University College Hospital

Continent urinary diversions

Urology Directorate
Introduction

The aims of this booklet are:

- To give you useful information about the operation
- To answer some of the questions you may want to ask
- To help you think about what to expect, prepare you for the operation and what life will be like afterwards.

The urinary system

To understand the operation you are going to have it is helpful to have an idea of how the normal system should work.

The urinary system consists of the kidney, the ureters, the bladder and the urethra. The kidneys are responsible for filtering the waste products from your blood. These waste products are excreted by the kidney as urine. The urine passes from your kidneys, down the ureters, to the bladder. Production of urine is continuous, although you may notice that you produce less urine at night.

The bladder acts as a reservoir for the urine. A sphincter muscle at the base of the bladder prevents leakage of urine when closed. The sphincter opens when this muscle relaxes. To empty out the bladder the sphincter opens, the bladder contracts and urine passes out of the bladder and through the urethra to the outside. Females have a short urethra while in the male it is much longer and has to pass through the prostate gland and down the penis before reaching the outside. (See diagram one).

Diagram 1
What is a continent urinary diversion?

A continent urinary diversion it is an alternative method of collecting and storing urine in the body when the normal method, as described above fails or has been removed. The Mitrofanoff pouch is one type of continent urinary diversion.

There are three main parts to this diversion:

- The reservoir to hold the urine
- The channel or tunnel to let the urine flow out of the reservoir
- The continence mechanism to keep the urine in until it is convenient to empty the reservoir

The reservoir for the urine can be made using your existing bladder or a bladder made bigger with bowel or a completely new bladder made entirely of bowel. This is connected to the outside of the body by a tunnel, which forms a small opening (called a stoma) on the surface of the skin usually through the umbilicus (belly button).

The tunnel can be made of various parts such as your appendix, ureter or bowel. One end of this tunnel will be buried into your new bladder and the other end will be brought out on to your tummy as a continent catheterisable stoma.

The reservoir is emptied of urine by using a plastic tube called a catheter. This is inserted into the stoma, through the tunnel and into the pouch. Once the pouch is empty, the catheter is removed. The stoma may discharge a small amount between catheterising.
How can a continent urinary diversion help me?

If you have been experiencing problems filling or emptying your bladder or you have to have your bladder removed (e.g. for a painful bladder) then a continent urinary diversion allows you to have a “replacement” system formed. It can be made out of bowel or a combination of bladder and bowel. It will allow urine to collect in the pouch until you are ready to empty using a catheter.
What are the risks of having a continent urinary diversion?

All treatments and procedures have risks and we will talk to you about the risks of having a continent urinary diversion.

The most common complications which may occur are:

- Urine infections (20 percent)
- Mucus build up (which may cause stones to form)
- Your blood may become too acid (known as hyperchlorimic acidosis. This causes no symptoms but must be treated with tablets) (16 per cent)
- Leakage via the stoma
- Stenosis (narrowing of the catheterisable tunnel).

Your surgeon will discuss any potential complications with you before you have surgery. Please feel free to ask questions.

What are the risks of a general anaesthetic?

There are a number of factors that affect the chances of suffering complications from anaesthesia; these may include age, weight, smoking, lifestyle and the general state of your health. Your anaesthetist and/or your surgeon can provide further details.

The following information on risks is provided by the Royal College of Anaesthetists.

**Very common (one in 10) and common (one in 100) side effects:** Feeling sick and vomiting after surgery, sore throat, dizziness, blurred vision, headache, itching, aches, pains, backache, pain during injection of drugs, bruising and soreness, confusion or memory loss.
**Uncommon (one in 1000) side effects and complications:**
Chest infection, bladder problems, muscle pains, slow breathing (depressed respiration), damage to the mouth, an existing medical condition getting worse, awareness (becoming conscious) during operation.

**Rare (one in 10,000) or very rare (one in 100,000 or less) complications:**
Damage to the eyes, serious allergy to drugs, nerve damage, death.

Death from anaesthesia is very rare, and is usually caused by a combination of four or five complications together. In the UK there are approximately about five deaths for every million anaesthetics.

**What will happen if I choose not to have a continent urinary diversion?**
If you decide not to have a continent urinary diversion, the doctor will talk to you about your options. It is possible that a problem with your urethra or bladder may not allow you to opt for the available alternatives. However if there are alternatives these will be discussed with you in detail to allow you to make your decision.

**What alternatives are available?**

**The ileal conduit**
An alternative to the continent urinary diversion is the ileal conduit. An ileal conduit is formed by detaching the ureters from your bladder and joining them onto a short length of the small bowel (ileum).
One end of this length 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. This system allows urine to drain directly from your kidneys, down the conduit and out into an external collecting system called a stoma appliance or bag which you wear on your abdomen over the stoma. The stoma is pink/red in colour. Urine will drain out of this stoma continually.

Diagram 3: Position of stoma on abdomen

The stoma bag can be a one or two piece system. In a two piece collecting system the base plate (flange) and bag come as separate components. The base plate fits around the stoma and sticks onto your abdomen. It has adhesive on one side especially for this. The bag is then clipped on to the base plate. Some patients prefer a one piece system where the bag and base plate come already attached to each other. Urine collects in the stoma bag on your abdomen and you can empty it out via a tap at the bottom of the bag.
Complications of having a stoma include:

- **Sore skin around stoma**: Patients may be sensitive to the adhesive on the base plate. Leakage and incorrectly fitting baseplate may also be the cause.

- **Stomal hernias and/or incisional hernias**: The muscle wall in these areas is weak because of 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 stoma**: The stoma may prolapse outwards making it difficult to apply the stoma bag.

- **Urinary tract infection**: High temperature, offensive smelling and cloudy urine may indicate a urine infection.

- **Stenosis of 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 and lead to kidney damage.

**The Mainz Pouch**

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

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 if you need to pass urine or if you need to have your bowels open, your stool is likely to be very soft because it will be mixed with urine. This means that you may also leak stool until you regain control.

- **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 conveniences.
- **Acidosis:** The bowel may absorb some of the urine making your blood acid. This may not give you 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 infections and incontinence.

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 into hospital for a continent urinary diversion**

**Length of stay**

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 7 - 10 days. You will then be discharged home and readmitted six weeks from your initial surgery. This second admission is usually for one to two days during which you will learn how to catheterise and care for your new continent diversion.

You should not expect to go back to work, school, or college for at least two to three months after the operation (please discuss this with your surgeon as it varies depending on the extent of your surgery).

You will slowly begin to feel stronger and more able to return to your normal lifestyle. Everything you do should depend on how well you feel you can cope.
Things you will need to think about before coming into hospital may include:

- Who will look after your partner, children or pets while you are in hospital?
- Who will help with housework, cooking, shopping once you get home?
- How will you get home after your discharge?
- Does your GP know and understand what you are having done and what support you will need afterwards (your Consultant or Nurse Specialist can be contacted for any information)?

Sorting out these things beforehand will mean you will have less to worry about once you become an in-patient and can concentrate on recovering as quickly as possible.

**How should I prepare for a continent urinary diversion?** You will have to have some tests done before your surgeon can assess your properly and to help him or her to decide on the correct treatment. These tests may be repeated after the operation to make sure your progress is monitored and help anticipate any complications that may arise.

How and why these tests are done will be explained to you beforehand to ensure you know what is expected.

Besides speaking to your surgeon and your nurse specialist you may wish to see the ward and this will be arranged for you.
Prior to admission you will need to attend a Pre-assessment clinic where the following investigations may be undertaken:

- Urine test,
- Blood tests,
- ECG (Electrocardiogram). This is a simple painless procedure which provides a paper printout of your heart rate and rhythm.
- X-rays,
- MRSA screening.

Please do not bring valuable items into the hospital, as we cannot accept responsibility for them.

**On admission**

You will come to the surgical reception and go to theatre from there.

**Pre-operative preparation**

The anaesthetist will also see you on the day of surgery. He or she will also discuss what pain relief you will be given after the operation and how it should work.

You will not be allowed any food for 6 hours before the operation and you can drink clear fluids (e.g. water) for up to 2 hours before surgery.

**How long is the operation?**

This depends on how much of the bladder is going to be reconstructed. A straightforward operation may take about two to three hours, while a more complicated one may last five hours or more.
Will I come back to the ward after the operation?
The majority of patients do come back to the ward straight away. However sometimes a patient is taken to the High Dependency Unit (HDU).
This depends on your general health, the length of the operation and the doctor’s decision. You will probably go to the ward within a day or two.

What should I expect after surgery?
Once back on the ward, your nurse will monitor your temperature, pulse, blood pressure, respiratory rate, and urine output very closely. As your condition becomes more stable these observations will become less frequent.
A number of different tubes may be attached to you. One or two of these tubes will be used to give you fluids and medication. Your new bladder will be drained by tubes (catheters) to ensure that it is empty at all times and so enable it to heal.

Will I experience pain?
Yes, as you are having major surgery you must expect to experience some pain. However, please be re-assured that the ward staff are aware of this. It is our aim to make you feel comfortable after the operation, as you will then be able to move, turn, cough and sleep better, and so recover quicker.
Please do not be embarrassed about telling us if you are in pain. We do not want you to “suffer in silence”. The staff will be able to give you regular painkillers. By assessing how effective these are and altering the type of drugs and the dosage we will be able to control the pain, keeping it at an acceptable level and helping you to feel comfortable.
**When do I get out of bed?**

You will usually be encouraged to sit out of bed on the first day after the operation.

**What tubes will be removed and when?**

This varies with each Consultant and depends on your progress and the type of operation you have had.

The following timescales are a guideline:

- The wound drainage tubes will be removed from around your operation site when they stop draining (usually two to three days post-operatively). The intravenous drip will be removed when your bowel starts to work again and you pass wind.

- There may be a tube draining your stomach via your nose which will be removed when you can drink without feeling nauseated.

- The two small stents (if they are used) which keep your ureters open will be removed depending on the instructions from your Consultant.

- Clips or stitches are usually removed form your wound site after about ten days although some stitches dissolve and do not need to be removed.

- The catheter tubes draining the urine from your pouch (the Mitrofanoff catheter and supra pubic catheter) remain *in situ* for six weeks until you are readmitted to learn how to catheterise your pouch.

- There may be a urethral catheter (*if in situ*) which is usually removed within three to seven days.
Frequently asked questions

How do I manage the catheter tubes from the bladder?

All your tubes will be taped securely to keep you comfortable and ensure they remain in place.

The tubes are needed because the pouch must be kept empty of urine to allow it to heal properly. If bowel has been used to create the pouch, it will produce mucus. This is what the bowel normally does. To prevent build up and blockage of the catheters by mucus, regular washouts of the pouch will be carried out. The nurse will do this at first, but when you feel well enough you will be shown how to do these for yourself.

When can I start eating and drinking?

On the doctor’s instructions you will be able to take small sips of water. Once you can drink normally, you will be commenced on a light diet, e.g. soup, toast etc. This can be gradually built up to a normal diet, although you may find that it takes sometime for you to regain your appetite fully. You might prefer to eat smaller snacks every few hours instead of three main meals a day.

What happens when I am discharged home?

Please allow yourself plenty of time for rest once you are discharged. You should not do anything too strenuous (e.g. gardening) or lift heavy objects (e.g. shopping bags or children) for the first six to eight weeks after the operation.

It is best to take gentle exercise at first, slowly increasing as you feel able. You should aim to reach your pre-operation level of activity, three months following your surgery.
Will I have to wash out my bladder?

Yes, especially if it is made of bowel. It should be done twice a day through both your stoma catheter and supra-pubic catheter to prevent blockage with mucus or debris, and at any other time you feel the tube is blocked and urine is not draining out.

It is important that you make sure the catheters are always kept unblocked and the pouch is kept drained by attaching both of the catheters to a small drainage bag, which is strapped to your thigh. This is called a leg bag. It is important that you know how to change these bags and how to empty them. You will be shown how to do this.

If urine stops draining and you cannot get it to flow again, please report by phone to the ward, nurse specialist or urology doctor on call at once.

Can I take a bath or shower with the catheter still in?

Yes. Just make sure you dry around the site carefully. You may use a cool hairdryer for this.

Where do I get more catheter bags from?

Your nurse will give you equipment on discharge and the ordering information for leg-bags and night drainage bags. Further supplies of equipment can be obtained by prescription either directly from your chemist or from a delivery company.

How much should I drink?

You must drink at least eight to ten cups of fluid a day. Mucus can build up and besides blocking your catheters, it can act as a medium on which bacteria can grow, causing infections. A good fluid intake will keep the mucus diluted, making it easier to flow out of a catheter.
Drinks which are high in vitamin C also help keep the urine free of mucus. Cranberry juice which is available from supermarkets or health food shops, also helps make the mucus less thick and helps reduce the risk of infection. It is recommended you drink one or two glasses of this daily. If you find the taste too sharp, you may dilute it with other fruit juices or water.

Please remember to drink more in hot weather.

**Do I need to be on any special diet?**
There is no need for a special diet, though it’s a good idea to try to eat a healthy well balanced diet with plenty of fruit, vegetables and fluids. If your bowel has been used in the construction of the bladder, you may find it will take some time for your bowels to return to their usual pattern. If you feel that your bowels are still a problem after a few weeks ask your GP for advice, or seek advice at your next outpatient’s appointment.

**What about sex?**
It is a good idea not to resume sex for the first six weeks after the operation. You should then resume your sex life when you feel ready and comfortable. It is recommended that you discuss this with your doctor and/or nurse specialist before the operation and at discharge.

**What about sport?**
You should check with your Consultant before taking up or resuming any sport, especially contact sports. The general rule is that you do not do anything too strenuous too soon and that you should not suffer any discomfort.
When will I start to catheterise my continent stoma?
Six weeks after your surgery you will be admitted to the ward and taught how to catheterise your stoma. Catheterising is a simple, clean procedure. It is not usually painful although it may take a little while for you to get used to the sensation of the catheter entering the tunnel and pushing through the valve into the bladder. During this admission you will also learn to identify what it feels like to have a full bladder as it fills with urine and expands. Your supra-pubic catheter is also removed at this time. You usually remain in hospital for one or two days, until you are confident in all aspects of the care and catheterisation of the pouch.

How often must I catheterise?
When first catheterising, you may find that you have to empty the pouch every two to three hours. As your pouch expands it will hold more and eventually you may only need to empty it every four to six hours. Never leave it longer than six hours or hold more than 500mls, as if the pouch becomes too full you may not be able to insert the catheter. Continual overfilling of the pouch will cause it to become overstretched and the pouch walls will begin to become thinner.

What happens at night?
Initially at night you will leave a catheter taped into your stoma on free drainage into a night drainage bag. Once the pouch capacity has increased most people find that by cutting down on their drinking two hours before bedtime and completely emptying the pouch before they sleep, they achieve a normal sleeping pattern.

If you produce a lot of urine at night or have had a lot of fluids before bedtime, you may have to get up to empty the pouch at night.
Allowing the pouch to get too full may cause it to “burst”. In time the full sensation of the pouch will probably wake you up. If you have no sensation of fullness you may have to set an alarm to wake you.

**How do I look after my stoma?**
There is no need to cover the stoma site with a dressing or plaster unless the skin in this area is sore or sensitive and a dressing would make you feel more comfortable. The same applies when you have a bath, shower or swim. If the site becomes red, painful, bleeds or leaks please contact your GP, your Nurse Specialist or the ward for advice.

**How long does it take to empty the pouch?**
Emptying the pouch should take three to four minutes depending on how full it is and what size catheter you are using.

**What happens if I cannot catheterise the stoma?**
If the pouch is left to become too full of urine, you may find that the urine might leak out slightly and/or you may not be able to push the catheter in at all. This may happen especially in people who have no sensation in their bladders.

**Never** go longer than four to six hours between catheterisations and catheterise before long trips. If you cannot catheterise your bladder do not make your stoma sore by repeated attempts. Stop for a few minutes, do not drink any fluids, then try again. There is a danger of the pouch “bursting” if it becomes too full or is not emptied regularly enough. Trying to insert a smaller size catheter than you normally use may solve the problem.
If all your attempts are unsuccessful please telephone your nurse specialist or the ward immediately for help and advice. You may need to come back into hospital or go to your local Accident and Emergency to have a catheter inserted into the pouch for you.

**How do I look after my catheters and where do I get them from?** Care of the catheters depends on the make of catheter and the manufacturer’s guidelines. Catheters should be stored in their boxes in a cool dry place. You should not use expired stock. Always remember to carry a catheter with you and have spare ones available at work, school, etc. Catheters are available on prescription from the manufacturer or through a supply company. Your Nurse Specialist will be able to give you all the details of what is available and how to order them.

**What appointments do I have?**

You will be seen in clinic three months following your discharge. After this your appointments are usually half-yearly and eventually yearly. You will also require further tests for your progress to be monitored and these will be explained and booked during your outpatients visits.

These follow up tests are very important to ensure any complications are detected early and treated without delay.

**Can I travel abroad?**

Yes you can. Please remember to carry plenty of spare catheters with you and some equipment to use for bladder washouts. (Always carry equipment in your hand luggage as well as in your suitcases in case these go missing). Use mineral water to washout the bladder. Please carry a letter from your doctor with you explaining what you have had done and why you need to carry your equipment with you. Please feel free to discuss your holiday plans with your nurse specialist or doctor. They will be able to give you some useful tips and advice.
It is advisable to wear a medical information bracelet or necklet as a safety precaution, whether abroad or not. Should you ever be in the unfortunate position of being taken to hospital and not being 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 necklets may stop any damage or unnecessary treatment being carried out.

**Further information**

Your nurse specialist will be able to help you obtain more information. You may also find the following addresses useful:

**Medic Alert Foundation**
Address:
17 Bridge Wharf 156 Caledonian Road
London, N1 9UU 020 7833 3034

**SOS Talisman Ltd.**
Address:
41 Grays Corner Ley Street Ilford Essex, IG2 7RQ
020 8554 5579

**Mitrofanoff Support**
http://mitrofanoffsupport.org.uk
info@mitrofanoffsupport.org.uk
01202886444
By monitoring the follow up tests ad seeing you in outpatients regularly we can screen you for any long-term complications that might occur. This follow up will be for life, it is important you attend to ensure early detection and management of any problems/complications.

Please remember you may contact your nurse specialist, the doctor, or the ward at any time if you are worried or need advice.

Remember:
Contact your GP, the Ward or your Nurse Specialist if:

- You think you have a urine infection (Urine becomes thick, smelly, if you suffer fevers, or shivering, feel unwell or you urine contains blood).

- Your operation scar becomes hard or reddened or inflamed or begins to ooze.

- You have persistent abdominal or back pain

- You suffer persistent nausea or vomiting
Outpatients appointments

Please keep your outpatient appointments. If the one given to you is inconvenient you should contact the hospital or your nurse. A new appointment will be made for you and any tests you were due may have to be re-arranged.

Where can I get more information?

NHS Advice
Telephone: 111

NHS Choices
Website: www.nhs.uk/Pages/HomePage.aspx

Patient UK
Website: www.patient.co.uk

Please also see our UCLH Surgery video information by going to:
www.uclh.nhs.uk/PandV/Pages/HavingsurgeryatUCLH-vids.aspx

UCLH cannot accept responsibility for information provided by other organisations.
Contact details

University College Hospital

Direct line: 020 3447 7966
Switchboard: 020 3456 7890 ext. 77966/bleep 2080
Website: www.uclh.nhs.uk

References


Acknowledgements

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Anaesthetic information provided by the Royal College of Anaesthetists www.rcoa.ac.uk
Notes and questions