Queen Elizabeth Hospital Birmingham
Part of University Hospitals Birmingham
NHS Foundation Trust

Having a Mitrofanoff (creation of a catheterisable urinary stoma)

– Information for patients

Delivering the **best** in care

UHB is a no smoking Trust

To see all of our current patient information leaflets please visit
www.uhb.nhs.uk/patient-information-leaflets.htm

It is essential that you have read this booklet carefully and that you understand the mitrofanoff operation and its effects on you.

If any questions arise from reading this booklet the urology nurse specialists are available to talk to. You will find their telephone number at the end of this booklet. If your call is not answered, please leave your name and telephone number on the answer phone and they will return your call as soon as possible.

The nurse specialists are also available for you after you have had your operation particularly in the 2 -3 weeks after discharge from hospital.

'Buddy' System

No matter how many leaflets and booklets you read after discussing this operation with healthcare professionals, it is sometimes helpful to talk to a patient who has undergone this operation.

If you feel you would benefit from speaking to another patient please ask your specialist nurse to put you in contact with someone. All 'buddies' have volunteered their services to help other patients through this process.

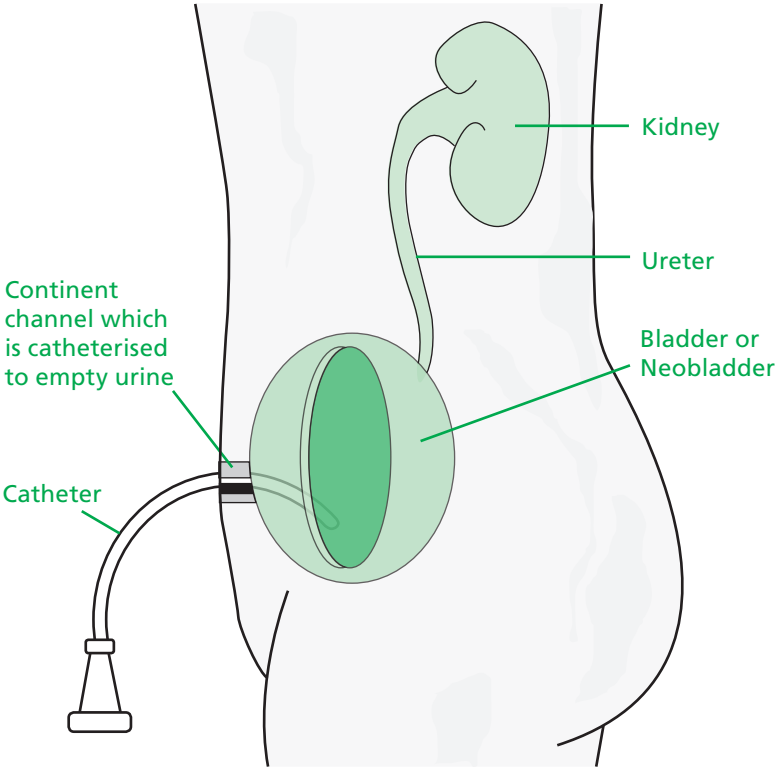
What is a Mitrofanoff?

A Mitrofanoff is a catheterisable channel which has been created between the skin and the urinary bladder (reservoir) or new (neo) bladder (see 'Having a Clam Cystoplasty' leaflet) which forms a small opening called a stoma on the surface of the skin. The procedure was first performed in 1980 by Dr Paul Mitrofanoff.

The channel is made out of the appendix or a piece of bowel and a valve is created by the surgeon where the channel joins the bladder. This squeezes shut as the bladder fills with urine. This reduces the chance of urine leaking out of the channel.

Urine is emptied every so often from the bladder by using a hollow plastic tube (catheter) which is passed down the channel into the bladder. Once the catheter has stopped draining it is removed and discarded. This process is called intermittent self-catheterisation and is painless. You will be taught how to perform this procedure by a specialist nurse.

There should be no leakage between catheterisations therefore there is no need to wear a bag over the stoma.



What are the alternatives to this procedure?

If you decide not to have a Mitrofanoff your Consultant will discuss other options suitable for your condition if available, for example:

- A long term indwelling catheter which is a temporary hollow flexible tube used to drain urine from the bladder either via the urethra (water pipe) or through a cut in the abdomen (see the leaflet 'Having a supra pubic catheter').
- A urinary diversion which is an operation to re-route urine flow from its normal pathway resulting in a stoma (opening on the abdomen). The stoma is pink/red in colour and will drain continuously out into an external collecting stoma bag that sticks on your abdomen over the stoma.

What are the benefits of having a Mitrofanoff?

If you are unable to empty your urinary bladder without the aid of a urinary catheter you may find this route more acceptable or convenient.

Having a Mitrofanoff can be a long term solution to enable you to maintain a normal quality of life.

What are the risks?

All procedures and treatments carry an element of risk. These will be explained to you in full by your Consultant. The most common risks or complications are:

- Urine infection
- Wound infection
- The catheter placed during surgery may fall out requiring a further operation to replace it
- The channel may become narrowed (stenosis) needing a catheter to be left in for a period of time (for one week or several weeks this varies from patient to patient) or further surgery to correct the problem
- The channel may leak urine requiring further surgery to correct the problem
- The tissue (connective structure) used to form the channel may die requiring further surgery to amend it
- Stones can form within the bladder when it is not fully drained and there is incomplete emptying.

Rare complications:

- Anaesthetic or cardiovascular problems such as chest infection, pulmonary embolus (blood clots in the lungs), stroke, deep vein thrombosis (blood clots in the veins), heart attack and death
- Scarring of the bowel requiring further surgery

What will happen before the operation?

You will receive an appointment for a 'pre-assessment' to assess your general fitness, perform baseline investigations e.g. blood pressure and to screen you for the presence of MRSA infection.

You will be given advice regarding your day of admission for example; asked not to eat and drink for 6 hours before surgery.

You are usually admitted on the same day as your operation via the admissions lounge. You will be asked to sign your operation consent form giving permission for your operation to take place, showing that you understand what is to be done and confirming that you wish to proceed. Make sure that you are given the opportunity to discuss any concerns and to ask any questions that you may still have before signing the form. An anaesthetist will also see you and will discuss pain relief for after the surgery.

You will be provided with elasticated stockings to help prevent venous thrombosis (clots in your legs) in addition to a drug called Clexane; an injection given under your skin.

The operation

This is performed under a general anaesthetic (being put to sleep) and takes approximately 3-5 hours. It is usually carried out through a vertical scar in the lower half of your tummy. The surgeon will create a channel using your appendix, a short segment of small intestine (bowel) or a combination of both. It will be joined to the skin by a flap which is shaped into a small pit rather like a second tummy-button.

What will happen after the operation?

Once back on the ward your temperature, pulse, blood pressure, breathing rate and urine output will be monitored closely until you are stable.

You will have a drip in a vein in your arm to give you fluids until you are able to eat and drink.

You will have three catheters in your bladder; one in the Mitrofanoff, one in the urethra (water pipe) and one through your tummy (supra pubic catheter) to drain your urine while your bladder is healing for about 4 – 6 weeks.

You may also have a drainage tube close to the wound to remove any excess fluid away from the internal area where the operation has been done. You may also have a small tube in your nose to drain your stomach to stop you feeling sick. Gradually these will be removed 3-5 days after your operation.

If stents (small tubes) are used which keep your ureters (the tubes that drain urine from your kidneys to your bladder) open they will be removed approximately 7- 10 days following the operation.

You must expect to experience some pain with this major surgery however please be re-assured that the ward staff are aware of this. It is our aim to keep you as comfortable as possible therefore please do not be embarrassed to tell staff if you are in pain.

You will be encouraged to mobilise as soon as possible after your operation to encourage your bowel to start working again. You will start to consume food and drink as soon as possible.

A Physiotherapist will show you some deep breathing and leg exercises.

It will take at least 6 weeks for you to recover fully from this surgery.

It will be necessary for you to avoid straining the abdominal muscles so you will be unable to do any heavy lifting for 3 months.

Spinal patients will need to slide transfer; this is where you transfer from one surface to another, for example sliding across a transfer board from one chair of a similar height to another. Or patients may use a hoist for 6 weeks after the operation.

Clips or stitches are usually removed from your wound site after approximately 10 days although some stitches dissolve and do not need to be removed.

Mucus production in the urine

Due to the type of tissue used for a Mitrofanoff, bladder augmentation or neo bladder there will be a buildup of mucus within the urine, which can create stones. Regular bladder washouts will need to be performed to prevent a blockage.

The nurses will perform this activity initially and then you will be shown how to perform this procedure yourself. You must feel confident performing these washouts before going home so if you are unsure please ask.

Catheters

To allow healing you will always have one or two catheters on free drainage, whilst the third will be capped off (plugged so it does not drain). If one catheter blocks off, release the other one. If there is no drainage and a washout fails to unblock it please contact the ward immediately.

You will need to perform your bladder washouts morning and evening to prevent blockage. You can perform another washout in between times if you notice the catheters are not draining.

The catheters should not be changed or removed by anyone apart from a member of the urology team here at the Queen Elizabeth Hospital Birmingham.

After approximately 6-8 weeks you will be taught how to perform intermittent catheterisation through your mitrofanoff channel. This is a clean procedure which involves passing a catheter into your bladder to drain the urine being stored.

The supra pubic catheter will be capped off and left in place until you have become confident with your catheterisation regime, after approximately 1-2 weeks.

You will need to catheterise every 2 to 4 hours depending upon how much you have drunk.

You should not let your bladder overfill i.e. catheterise less often than every 4 – 6 hours as this may cause catheterisation difficulty if the bladder is too full. By cutting down on fluids 2 hours before bed will enable you to have normal night's sleep.

Urinary tract infections

These may be more common after this surgery due in part to the difficulty in completely emptying the bladder. Drinking a good volume of fluid and regular self-catheterisation will help prevent these occurring. If symptoms occur, a urine test is required by your GP. Antibiotics are usually only needed if you have a temperature and feel unwell.

Fluid intake

You are advised to drink at least 8 - 10 cups of fluid each day to keep the mucus diluted (weak). Drinks which are high in Vitamin C also help keep the urine free of mucus. Cranberry juice also helps make the mucus less thick and helps reduce the risk of infection. It is recommended that you drink 2 small glasses daily. If you find the taste too sharp you may dilute it with other fruit juices or water. Drink more in hot weather.

What should I expect when I get home?

The average hospital stay is 2 weeks.

Allow time to rest but continue gentle exercise such as walking, gradually increasing your activity as you recover. Aim to reach the same level of activity you were able to do before your operation in approximately 3 months.

Bathing and showering

Showering is preferred until your wound is healed. Avoid the use of highly perfumed soaps, creams and talc near the site and make sure you dry the area carefully. If the wound site becomes red, hot, swollen or starts to leak an offensive discharge please seek advice from your GP, district nurse or nurse specialist.

Equipment supplies

The nurse who discharges you home will give you the required equipment for performing your bladder washouts and ordering information. Further supplies can be obtained by prescription either directly from your chemist or from a delivery company such as Fittleworth or Charter. You and your GP will be informed of the products you require by the nurse and the first order placed with the home delivery company should you choose to use one.

Diet

Try to eat a healthy well balanced diet with plenty of fresh fruit and vegetables and fluids. In hot weather increase your fluid intake.

Bowel

You may find that your normal bowel habit is affected by this surgery. This is temporary for a few weeks or months , and this varies from patient to patient.

Sex

You may resume your sex life after 6 weeks if you feel ready and comfortable. Speak to your urologist if you want to become pregnant. Although there should be no undue difficulties with pregnancy, you should be closely monitored. Urinary infections may be more of a problem than usual.

This surgery does not affect male sexuality or fertility.

Return to work

You may return to work approximately 8 weeks after the operation but you may need longer if you need to establish a confident programme of clean intermittent self-catheterisation.

Playing Sports

Contact sports such as rugby and netball are to be avoided indefinitely unless your consultant advises otherwise. There are no restrictions with swimming.

Going on holiday

There are no restrictions when going on holiday but do not forget to take an adequate supply of catheters, appropriate equipment and an antibiotic course if you suffer from urinary tract infections. Always carry equipment in your hand luggage as well as in your suitcases in case these go missing.

Drink a good volume of fluid (1.5 to 2 litres) in hot weather and during long flights.

You should catheterise yourself immediately before any long journey. Some patients prefer to have an indwelling catheter; a tube that remains in place in the bladder by means of a deflatable balloon connected to a leg bag for long flights or journeys. Please carry a letter from your doctor with you explaining what you have had done and the need to carry equipment with you.

It is advisable to wear a medical information bracelet or necklet as a safety precaution. Should you ever be in the unfortunate position of being taken to hospital and not be able to communicate with the hospital staff for whatever reason, they may not realise what type of operation you have had. The information they can obtain from such bracelets or necklets may stop any damage or unnecessary treatment being carried out.

Driving

We would recommend that you refrain from driving for 4 weeks but it is your responsibility to ensure that you are fit to drive following your surgery. It is advisable to inform your car insurance company of your surgery before returning to drive.

Long term follow-up

It is very important that you are followed up regularly by the Urology Department. Frequency of appointments will be determined by need, and these will be arranged by the medical or nursing staff. Once stable you will have an annual review and annual ultrasound scan of your Kidneys and blood samples taken.

REMEMBER:

Contact your GP, the Ward or your nurse specialist if:

- You think you have a urine infection
- Your operation scar becomes hard or reddened or inflamed or begins to ooze discharge
- You have persistent abdominal or back pain
- You suffer persistent nausea or vomiting

Ongoing care of a Mitrofanoff

Please follow the guidance below to ensure that you care for your Mitrofanoff appropriately.

Catheterising

- Always start by washing your hands
- Prepare equipment and work space
- Remove the catheter from the packet
- Gently introduce the catheter into the Mitrofanoff
- Insert as far as necessary until urine drains, then push a little further into the bladder to ensure complete drainage
- When the flow of urine has stopped slowly withdraw the catheter
- After finishing the procedure, discard catheter and equipment carefully and wash your hands

If you have difficulty inserting the catheter, remove it and try again with a new catheter.

If urine does not drain, the catheter may be blocked. Try changing position; i.e. standing up, lying on your side. If this is not successful, you may have to flush or washout the Mitrofanoff and bladder.

Note: If you insert the catheter too far it can coil up inside the bladder, which can adversely affect drainage and possibly cause pain. The Mitrofanoff is usually 10-15cm long therefore only a few centimetres more of the catheter needs to be inserted; the extra length of catheter should be kept outside the body to give added distance to drain into a toilet or receptacle.

Performing a washout

- Wash hands thoroughly
- Prepare equipment and work space
- Draw up 25 – 50mls of sterile saline into a bladder (catheter tip) syringe
- Introduce catheter into Mitrofanoff stoma and gently advance into bladder
- Attach the bladder syringe to the catheter
- Instil the saline into the bladder gently and then gently withdraw the saline back into the syringe
- Empty syringe into another container
- If there is a lot of mucus visible then repeat the washout until the saline from the bladder is clear
- Withdraw the catheter completely and dispose of it
- After finishing the procedure, discard the catheter and equipment carefully and wash your hands

When to seek medical advice:

- There is blood in urine
- You have a temperature/sweating/shivering
- The urine smells offensive
- You are leaking between catheterisations
- You are unable to insert or withdraw the catheter

Contact numbers:

If you have any questions regarding the content in this leaflet, please contact the Urology Team via the numbers below.

Urology Nurse Specialists	0121 371 6932 0121 371 6929
Urology Ward (624)	0121 371 6263
Medic Alert Foundation	01908 951045 www.medicalert.org.uk
SOS Talisman Ltd	020 8554 5579 www.sostalisman.co.uk

Acknowledgements

BAUS Mitrofanoff Procedure (Creation of a Catheterisable Urinary Stoma) Information for Patients March 2016

www.mitrofanoffsupport.org.uk

Guy's and St Thomas' Hospitals NHS Foundation Trust Having a Mitrofanoff Continent Urinary Diversion January 2014

Image taken from www.mitrofanoffsupport.org.uk

The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm

Urology

Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston, Birmingham B15 2GW

Telephone: 0121 627 2000

PI16/1833/01 Author: Fran Harries
Date: September 2016 Review date: September 2018