

# Having a Mitrofanoff continent urinary diversion

**Your surgeon has recommended that you need a continent urinary diversion. This leaflet explains more about having a Mitrofanoff continent urinary diversion including the benefits, risks and any alternatives. It also provides information on what you can expect when you come to hospital.**

**If you have any further questions, please speak to a doctor or nurse caring for you.**

## What is continent urinary diversion?

A continent urinary diversion, or continent urinary pouch, is an alternative method of collecting and storing urine in the bladder when the normal mechanism is not working properly. The Mitrofanoff pouch is one type of diversion. The different types of diversion are explained later in this leaflet.

There are three main parts to a continent urinary diversion (see diagram on the next page):

1. The formation of a reservoir to hold the urine.
2. The formation of a channel to allow urine to flow out of the reservoir.

The continence mechanism or valve, which keeps the urine in the reservoir until it is convenient to empty it

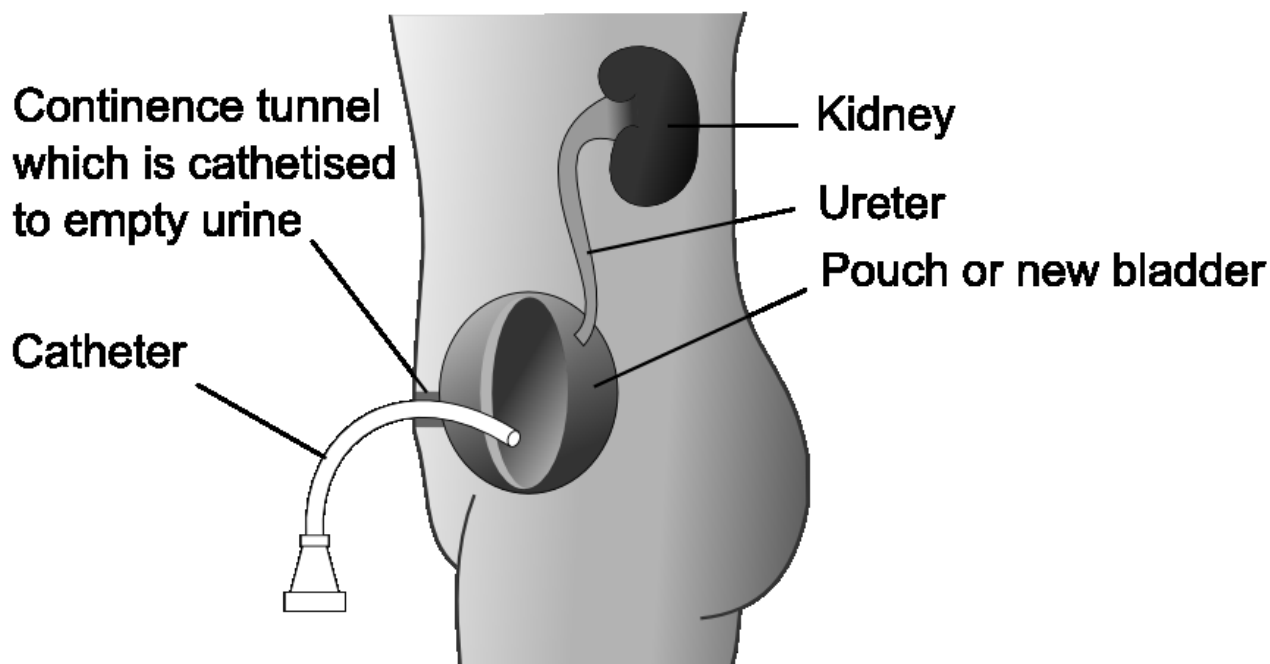
The reservoir for collecting the urine can be created from the existing bladder, the bladder can be made bigger with a piece of bowel or a new bladder can be made entirely from bowel.

The reservoir is connected to the outside of the body by a channel which forms a small opening, called a stoma on the surface of the skin. The channel is made out of the appendix, ureter or bowel. This channel is often called a Mitrofanoff channel.

The surgeon will also create a valve where the channel joins the reservoir, which squeezes shut as the bladder fills with urine. This reduces the chance of urine leaking out of the channel.

You will need to empty urine from the reservoir by using a hollow plastic tube called a catheter. The catheter is passed into the stoma and down the channel to the reservoir, and the urine is drained off. Once the catheter stops draining it is removed and discarded. This process is called catheterisation and is a painless procedure. You will be taught how to catheterise by a specialist nurse.

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



## What are the benefits of having a Mitrofanoff continent urinary diversion?

If you have been experiencing problems filling or emptying your bladder, or have had to have your bladder removed, then a continent urinary diversion allows you to have a replacement system formed. This can be made out of bowel, or a combination of bladder and bowel, to form a reservoir or pouch.

The Mitrofanoff pouch is a reservoir that will allow urine to be stored until a catheter is passed to drain it. This will stop you being incontinent of urine. The stoma should not leak between catheterisations and therefore does not require a bag over it, making it much more discreet.

## What are the risks?

All treatments and procedures carry risks and these will be explained to you in full by your doctor. Some of the more common complications which may occur when having a Mitrofanoff continent urinary diversion are:

- Urine infection.
- Mucus builds up in the pouch which can form stones.
- You may develop metabolic problems. This means your blood may become too acidic (hyperchlorimic acidosis), which can be treated with medication. You will need regular blood tests to check for this.
- Leakage from the stoma.
- Narrowing (stenosis) of the channel, which may need further surgery.
- If the pouch becomes overfilled there is a risk of tearing and leaking internally.
- There is a theoretical risk that tumours may develop in the pouch after many years. Current evidence suggests that the risk of this is very small.

Your surgeon will discuss any potential complications with you but please feel free to ask questions at any time.

## Are there any alternatives?

If you decide not to have a Mitrofanoff continent urinary diversion, the doctor will discuss any other options that are suitable for your particular condition. It is possible that the problem with your bladder or urethra may not allow you to opt for available alternatives. If there are any other options these will be discussed with you in detail to allow you to make your decision. Alternative continent diversions are:

### A) The ileal conduit diversion

An ileal conduit diversion is formed by detaching the ureters (tubes that drain urine from the kidneys) from your bladder and joining them on to a short piece of the small bowel (ileum). One end of this piece of ileum is sealed off and the other is brought to the surface of the abdomen as a small spout or conduit. This is called a urinary stoma. The remaining ileum is joined back together and should not affect your bowel function. The stoma is pink/red in colour and will drain continuously allowing urine to drain directly from your kidneys, down the conduit and out in to an external collecting system called a stoma bag that sticks on your abdomen over the stoma.

There are a number of different stoma bags available and you will be advised and supported by a nurse specialist about the one that is right for you.

Complications of the ileal conduit diversion:

- Sore skin around the stoma site: Patients may be sensitive to the adhesive on the bag or there can be leakage around the site.
- Stomal hernias and/or incisional hernia: The muscle wall in this area is weak due to the surgery. This sometimes results in parts of the stoma or parts of the intestine pushing through the weakened muscle wall to form a hernia.
- Prolapse of the stoma: The stoma may prolapse (fall or extend outwards) making it difficult to apply the stoma bag.
- Urinary tract infections: High temperature, offensive smelling urine and cloudy urine may indicate a urine infection.
- Stenosis (narrowing) of the ureter: The area where the ureters (the tubes that drain urine from your kidneys) are attached to the conduit may narrow down causing obstruction. This in turn may cause pressure on the kidneys leading to kidney damage.

### B) The Mainz pouch

This is another type of urinary diversion where after surgery the patient is able to pass urine via the rectum (back passage). The ureters are plumbed in to the rectum which has been surgically made into a reservoir for urine. Unlike the ileal conduit, this is an internal system.

Unlike the Mitrofanoff or ileal conduit, you do not need to use a catheter or wear a bag. Instead you will be able to pass urine and have your bowels open through the anus.

The main complications are:

- Incontinence: It may take several months for you to regain continence, especially at night. Though you will be able to tell when you need to have your bowels open, your stool is likely to be very soft because it is mixed with urine. This means that you may leak until you regain continence.
- Offensive odour: The bacteria which live in the bowel will give a pungent odour which some patients may find offensive and may mean you have to carry deodorising spray when using public toilets.
- Acidosis: the bowel may absorb some of the urine making your blood acidic. This may

- not give you any symptoms and can easily be put right with medication.
- Incomplete emptying: You may find you are unable to empty all the contents of your rectal bladder. This means you will always have some urine and/or faeces in your bladder which may cause acidosis, urine infection and incontinence.
  - Tumours can form on a small number of patients having this operation so they should undergo regular telescope testing (colonoscopy) to check for this.
  - Further surgery: If you are unable to empty your rectal bladder and as a result have acidosis and/or recurrent infections your surgeon may advise you that further surgery may be needed. This may mean changing to an alternative urinary diversion.

## Coming in to hospital

We will send you information about how to prepare for your hospital visit with your admission letter. Please read this information carefully.

## How long will I need to be in hospital?

Your admission to hospital will be in two stages. The first admission will be for the operation itself and you should expect to be in hospital for about ten days. You will then be discharged home and readmitted six weeks after your initial surgery. The second admission will be for one to three days when you will be taught how to catheterise and care for your new continent diversion.

You should not expect to go back to work/school/college for at least two to three months after your operation but this will be discussed with you before your operation.

## How can I prepare for a continent urinary diversion?

Before you come into hospital you will be seen in the pre assessment clinic and undergo investigations to ensure you are fit for surgery. These will include:

- blood tests
- urine tests
- x-rays
- electrocardiogram (ECG), which provides a printout of your heart rate and rhythm
- MRSA screening.

If specific bowel preparation is required you may be admitted to hospital the day before your surgery.

Before your surgery you will need to fast. Fasting means that you cannot eat or drink anything (except water) for six hours before surgery. We will give you clear instructions if you need to fast and when to start fasting. It is important to follow the instructions. If there is food or liquid in your stomach during the anaesthetic it could come up to the back of your throat and damage your lungs.

We will also ask you about any medications you take, please bring them with you to your appointments.

## Giving my consent (permission)

We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

## What happens after the operation?

The surgery usually takes two to five hours depending on the type of operation. Following this you will either return to the ward or go to the high dependency unit (HDU). This will depend on your general health, the length of the operation and your doctor's decision.

Once back on the ward your temperature, pulse, blood pressure, respiratory rate and urine output will be monitored closely. These checks will happen less often as your condition becomes more stable.

You will have a drip in the vein in your arm and/or in to your neck to give you fluids, as you will not be able to eat or drink for the first few days. You will be allowed to start eating again once you have passed wind, as this indicates your bowels are moving again.

You may have a fine plastic tube in your nose that runs in to your stomach, called a naso gastric (NG) tube. This will drain off any fluid and stop you feeling sick.

Your new bladder will be drained by tubes (catheters). This makes sure that your bladder is empty at all times and helps it to heal. The number of tubes varies depending on what operation you have had. The nurses caring for you will clearly label which tubes are which and explain what they are for.

You will get out of bed the day after your operation and sit in your chair. The tubes and drains will be removed on your consultant's instructions. The following timescales are a guideline:

- Wound drains will usually be removed when they stop draining after about two to three days.
- The naso gastric tube will be removed when you can drink without feeling nauseated.
- The intravenous drip in your arm or neck will be removed when you are drinking and your bowels are working and you pass wind.
- Two very small tubes called stents, which you may have to keep the ureters open, usually stay in for seven to ten days.
- The clips or sutures (stitches) will be removed from the wound site after seven to ten days. Some sutures may be soluble so won't need to be removed.
- The catheters in to your pouch (Mitrofanoff and supra pubic catheter) remain in place for six weeks until you are readmitted to learn how to catheterise your pouch.
- The urethral catheter, if in place, is usually removed after three to seven days.

The bowel produces mucus and will continue to do so. This mucus can sometimes build up and cause a blockage. If your continent pouch has been made from bowel, regular washouts will need to be performed to prevent a blockage. The nurse will do this for the first few days and then you will be shown how to perform this yourself. Before going home you must feel confident in washing out your pouch so please ask if you are unsure.

## Will I feel any pain?

You have had major surgery and will experience some pain. However, we want you to be as pain free as possible. There are different options to control your pain and you will be seen by an anaesthetist before your surgery who will discuss pain control and how it works with you. It is our aim to make you feel as comfortable as possible so you will be able to move around and recover sooner. The pain will lessen over the first couple of days and you will generally not need as much pain relief. Please tell the staff looking after you if you are in any pain or discomfort – we do not want you to suffer in silence.

## What do I need to do after I go home?

### On leaving hospital

Please allow time to rest after you leave hospital but you should do some gentle exercise and gradually increase this. You should not do anything too strenuous or lift anything heavy such as shopping for six to eight weeks. You should aim to reach the same level of activity you did before your operation in about three months.

### Catheters

You will need to perform bladder washouts twice a day through the supra pubic catheter and the Mitrofanoff (pouch) catheter to prevent blockage. You can do a washout in between times if you notice the catheters are not draining.

You will always have one catheter on free drainage, whilst the other catheter will be capped off. 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 or urology registrar on call immediately (contact details at the end of this leaflet).

### Diet and fluids

There is no need to follow any special diet but it is a good idea to eat a healthy nutritious diet of fruit and vegetables. If your pouch is made up from bowel you may find it takes time for your bowels to return to their usual pattern. If your bowels are still a problem please discuss this at your next appointment or talk to your GP.

Fluid intake is very important – you must drink at least eight to ten cups of fluid a day. This will help prevent the build up of mucus, which not only blocks the catheters but also acts as a medium on which bacteria can grow, causing infection.

### Supplies

When you are discharged we will arrange for all the supplies you need to be delivered to your home. This will include drainage bags and equipment to carry out bladder washouts. We will give you clear instructions on how to order more supplies. We will also refer you to a district nurse. The district nurse will look after your wound sites and offer general advice.

The catheters should not be changed or removed by anyone apart from this hospital unless instructed by us. If you have any specific questions please contact the nurse specialist or ward.

### Activities

It is not a good idea not to resume sex for at least six weeks after surgery. You can then resume your sex life when you feel ready and comfortable. Please discuss this with your surgeon or nurse specialist. Please speak to your surgeon before resuming any sports.



## Re-admission to be taught catheterisation

After about six weeks you will be readmitted to be taught how to catheterise your pouch/Mitrofanoff. This is a clean procedure which entails you passing a catheter in to the pouch and draining the urine.

On admission we will remove the Mitrofanoff or pouch catheter and leave the supra pubic catheter clamped off. At first you will need to catheterise the pouch every two to three hours but over time the pouch will expand to hold more urine and you will only need to catheterise every four to six hours. The pouch should never be left longer than six hours as this will overstretch it causing the walls to thin. The pouch may also be difficult to catheterise if it is too full.

During the night we can insert a catheter and tape it in place so that it drains freely and you don't need to wake. Over time, once the pouch capacity has increased you may find that emptying the pouch and cutting down on fluids two hours before bed enables you to have normal nights sleep.

## Going home

Once you are totally confident with catheterising you will be discharged from hospital (go home). We will arrange for your products to be delivered and inform you how to re-order. You will already have a district nurse and we will notify them of your discharge.

## What should I do if I have a problem?

Should you experience any problems catheterising, please do not hesitate to contact the ward or specialist nurse (contact details at the end of this leaflet).

Please contact the district nurse, your GP or the hospital if:

1. You think you have a urine infection (urine becomes thick or smelly, you have a fever or feel unwell, or there is blood present in your urine).
2. Your operation scar becomes hard red, oozes or becomes inflamed.
3. You have persistent abdominal or back pain.
4. You suffer persistent nausea or vomiting.

## Will I have a follow-up appointment?

You will be given a follow up appointment usually 6 -12 weeks after discharge.

## Useful sources of information

Further information and support are available from Mitrofanoff Support at:

**w:** [www.mitrofanoffsupport.co.uk](http://www.mitrofanoffsupport.co.uk) **e:** [info@mitrofanoffsupport.co.uk](mailto:info@mitrofanoffsupport.co.uk) **t:** 01202 886 444

It is advisable to wear a **medical information bracelet or necklace** as a safety precaution. Should you ever be in the unfortunate position of being taken to hospital and unable to communicate the staff will not know your medical condition. A medical alert bracelet or necklace will alert them to your condition, enabling them to provide you with the specialist care you need. The following addresses may be useful.

### Medic Alert Foundation

17 Bridge Wharf  
156 Caledonian Road  
London N1 9UU  
**t:** 020 7833 3034

### SOS Talisman Ltd

41 Grays Corner  
Ley Street  
Ilford Essex IG2 7RQ  
**t:** 020 8554 5579

## Contact us

If you have any questions or concerns about your condition please contact:

**Aston Key Ward** 0207 188 8860

**Florence Ward** 0207 188 2441

**Clinical nurse specialist** 0207 188 6783 or 0207 188 0136 (Monday to Friday, 8am to 5pm)

You can bleep the clinical nurse specialist by calling the hospital switchboard on **020 7188 7188** and asking for the bleep desk. Ask for bleep **1596** or bleep **0856** and wait for a response. This will connect you to the clinical nurse specialist directly.

If you have an urgent problem **out of hours**, please call the switchboard on **0207 188 7188** and ask to speak to the urology registrar on call.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

## Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS) **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints) **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

**t:** 020 7188 8815 **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

## NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111

## NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

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