

My guide to having a Mitrofanoff and Bladder Augmentation

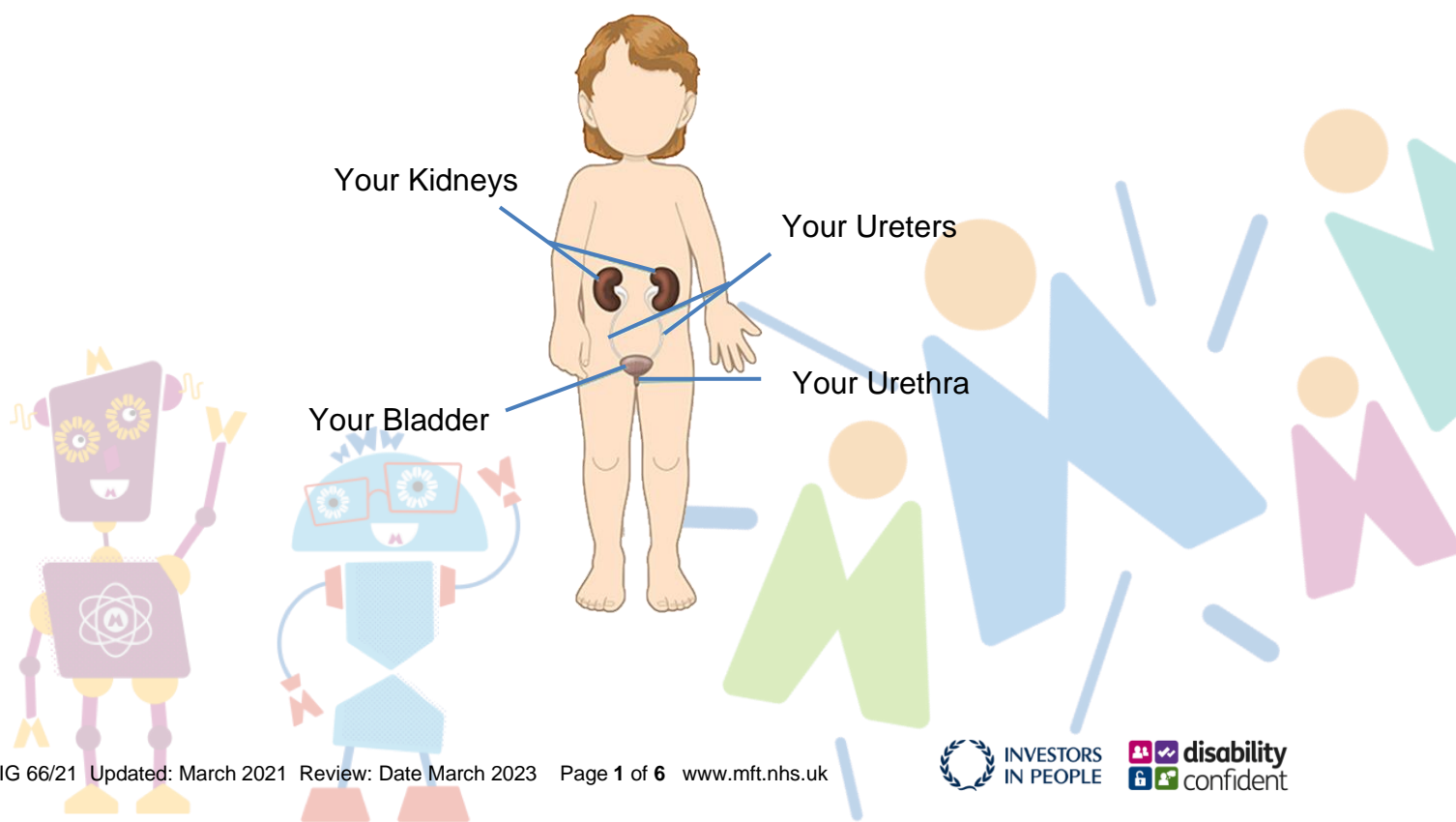
You have been given this leaflet because your bladder is not working as it should, therefore the doctors along with you and your parents/carers are thinking about having a Mitrofanoff, either with or without a bladder augmentation.

This booklet is designed to help you understand:

- What a Mitrofanoff is
- How it works
- What the operation involves
- How to use your Mitrofanoff when you go home from hospital

How does my bladder work?

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



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

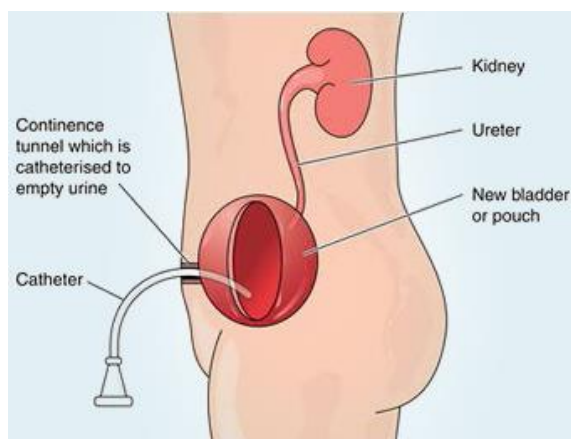
Not all bladders work as they should do and there are a lot of reasons why. Having a Mitrofanoff will help make sure that:

- You can properly empty your bladder
- It will help you stay dry
- Help to prevent infections
- Helps keep your kidneys safe and 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 had your Mitrofanoff:

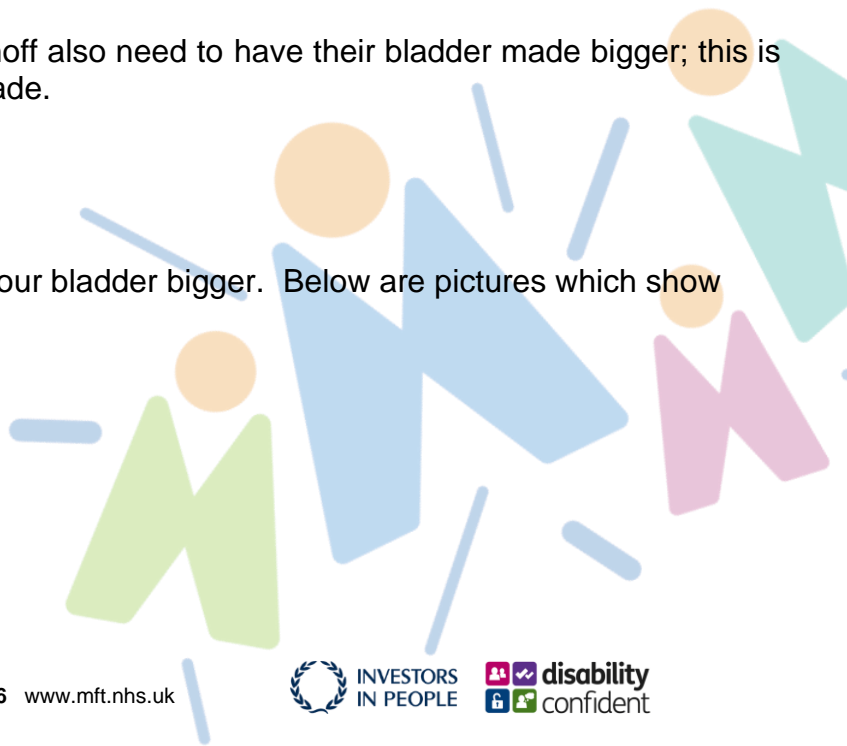
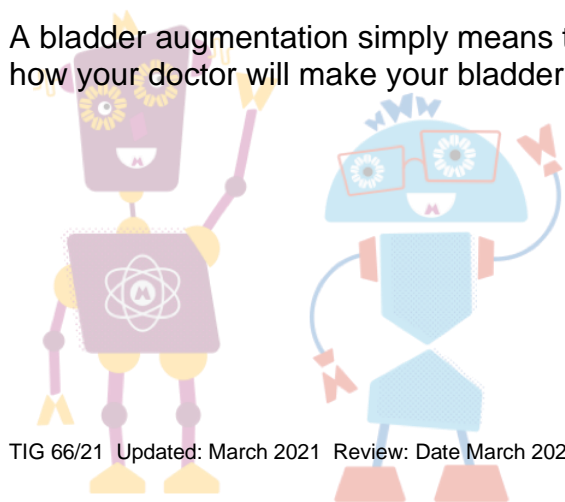


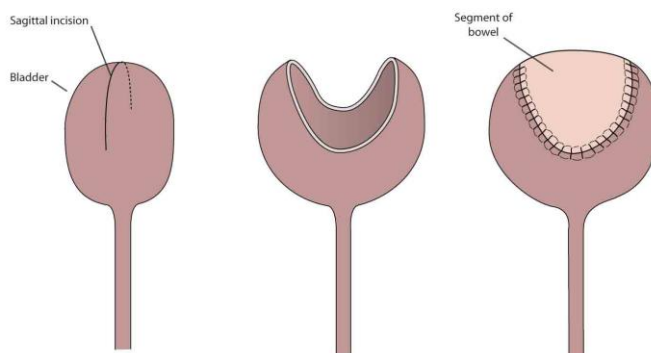
When you have your Mitrofanoff you will need to empty your bladder every **3 to 4 hours**. It is really important you empty your bladder when you should. Not doing so could make you very poorly!

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 which show how your doctor will make your bladder bigger.





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).

Your bladder has two 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 to hospital?

You will come into hospital on the day of your operation. You must follow the guidance regarding when to stop eating and drinking before your operation, you will receive a letter explaining this prior to your operation.

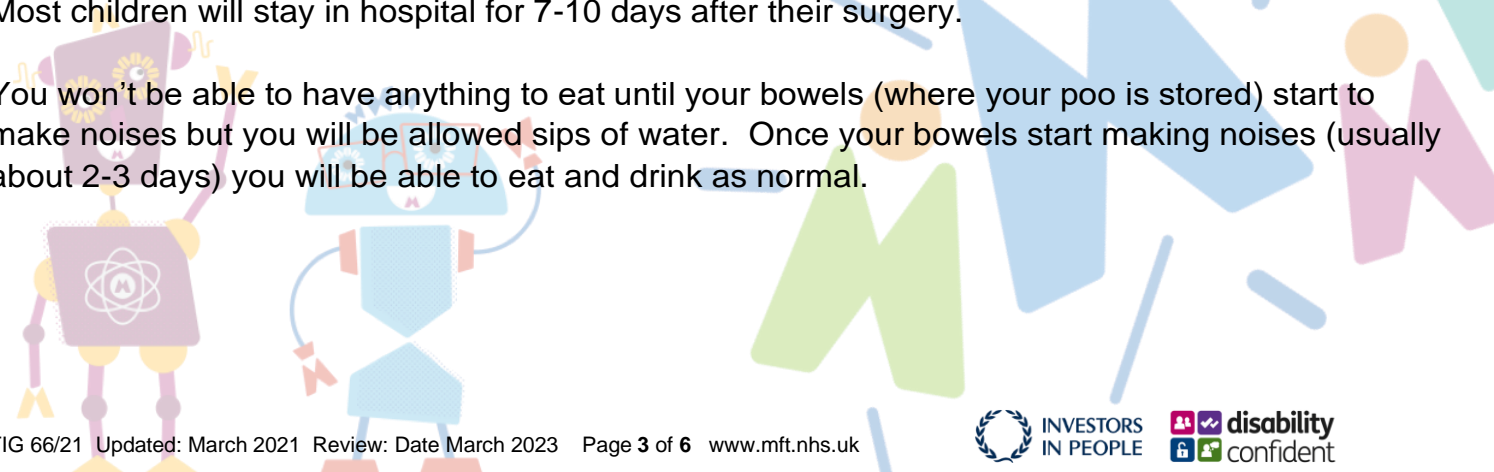
When you arrive on the ward, you will be shown to your bed and the nurse will need to do a few observations such as blood pressure, temperature, height and weight. They will also ask your parents/carers a few questions. Your doctor will also come and see you before you go for your operation. This gives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

One of your parents/carers can go to theatre with you and stay with you until you are asleep. The doctor will put a small tube called a cannula into the back of your hand so that they can give you your medicine that will send you off to sleep, some children will prefer to use a facemask to go to sleep but this can be discussed with the anaesthetist.

How long will I stay in hospital?

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

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

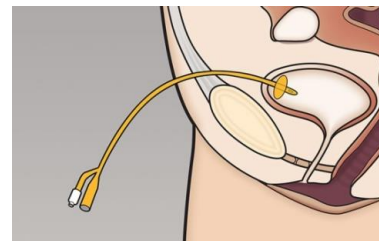


How will I look when I wake up from my operation?

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.

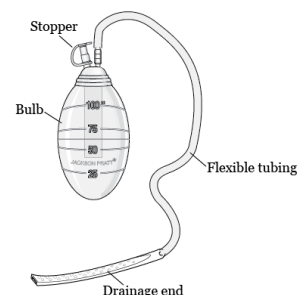


- **Indwelling Mitrofanoff catheter**

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 your bowel to make your Mitrofanoff it stops working for a 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 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 a 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.

When you are admitted for training in using your Mitrofanoff we will clamp your suprapubic catheter and begin catheterising your Mitrofanoff every 1.5 – 2 hours we will then stretch this to every 3 – 4 hours.

When your suprapubic catheter is clamped it is common to have a strange sensation in your bladder, this is completely normal and is because your bladder has not been used for a few weeks. This is the reason we start with catheterising every 1.5 – 2 hours, if you become uncomfortable before your catheter is due then you can always catheterise early.

Overnight, depending on your condition, you may be required to tape a catheter in overnight or you may not have to catheterise at all overnight. We will inform you of this on your admission.



Bladder Washouts

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

Bladder washouts 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.

Whilst you are in hospital you and your parents/carers 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 shapes and sizes but they all empty the bladder. The nurse will tell you which size catheter you will need to use.

Some catheters come with a handle and the water (which makes the catheter slippery) 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 scared or anxious about coming to hospital or going to theatre for your operation, or would like some more information about having a Mitrofanoff or Bladder Augmentation you can come and see the play specialist and nurse specialist before having your operation. The play specialist can go through everything with you and help you to be less anxious when you go for your operation.

In case of problems or advice please call:

Urology Clinical Nurse Specialists

Jenny Powell
Sue Wright
Hayley Wynne

Play Specialist

Yvie Morley

Paediatric Urology Secretaries

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(0161) 701 1637
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