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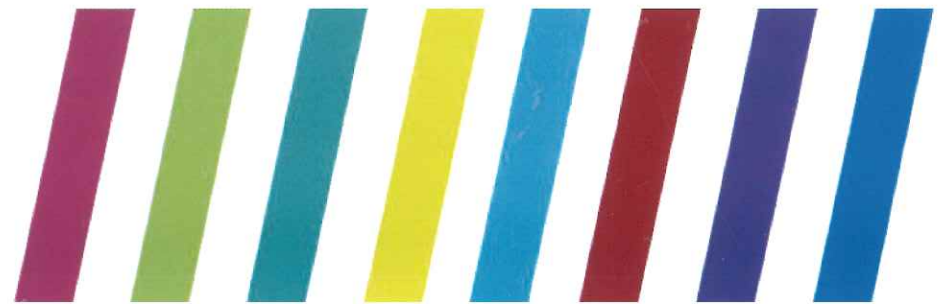
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My guide to having a Mitrofanoff and Bladder Augmentation



Information for children and teenagers

By Yvie Morley Health Play Specialist
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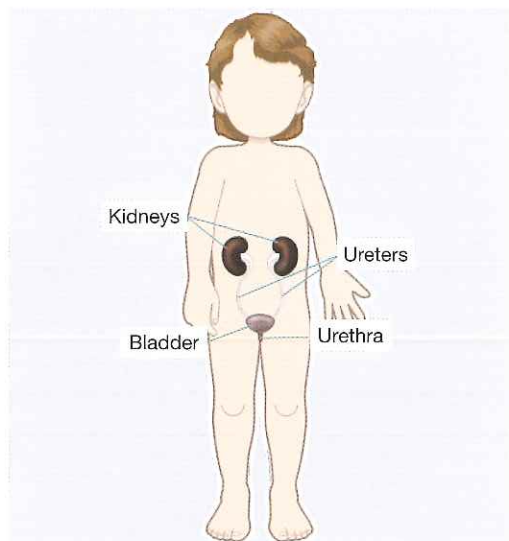
You have been given this leaflet because your bladder is not working as it should and the doctors along with you and your Parents/carers are thinking about having a Mitrofanoff.

This booklet has been designed to help you to understand

- what a Mitrofanoff is
- how it works
- what the operation involves
- how to do it when you go home from hospital

How does my bladder work now?

Your bladder is a balloon shaped sack that is below your Kidneys (see picture below) It is the place where your body stores your wee.



When your bladder is full your brain sends a message to it to empty, the bladder does this by squeezing and pushing the wee out when you sit on the toilet.

Not all bladders empty as they should and there are lots of reasons why this happens, having a Mitrofanoff will help make sure that:

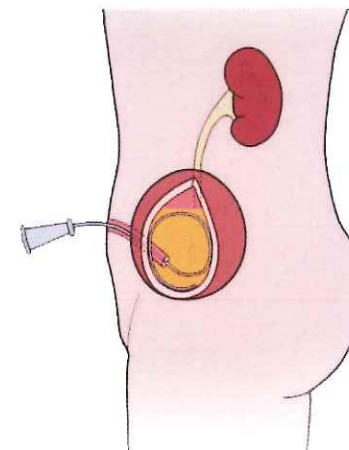
- you can completely empty your bladder
- Help you to stay dry
- Help to prevent infections
- Help your Kidneys stay healthy

What is a Mitrofanoff?

A Mitrofanoff is a small channel that is made from either a small piece of your bowel or your appendix.

It goes from your bladder to the outside of your tummy so that you can empty your bladder completely using a special tube called a catheter.

This is what you will look like on the inside once you have your Mitrofanoff.



This is what you will look like on the inside once you have your Mitrofanoff.

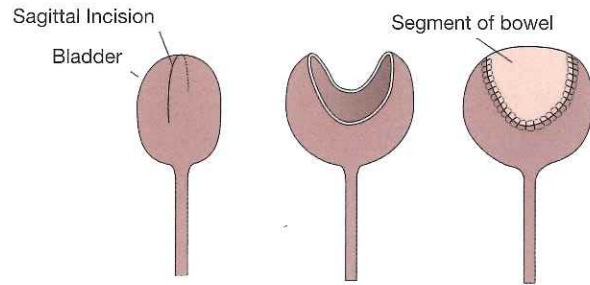
When you have your Mitrofanoff you will need to empty your bladder every 3 to 4 hours. It is really important that you do empty your bladder when you should. Not emptying your bladder could make you very poorly!

Sometimes children who need to have a Mitrofanoff also need to have their bladder made bigger this is done at the same time as having a Mitrofanoff made.

What is a Bladder Augmentation?

A bladder augmentation simply means to make your bladder bigger.

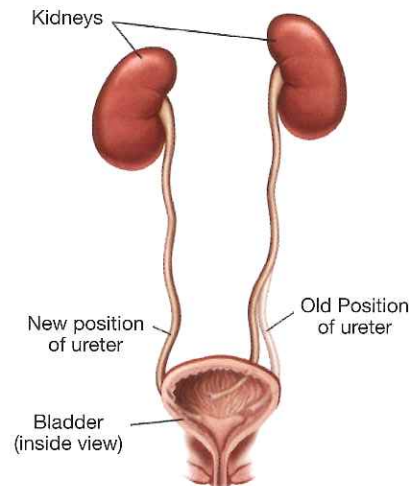
Below are pictures to show you how the doctor will make your bladder bigger.



Bladder Augmentation

As you can see the doctor opens up your bladder from the top to make a cup shape. Then they take a piece of your bowel and stitch it over the gap (these stitches dissolve by themselves when your bladder has healed to the piece of bowel)

Your bladder has 2 tubes called ureters attached to it. These tubes bring the wee down from your kidneys into your bladder. When your bladder is made bigger the end of these tubes may also need to be moved so that they are in the right position on your new bladder.



What will happen when I come into Hospital?

You will come into hospital on the day of your operation. you must not have anything to eat or drink on the day of your operation but your parents will have had a letter explaining this.

When you arrive on the ward you will be shown to your bed and the nurse will need to do a few observations such as blood pressure, temperature, height and weight and they will ask you and your parents/carers a few questions. Your doctor will also come and see you before you go for your operation. This gives you or your parents a chance to ask any questions that you might have about your surgery.

Your mum or dad can go to theatre with you and stay with you until you are asleep. The doctor will put a small tube called a canula into the back of your Head so that they can give you the medicine that will send you off to sleep, some children prefer to use a face mask to go to sleep but this can be discussed with the anaesthetist.



How long will I stay in Hospital?

Most children stay in hospital for 7-10 days after their surgery.

you won't be able to have anything to eat until your bowels start to make noises but you will be allowed to have sips of water. Once your bowels start making noises (usually about 2-3 days) you will be able to eat and drink as normal.

How will I look when I wake up from my operation?

After your operation your body will need time to heal inside, to help this happen you will wake up with a few special tubes in. All the tubes are put in whilst you are asleep.

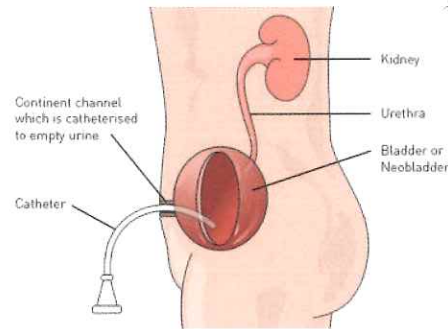
- **Suprapubic catheter:**

This is a tube that goes into your bladder to drain away the wee until your Mitrofanoff can be used.



- **Indwelling catheter:**

This tube stays in the Mitrofanoff channel until everything has settled down and healed inside. It helps to keep the channel open until your Mitrofanoff is ready to use.



- **JP Wound drain:**

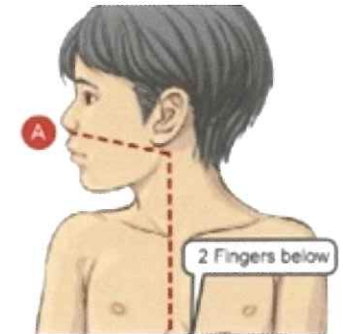
This is a small soft rubbery tube that is very close to Your Mitrofanoff. It is there to drain away any fluid that might have leaked out when Your Mitrofanoff channel was joined to your bladder.



- **NG tube:**

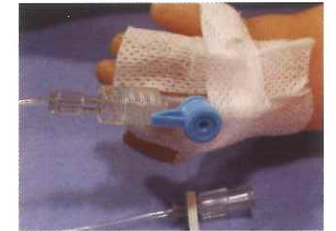
This goes up through your nose and into your Stomach. Because the doctor uses bowel to make your Mitrofanoff it stops working for short while.

The NG tube stops bile building up inside your Stomach which can make you sick. It drains it away into a small bag that is fixed to the outside end of it.



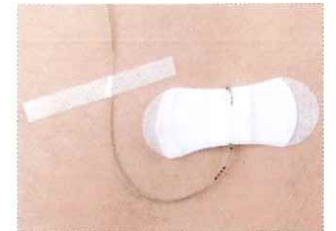
- **Cannula:**

This is a small plastic straw like tube that goes into a vein either on the back of your hand or in your arm. It is used to give you medicine to send you to sleep for your operation and to give you antibiotics and fluid after your operation.



- **Epidural:**

This is a small fine tube that is put into your lower back. It is used to give you strong pain medicine that will numb the area around your Mitrofanoff, you will need this medicine for the first couple of days.



You will go home with your suprapubic catheter and indwelling catheter still in. These tubes stay in for 4 – 8 weeks then you will come back to the hospital to have them taken out. The other tubes will come out before you go home.

When do I start to use my Mitrofanoff?

Your Mitrofanoff needs at least 4 weeks (sometimes longer) to settle down. After that you will come back to the hospital for a few days and we will begin to teach you how to catheterise your Mitrofanoff. The process we use will also help to stretch your bladder so that it can hold a good amount of wee before you need to catheterise. Your suprapubic catheter will have a clamp put on so that the wee will not drain through it.

DAY 1: The catheter is taken out of your Mitrofanoff and we start by putting the catheter in every 2 hours to drain away the wee. At night your suprapubic catheter will be put on free drainage (that means the small tap on the tube will be opened so that the wee in your bladder will just drain into the bag attached.) this is to keep your bladder empty overnight so that everything inside can continue to heal.

DAY 2: Your suprapubic catheter will be clamped in the morning. (a clamp is a small clip on the catheter that squashes the tube so that wee can't come out of it.) You will need to catheterise every 3 hours throughout the day. your suprapubic catheter will be put on free drainage overnight.

DAY 3: In the morning your suprapubic catheter will be clamped and you will need to catheterise every 4 hours, once you are able to do this through the day you will also need to catheterise every 4 hours overnight for several months eventually this should stop.

Once you are catheterising every 4 hours your suprapubic catheter is usually removed before you go home.



This is how your Mitrofanoff will look before the indwelling catheter is taken out. As you can see there is a tiny stitch that holds the catheter in place. This is taken out by the nurse and the catheter is then removed.



This is how your Mitrofanoff will look after all the tubes are out and every thing has healed.

Bladder wash outs

Once you have your Mitrofanoff you will need to begin twice daily bladder wash outs.

Bladder wash outs are really important. They keep your bladder healthy and wash out any mucus that builds up inside your bladder. Mucus is thick goeey stuff that is made in your bowel. If the mucus is not washed out from your bladder it can build up and cause infections and something called bladder stones.

Bladder stones can be very painful and you will need another operation to have them removed.



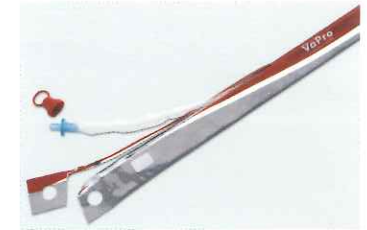
This is what a bladder stone looks like

While you are in hospital you and your parents/carer will be shown how to do washouts at home. You will also be given an information sheet to remind you what you need to do.

What do the catheters look like ?

Catheters come in different sizes but they all empty the bladder.

The nurse will tell you which size catheter you need to use.



Some catheters come with a handle and the water is ready to use in the packet.



REMEMBER: you should **NEVER** leave it longer than 4 hours to catheterise. You will become very poorly if you don't empty your bladder. You should always carry a catheter with you.

I feel a bit scared about coming to hospital

If you feel or anxious or worried about coming to hospital or going to theatre for your operation or you want to know more about having a Mitrofanoff or bladder augmentation you can come to see the play specialist before you have your operation. The play specialist can go through everything with you and help you to be less anxious when you go for your operation.