

# So you think you might need a Mitrofanoff



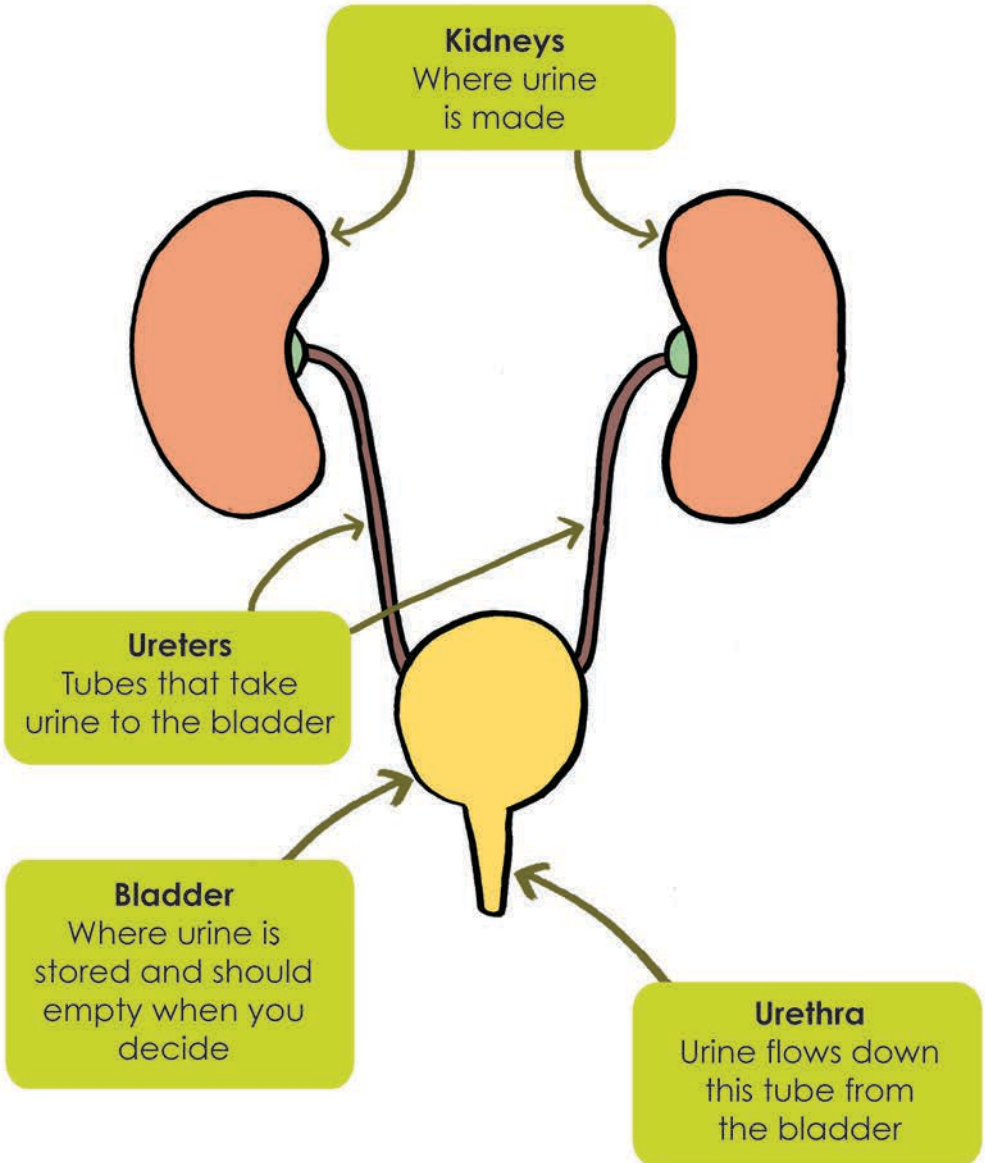
This is very general information about the Mitrofanoff procedure. This booklet is for you to read with your parents/carer, to make you and your family think about and discuss the operation. It is intended to make you think about what this operation will mean for you and what changes you and your family will have to make in your daily life.

Every Consultant and hospital approach the Mitrofanoff procedure slightly differently and it is important that you get specific information about the procedure from your Nurse Specialist and Consultant.





How does a healthy bladder work?





How does my bladder work and how does this affect me everyday?

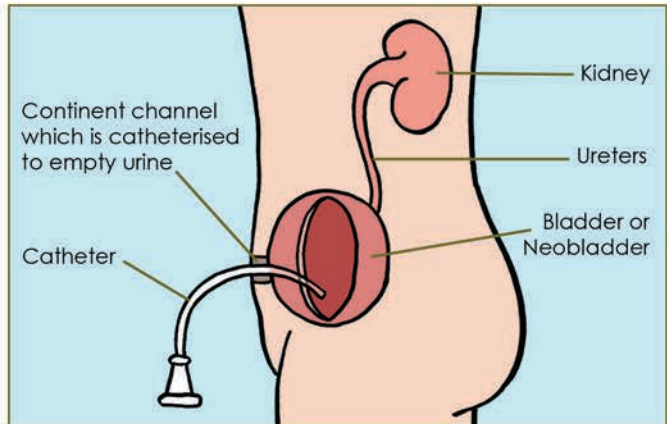
For you to write or draw about your bladder. To fill in with a Healthcare Professional or parent.

A large, empty rectangular box with a thin black border, intended for the student to write or draw their response to the question.



What is a Mitrofanoff?

A Mitrofanoff is a catheterisable channel from the abdomen to the bladder. It allows the bladder to be emptied when the urethra cannot be used.



Why is a Mitrofanoff good for me?

Section for you to answer and discuss with the Healthcare Professional (it's going to make me dry, going to wear pants).

Blank space for writing an answer to the question: Why is a Mitrofanoff good for me?



This is a big operation. Each hospital is different in their approach to this operation. Therefore, the best people to discuss your operation with are your Nurse Specialist or Consultant. Here are some questions you may want to consider discussing...

### **The operation**

- Bowel prep?
- Length of the operation?
- What will they use to make the Mitrofanoff?
- What tubes will I have when I wake up from my surgery?
- What are bladder spasms?
- Pain relief?
- When can I eat?
- Can my parents stay?
- How am I going to get the wee out?
- How often will I need to catheterise my Mitrofanoff?
- Length of stay in hospital?

## **After discharge**

- What is the plan for going home regarding my tubes?
- Will it hurt to catheterise?
- Pain relief?
- How do I get my catheters?
- How often do I need to come back to hospital?
- Medication?
- When can I have a bath?
- What activities can't I do and for how long?

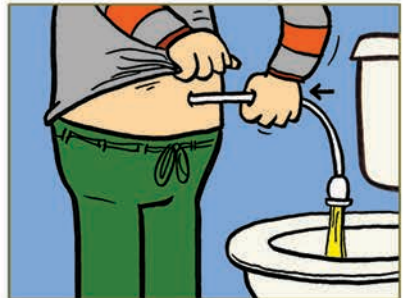
## **Long term**

- Are there any activities I can't do?
- When can I go back to school?
- How do I manage at school?
- Who will help me in the community?
- Who do I contact if I have any problems?



## How to catheterise...

- Take your catheter to the toilet.
- Wash hands.
- Sit or stand near the toilet.
- Touching the catheter as little as possible insert into the Mitrofanoff until urine starts to flow.
- Ensure bladder is empty.
- Slowly remove the catheter.
- Stop removing the catheter and wait if urine flows.
- Remove fully.
- Dispose of catheter.
- Wash hands.







## Some general advice...

- It is important that you drink regularly. This will help flush out your bladder and prevent your urine from becoming too concentrated and prevent Urinary Tract Infections (wee infections).
- It is important that your Mitrofanoff is catheterised at the time agreed with your Nurse Specialist. This will help prevent your bladder from stretching, reduce your risk of urine infections and leakage.
- It is important that you wash your hands before and after you catheterise your Mitrofanoff.
- It is important that you have the details of your Nurse Specialist or Community Nurse in case of an emergency.
- It is important that you order enough catheters in plenty of time so you don't run out.
- You may be required to washout your bladder which helps prevent infections, mucus or bladder stones. You will be taught how and when to do this by your Nurse Specialist.





**Questions you want to ask  
your Nurse or Consultant.**

Fill in this section to discuss this  
with your Nurse or Consultant.



**It's understandable to be nervous about  
the surgery, you may want to write your  
worries here and discuss with your Nurse  
or Consultant.**



Here are recognised complications that you may want to discuss with your Nurse or Consultant. The advice is very general but if you are worried always contact a Healthcare Professional straight away.

### **What if my Mitrofanoff leaks?**

Try draining your bladder earlier than you usually would. You may want to use padding to absorb the urine. Speak to your Nurse Specialist.

### **What if the catheter blocks?**

Try flushing the catheter with some cooled boiled water to dislodge the debris. Consider bladder washouts if the problem continues.

### **What if I run out of catheters?**

Contact your delivery company straight away and ask if they can deliver them as soon as possible. Contact your a Healthcare Professional straight away for support. They may consider putting in a indwelling catheter until you have supplies. We advise you to put your catheter order in 2 weeks in advance, before running out.

### **What if I suspect a Urinary Tract Infection?**

Take a urine sample (from catheterising your Mitrofanoff) to your GP as soon as possible. Inform your GP of your symptoms as they may wish to start oral antibiotics. Drink plenty to try and flush your system.

### **What if I see blood in my urine?**

Inform a Healthcare Professional and ensure you drink plenty. Take a urine sample as you would usually for a suspected Urinary Tract Infection.

### **What if my catheter won't go into my Mitrofanoff?**

Don't panic, leave and try again in half an hour. If it still won't go in, call a Healthcare Professional.



## Useful numbers and email addresses

### Hospital Ward

Name: \_\_\_\_\_

Number: \_\_\_\_\_

Email: \_\_\_\_\_

### Nurse Specialist

Name: \_\_\_\_\_

Number: \_\_\_\_\_

Email: \_\_\_\_\_

### GP

Name: \_\_\_\_\_

Number: \_\_\_\_\_

Email: \_\_\_\_\_

### Community Nurse

Name: \_\_\_\_\_

Number: \_\_\_\_\_

Email: \_\_\_\_\_

### Catheter delivery company

\_\_\_\_\_

### Mitrofanoff Support

[mitrofanoffsupport.org.uk](http://mitrofanoffsupport.org.uk)

[info@mitrofanoffsupport.org.uk](mailto:info@mitrofanoffsupport.org.uk)

### Bladder and Bowel Community

[bladderandbowelfoundation.org](http://bladderandbowelfoundation.org)

[support@bladderandbowelfoundation.org](mailto:support@bladderandbowelfoundation.org)

### Breakaway Foundation

[breakawayfoundation.org.uk](http://breakawayfoundation.org.uk)

[info@breakawayfoundation.org.uk](mailto:info@breakawayfoundation.org.uk)

### Diversions

[diversions.org.uk](http://diversions.org.uk)

[diversions@live.co.uk](mailto:diversions@live.co.uk)

### Shine Charity

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

[firstcontact@shinecharity.org.uk](mailto:firstcontact@shinecharity.org.uk)

### Spinal Injuries Association

[spinal.co.uk](http://spinal.co.uk)

[sia@spinal.co.uk](mailto:sia@spinal.co.uk)

### Urostomy Association

[urostomyassociation.org.uk](http://urostomyassociation.org.uk)

[secretary@urostomyassociation.org.uk](mailto:secretary@urostomyassociation.org.uk)

### Mitrofanoff Support Australia

[mitrofanoffaustralia.org.au](http://mitrofanoffaustralia.org.au)

[info@mitrofanoffaustralia.org.au](mailto:info@mitrofanoffaustralia.org.au)

The date of my Mitrofanoff surgery is

*This booklet was written by Paediatric Urology Nurse Specialist's Angela Downer and Louiza Dale. The booklet enables children to understand if a Mitrofanoff is suitable. Special thanks to Angela and Louiza.*

*Mitrofanoff Support also thanks Hollister for sponsoring the illustration of this informational children's leaflet.*

