If you require a large print, audio or translated version of this leaflet, please contact us on 0845 155 5000 or 020 3456 7890 ext 77966. We will try our best to meet your needs.

Contents
Introduction 5
The urinary system 5
What is a neobladder? 6
Is the new bladder continent? 7
What are the risks of having a neobladder? 8
What are the risks of erectile dysfunction following neobladder? 8
What are the risks of a general anaesthetic? 9
What alternatives are available? 10
Coming into hospital 15
Asking for your consent 16
How should I prepare for a neobladder? 16
On admission 16
What can I expect after the operation? 17
Frequently asked questions 19
Further information 25
Where can I get more information? 26
Contact details 26
References 27
Acknowledgements 27
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 1).

![Diagram 1](image_url)
**What is a neobladder?**

A diseased or malfunctioning bladder is usually surgically removed by a procedure known as a cystectomy. The bladder is completely removed only leaving behind some of the urethra, the tube you pass urine through. The bladder is completely replaced by a new or “neo” bladder made entirely out of bowel. A section of bowel, usually the ileum which is part of the small bowel, is detached from the rest. This section is opened out and refashioned into the new bladder. The remainder of the bowel is joined back together again so the bowel will continue as before. There is plenty of bowel in the body so a small part can be safely used for this. The ureters, the tubes which drain urine from the kidneys are detached from the old bladder and plumbed into the neobladder. This is then attached to the remainder of the urethra.

**Please note that if your cancer has spread to the urethra than this is not a suitable operation for you as the urethra will have to be taken out to ensure all the cancer is removed. This means there will be no urethra left to attach the neobladder to.**

Diagram 2: The neobladder
Is the new bladder continent?

It is important that you have good bladder control and do not suffer from incontinence before having this surgery. Since not only all of the bladder but part of the urethra are removed during surgery, this may effect your continence afterwards. The surgeon will leave behind the section of the urethra where the sphincter muscles are located. These are the muscles which work to help keep you dry. During surgery the surgeon will also attempt not to remove as many of the nerves in this area as possible. This will depend on why you are having the surgery for example if you are having it for bladder cancer then the surgeon may have to remove more tissue in this area than for someone who does not making it more likely that you will experience incontinence after the surgery.

The bladder can often be emptied in the normal way. However you must be aware that you may be incontinent at first. Day time continence should return over a period of four to six months though you may be incontinent at night for up to a year following surgery. Unfortunately a small percentage of patients may continue to be incontinent by day and/or by night even after this time has elapsed.

However some patients find they are unable to empty out their bladders adequately or at all. This can happen immediately after surgery or later on. The only way to empty the bladder in these cases is by clean intermittent self-catheterisation (CISC). This means inserting a narrow hollow plastic tube called a catheter up the urethra and into the neobladder. Once the urine has drained out the catheter is removed. This procedure is taught to all patients who are having a neobladder before surgery in case they need to use it afterwards. Your surgeon will discuss this with you and refer you to a nurse specialist who will make an appointment to teach you how to do it.
What are the risks of having a neobladder?
All treatments and procedures have risks and we will talk to you about the risks of having a neobladder. The most common complications of having a neobladder which may occur are:

• Urine infections (20 per cent)
• Mucus build up (which may cause stones to form)
• Your blood may become too acid (known as hyper chlorimic acidosis. This causes no symptoms but must be treated with tablets) (16 per cent)
• Incontinence by day and/or night
• Inability to empty the new bladder completely. This means starting self catheterisation.
• Erectile dysfunction (in male patients with bladder cancer)
• Sexual dysfunction (in female patients with bladder cancer)

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

What are the risks of erectile and sexual dysfunction following neobladder?
The more tissue and nerves the surgeon removes during surgery the greater the risk of you having problems getting and maintaining an erection if you are a man. Please be assured your sexual function will be discussed with you when you are ready and your options discussed e.g. medications and appliances which are designed to help men get an erection. In women the surgery to remove the bladder also removes other tissue which means the vagina is shortened and can be narrowed so leading to difficulty or discomfort during sexual intercourse. Using vaginal dilators to stretch the vagina can help make sex easier and more enjoyable. Again your options will be discussed with you when you are ready.
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 alternatives are available?

Your surgeon will discuss the different options which are available and which are suitable for your particular condition. These options include:

**The ileal conduit**

In some cases an ileal conduit may be suitable as an alternative to the enterocystoplasty. 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.
A continent urinary diversion (also called a continent urinary pouch) is a type of 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.
The tunnel can be made of various parts such as your appendix, ureter or bowel.

Various continence mechanisms can be created during surgery depending on the surgical technique the surgeon has decided would work best for you.

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. You do not need to wear a bag over this opening as this stoma is continent and does not leak in between catheterisations.

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.

Unlike urinary diversions such as the Mitrofanoff or the ileal conduit, you do not need to use a device to either empty the bladder (a catheter) or collect urine (stoma bag). With the rectal bladder you will be able to pass urine and have your bowels open through the same opening i.e. the anus.

Diagram 6: The rectum (back passage) is formed into a rectal bladder
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

Length of stay

Your admission to hospital will be in two stages. The first admission is for the operation itself and you should expect to be in hospital for about ten days. You will then be discharged home with a catheter and readmitted four weeks after your initial surgery for us to assess how well you are emptying your bladder and whether you will need to self catheterise at this stage. This second admission is usually for one to two days.

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?
- Will you need to organise somewhere to convalesce?
- 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.
Asking for your consent
If you decide to go ahead, you will be asked to sign a consent form to confirm that you agree to have the procedure and understand what it involves. It is your right to have a copy of this form.

How should I prepare for a neobladder?
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. If specific bowel preparation is required you will be admitted to the ward one day prior to surgery.
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 or fluids six to eight hours before the operation.

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 Critical Care Unit (CCU). This depends on your general health, the length of the operation and the doctor’s decision. You will probably go back to the ward within a day or two.

What can I expect after the operation?
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 be 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 also be drained by tubes (catheters) to ensure that it is empty at all times and so able to heal.

Not all of these tubes are used in every patient; the general rule is – the bigger the operation the greater number of tubes.

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.

• The tube draining your stomach via your nose will be removed when you can drink without feeling nauseated. This could be between two to three days post-operatively.

• The two small stents which keep your ureters open will be removed approximately seven to ten days post-operatively.

• 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 tube draining the urine from your rectal bladder is usually removed the day after the stents are removed i.e. eight to eleven days.
Frequently asked questions

How do I manage 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 rectal bladder must be kept empty of urine to allow it to heal properly. As your new bladder is made of bowel it will produce mucus. This is what the bowel normally does. To prevent build up and blockage and by-passing of the catheter by mucus and any faecal matter that forms, regular flushes of the pouch may be carried out. The nurse will do this at first, but when you feel well enough you will be shown how to do so for yourself.

When can I start eating and drinking?
On the doctor’s instructions you will be able to take small sips of water. However, you will not be able to drink properly until your bowel is working again and you begin to pass wind. 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 some time 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 four to six 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.

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.
Will I have to wash out my bladder?
Yes, especially if it is made of bowel. It should be done twice a day through the 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 catheter is always kept unblocked and the bladder is kept drained by attaching 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 this bag and how to empty it. 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 hospital at once.

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 (two litres) a day. Mucus can build up and besides blocking your catheter, 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. Alternatively you may find cranberry tablets or capsules as effective.

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 four to 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. If the surgery has had an effect on your erections or your ability to enjoy sex then you can discuss any problems with your surgeon when you go back to clinic for your outpatient appointment.

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 do I start passing urine again?
At approximately three to four weeks you will return to the ward or clinic for the suprapubic catheter to be clamped and the urethral catheter to be removed if this was not removed before your first discharge. This allows the urine to start filling and expanding the bladder.

How often should I empty my bladder?
You may find that at first you will only hold small amounts of urine and will have to empty your bladder every hour or less. As your bladder stretches to hold more urine you should be able to pass urine every three to four hours. This depends on how much you can hold comfortably, how much you have had to drink and how much sensation of wanting to pass urine you get. Some patients do not need to pass urine for four to six hours. Never leave it longer than six hours as it the bladder becomes too full it may “burst”.
How will I know if I need to start catheterising myself?
If you are unable to empty your bladder completely you may:

• Start having to pass urine more frequently
• Feel you have to strain to empty completely
• Always feel “full” after passing urine
• Suffer from re-occurring urine infections

Your surgeon may arrange for you to have an ultrasound test. You will be asked to attend with a full bladder and after they have taken an ultrasound of this, you will be asked to empty your bladder and another ultrasound will be performed. If there is urine left behind, this is called a residual urine. If this is more than 100 ml it means you will probably need to start catheterising.

How often must I catheterise?
You may only need to do this once or twice a day. This depends on how much of a residual you will have. Usually the less you pass urine the great the residual and therefore the more frequent the catheterisations. Some patients have to catheterise each time they pass urine. This may be due to large residuals or occasionally, the patient may not be able to pass urine urethrally at all.

What happens at night?
Most people find that by cutting down on their drinking two hours before bedtime, and completely emptying the bladder (either naturally or by clean intermittent self catheterisation, CISC) 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 bladder at night. Allowing the bladder to get too full may cause it to “burst”. In time the full sensation of the bladder will probably wake you up naturally though if you have no sensation of fullness you may have to set an alarm to wake 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?
Once you are discharged you will be seen in clinic within six to eight weeks. After this your appointments are usually at three monthly intervals, then six monthly 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.

What are the complications of having surgery?
All surgery has a number of potential complications. These will be explained to you by your surgeon, your nurse specialist and the ward staff.

The most common complications of having a neobladder which may occur are:

- Urine infections
- Mucus build up (which may cause stones to form)
- Incontinence—though usually improves with time
- Inability to empty the bladder completely (or at all) urethrally
- Your blood may become too acid (known as hyperchlorimic acidosis. This causes no symptoms but must be treated with tablets)
Cancer patients may also experience these symptoms:

- Cancer can reoccur in the remaining urethra
- Men may have problems getting and maintaining an erection
- Women may experience discomfort during sex
- Your surgeon will discuss any potential complications with you before you have surgery. Please feel free to ask questions.

**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.

**Can I travel abroad?**

Yes, you can. Please carry a letter from your doctor with you explaining what you have had done. 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
Telephone: 020 7833 3034

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

By monitoring the follow up tests and 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
Where can I get more information?

NHS Advice
Telephone: 111
Website: www.nhsdirect.nhs.uk

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

Macmillian Cancer Support
Telephone: 0800 808 0000
Website: www.macmillan.org.uk/Home.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
Switchboard: 0845 155 5000
020 3456 7890
ext 77966/bleep 2080
Website: www.uclh.nhs.uk
References

Acknowledgements
Anaesthetic information provided by the Royal College of Anaesthetists www.rcoa.ac.uk
With thanks to United Bristol Healthcare NHS Trust for allowing use of one of their diagrams from their booklet on neobladders.