empty the bladder of urine, instead of passing urine in the usual way through the urethra.

How is the Mitrofanoff made?

The channel will usually be created using your child's appendix. The surgeon will disconnect your child's appendix from its usual position on the large intestine and open it up to form a tube. The doctor will then connect one end to your child's bladder and the other end to your child's abdomen or tummy button.

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.

Prescription information for your doctor and chemist

Nelaton catheter

Nelaton catheters single use

The catheters are available through most regional and national wholesalers.

To be filled in by the doctor/nurse:

Patient's name

Catheter type—Male/Female/Paed

Catheter size

Telephone Contact

Doctor/Nurse Signature

Date

What happens before the operation?

In order to decide what procedure is best for your child, your doctor will need a recent kidney ultrasound scan and an investigation called bladder pressure studies.

Sometimes it is also necessary to find out how well the kidneys are working and this would involve having another test. However, this is not a routine investigation and would only usually be necessary if the ureter was being considered as a channel and the kidney was no longer functioning.

When will we need to come into hospital?

When your child is admitted to hospital will vary, but it is normally on the day of surgery. Each child is individual and your consultant will inform you which day and what time you should bring your child to hospital.

Will my child need bowel preparation?

When a piece of bowel is used to create the channel the doctor may request that you clean out the bowel prior to surgery, to reduce the risk of infection.

Bowel preparation usually involves your child taking some form of oral medication to help soften the poo and help your child to empty their bowels.

What happens after the operation?

Your child will return to the ward with two intravenous infusions (drips), one infusion will contain a sugary fluid to replace the fluid your child would normally drink. The second infusion will have a medication called morphine or fentanyl in it, this will help control your child's discomfort following surgery.

They will also have two catheters in place. Catheters are thin plastic tubes which will help drain urine from your child's bladder. One catheter will enter the bladder through the tummy wall and is called a supra-pubic catheter. The second catheter will be placed in your child's mitrofanoff channel.

Again each child's operation will be different and your doctor or nurse will talk to you about how many catheters your child will have and why they are required. The catheters have a balloon inside, which is filled with water to make sure they do not fall out.

What will happen next?

Over the next few days the doctor will listen to your child's tummy to see if they can hear gurgling sounds. If they can it means that your child's bowel is working correctly and we can start to give oral fluids. For some children this will be the day after surgery; for others it may take a few days longer.

Once he/she is eating and drinking again the intravenous infusion will be removed. The morphine or fentanyl infusion will also be removed and your child will be given oral pain relief.

A few days after the operation, Paracetamol and Ibuprofen will normally be enough to deal with any remaining discomfort.

Some questions answered

Do I need to wear special clothes?

No.

Do I need to eat a special diet?

No, but you should eat a healthy well balanced diet with plenty of fresh fruit and vegetables as vitamin C helps to keep the urine clear.

Do I need to drink extra fluids?

Children should aim to drink 6-8 full glasses of water/dilute to taste drinks a day.

Cranberry juice is recommended since it prevents mucous build up and is also high in vitamin C.

Can I bathe and shower?

Yes.

Can I still go away on holiday?

Yes, but always ensure that you have an adequate supply of catheters with you and if travelling abroad carry some catheters in your hand luggage in case your luggage is lost.

It is also advisable to catheterise before starting any long journey.

Can I still play sports?

Please speak to your nurse specialist or doctor before re-starting sporting activity.

We often recommend waiting until the clinic appointment at three months before restarting sports, but this can vary from child to child.

What to look out for?

You should notify your doctor or specialist nurse if your child's urine becomes infected. You may notice the following:

- Blood in their urine.
- Your child may have a temperature and be sweating or shivering.
- Their urine might be smelly and/or cloudy.

If you observe any of these signs please take a urine sample to your family doctor, as a course of antibiotics may be required.

If your child's Mitrofanoff is red, inflamed, sore or bleeding or oozing, please contact your doctor or specialist nurse.

Infections can occur so we would need to check this out but often weeping from the Mitrofanoff is likely to be mucous from the appendix or bowel that was used to create the Mitrofanoff. This will not cause your child any harm and a small dressing can be applied if the mucous is troublesome.

Remember: During the day **never** leave catheterisation longer than four hours.

If you cannot pass the catheter, or are unable to drain urine, you should contact your hospital doctor/ specialist nurse immediately – bladder perforation can occur and may be life threatening.

During this time, the nurses will carefully monitor the amount of urine drained into the catheters and may need to give your child a bladder washout.

It is quite normal for your child 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 give your child medication to deal with the bladder spasms before you go home.

When will we be able to go home?

Your child will be discharged from hospital when we are happy that they are making good progress, this varies from child to child but is usually five to ten days after surgery with all of their catheters still in place.

An appropriate time will be given (usually three weeks following your child's operation) for you to bring your child back to the ward for removal of these catheters and commencement of clean intermittent catheterisation.

Learning how to catheterise your child's Mitrofanoff

Your specialist nurse will tell you when you are due back into hospital to learn how to catheterise the Mitrofanoff. This will usually be three to four weeks after the operation.

The nurse will remove the remaining catheters and catheterise the Mitrofanoff channel with a catheter.

Many of you may already be familiar with catheterisation having carried it out urethral on your child prior to the operation.

For those of you who are not we have written the step by step instructions in the following pages.

How to catheterise the Mitrofanoff?

Clean intermittent catheterisation is a method used to empty urine from the bladder at regular intervals during the day.

This is carried out by passing a fine flexible catheter(soft plastic tube) into the Mitrofanoff.

We suggest you collect all the things you will require before starting. These may include:

- Catheter
- Lubricating jelly
- Jug or receiver
- Baby wipes/ soap and water

Clean intermittent catheterisation is a clean technique so, most importantly, you need to wash your hands.

Once you have washed your hands try not to touch anything other than the items you need to prepare for catheterisation.

STEP 1: Open the catheter package, trying not to touch the tip of the catheter if possible, and prepare the catheter as per manufacturer's instructions (you will be shown how to do this).

STEP 2: Wash your child's Mitrofanoff. You will be shown the correct way to do this.

STEP 3: Wash you hands again.

STEP 4: Gently introduce the catheter into your Mitrofanoff to drain the urine. Insert as far as necessary until the urine drains. You will be shown the safe and correct method to do this.

Some people may experience a slight 'pop' as their catheter goes into the bladder.

STEP 5: When the urine begins to drain out insert the catheter a further 2 to 5 cms., hold the catheter in position until the urine has stopped, then **slowly** withdraw it, stopping if more urine runs out. Continue to do this until the catheter is completely out.

The nurse/doctor who teaches you this will tell you if you are able to re-use the catheter.

Please try to keep to the technique you will be taught.