Caring at its best

NHS
University Hospitals of Leicester
NHS Trust

Having a Cystectomy and Bladder Reconstruction (Continent Urinary Diversion)

Department of Urology

Information for patients

Produced: Jun 2024
Review: Jun 2027
Leaflet number: 644 Version: 7

Introduction

You and your consultant have decided that you need a cystectomy (removal of your bladder) and that you are suitable for a continent urinary diversion.

The operation to remove your bladder is carried out whilst you are asleep, under general anaesthetic.

Once your bladder has been removed, your kidneys will continue to make urine and this urine needs to be diverted.

This leaflet gives you information about the operation

Why do I need this operation?

The aim of the cystectomy and continent urinary diversion is to remove the cancer and cancer cells from the bladder area. During the operation a new bladder will be made out of bowel tissue.

The advantage of this operation is that in the long term you will not need to wear a bag on your abdomen to collect your urine. Instead there will be a small opening on your abdomen through which a catheter is passed each time the new bladder is full and needs emptying.

Occasionally, at the time of surgery it may not be possible to do this operation. If this happens, your surgeon will perform a urostomy. A separate leaflet about this operation is available.

Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

How is the operation carried out?

The operation to remove the bladder includes removal of the bladder, and :

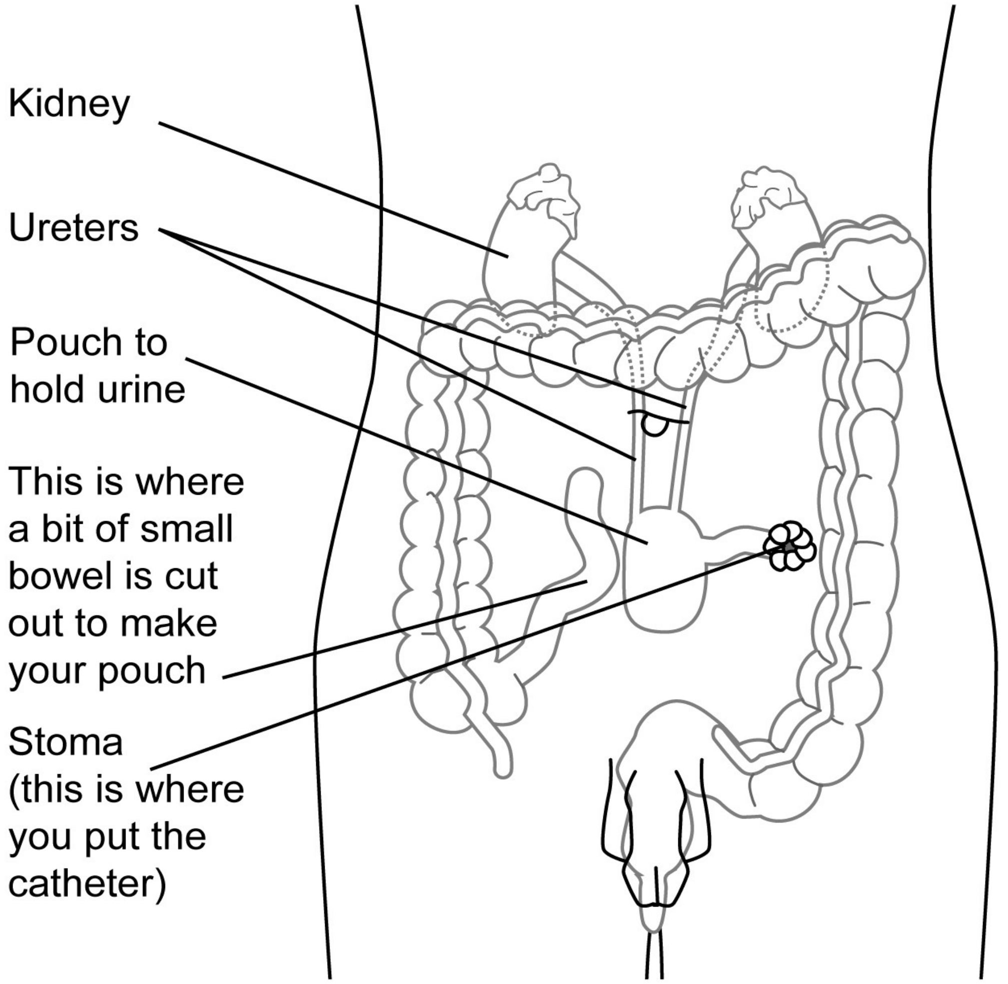
in men: removal of the prostate gland and urethra (water pipe), although in some men the urethra may be left.

In women: the urethra, the uterus (womb) and the front wall of the vagina are removed. If you are a woman who has not gone through the menopause, your ovaries may be left to provide the usual hormone balance.

What is a continent urinary diversion?

A continent urinary diversion can be formed in several ways and is known by different names such as the “Indiana Pouch” or the “Mitrofanoff Procedure”. These terms refer to different styles of surgical procedure.

The operation involves using a section of your bowel, about 60 - 70 centimetres (around two feet) long, to make the reservoir that replaces your bladder. The tubes from the kidneys (ureters) are implanted into this reservoir. A channel for catheterisation from the abdomen to the reservoir is then constructed. Internally, the surgeon creates a valve that prevents leakage.



How will this affect me?

As you will see from the description of the operation, there are permanent changes made to your body. These changes affect your urinary function, your sexual and reproductive functions and, to some extent, your bowel function.

Passing urine

After the operation, your kidneys will produce urine in the normal way and the ureters will drain urine into your new bladder.

Your new bladder will store urine until it is emptied using a catheter. You will learn to recognise how it feels when your new bladder is full, and each time this happens you will need to pass a catheter into the opening on your abdomen to let the urine out. To start with, you will be advised to catheterise on a timed basis.

The capacity of the new bladder will increase over time until, after a few months, it should hold around a half a litre of urine (about a pint), similar to a normal bladder capacity. This means that immediately after this operation, and until your new bladder expands, you will have reduced capacity. There may also be some leakage of urine from the opening of the new bladder until it has expanded to its full capacity, which can take up to six months.

Sexual and reproductive function

This means that other tissues that touch or lie close to the bladder are removed at the time of the operation. These other organs and tissues affect sexual function.

In men: The prostate, which is directly below the bladder, is removed. The nerves that are responsible for obtaining an erection touch the prostate and are removed at the time of the operation. It may be possible in some cases to restore potency (the ability to get an erection) by using tablets and / or injections. These options can be discussed at the follow up clinics.

In women: There is tissue between the bladder and vagina which has shared blood supply. This means that when this tissue is removed, the front wall of the vagina is removed along with the uterus (womb). A repair is made using the back wall of the vagina, but this results in a very short vagina. Full sexual intercourse may not be possible after this operation. A period of several weeks after surgery should be left before attempting intercourse and it is advisable to use a lubricant, such as KY jelly.

Bowel function

Initially, following this operation, some people notice a change in bowel habit. You may find that you go to the toilet to open your bowels more often or that you are “more loose” than before. However, this is not the case for everyone.

What are the possible early complications of the operation?

As with all operations, there are associated risks. These include:

- **Chest infections**: which can result from difficulty in breathing deeply because of the wound, and reduced activity.
- **Wound infection**: which may require treatment with antibiotics. In rare cases, further surgery is necessary.

What are the possible early complications of the operation continued

- **Deep vein thrombosis (DVT)**: this kind of surgery has a small risk of clots in the leg veins which occasionally travel to the lungs and cause breathing difficulty (pulmonary embolus). Heparin (blood -thinning) injections will be given to you, starting before the operation, to minimise the risk.
- **Urine infection**: which may require treatment with antibiotics.
- **Men**: Impotence (lack of an erection)
  Dry orgasm with no semen produced
- **Women**: Narrowing / Shortening of the vagina may result in pain or difficulty with sexual intercourse.

What are the possible later complications of the operation?

Your urologist will have discussed with your that you may need further surgery at a later stage. About 10 to 20% (up to 1 in 5) of patients need further surgery due to problems that may develop following the operation. It may be necessary for your surgeon to:

- Remove any stones that form in your pouch over a period of time.
- Widen the opening of the catheterisable stoma on the abdomen if it becomes too narrow.
- Alter the valve that holds urine within the reservoir.
- Alter the join where the ureters go into the new bladder, as a narrowing can slowly develop. This narrowing could otherwise affect your kidney function.

You will have time to discuss all these risks with the doctors and nursing staff before you consent to your operation.

How am I prepared for theatre?

You will be prepared for your operation in the usual way, except that the bowel needs to be cleared before surgery.

In order to do this you will be given a laxative drink the day before your operation. This will make you empty your bowels. You will not be allowed to have anything to eat although you will be encouraged to drink plenty of clear fluid.

What happens after my operation?

Following your operation, you will go to the High Dependency Unit where you will be cared for until you are ready to go back to the ward.

You will have:

A drip (an intravenous infusion)
This may be in your neck, hand or arm. It replaces any fluids that you may have lost during surgery or by fasting. You may also have a blood transfusion.

What happens after my operation (continued)

Pain relief
You will have some form of pain relief. This will be explained to you before your operation. If you need more information, please ask to speak to a member of the Pain Team.

Wound
You will have a wound on your abdomen. There will be at least one drain into the wound, to drain fluid from the operation site.

Stents
You will have two temporary fine plastic tubes (stents) which help the urine to drain from the kidneys and these will remain in until healing takes place. The stents will be removed before you go home.

Catheters
You will have two catheters, which are tubes into your new bladder to drain the urine away. One enters the bladder down the catheterisable stoma and the other through the abdomen. These catheters give the new bladder a chance to heal without overfilling.

You will go home with the catheters in place.

When will the catheter be removed?

While you are at home with the catheters in place you will need to carry out bladder wash-outs. Before you go home you will be taught how to do these. The catheters are usually removed three to four weeks after surgery. You may require a special X-ray of your bladder to ensure that it is completely healed beforehand. You will be admitted to hospital to have the catheters removed and will usually stay in hospital overnight.

What will happen after the catheters are removed?

Following removal of your catheters, you will have some sensation of your bladder filling. Most people describe this as a feeling of ’fullness’.

It is not unusual for urine to leak from the catheterisation stoma following removal of the catheters. This is due to the surgery and also because the new bladder is not as big as your old one. Over time your new bladder will grow, allowing it to hold more urine.

What happens when I go home?

Cystectomy and bladder reconstruction is major surgery and it will take you several months to fully recover.

When at home with the catheters in, and following their removal, you will have the support of your district nurse, who will check your wounds and help you to obtain any equipment that may be necessary. The district nurse will also be able to answer some of your questions.

How will I care for my new bladder?

Learning to pass a catheter into the stoma is not as difficult as it may sound, and it does not take long to become an expert.

It is a safe procedure when done under clean conditions and can be carried out with a minimum of fuss. The catheters can be obtained on prescription and can either be collected from the local chemist or delivered to your home.

There are specially trained staff to help you make these adjustments to your new lifestyle. They are there to offer support and as someone to talk to. They are also there as teachers, to help you regain your independence. A number of patients who have undergone this procedure in the past are willing to be contacted. Please ask if you would like to talk to them.

How do I catheterise my new bladder?

Whilst in hospital you will be taught how to catheterise your new bladder. You will learn to recognise how it feels when your new bladder is full, and at first you may occasionally notice a slight leak from the catheterisable stoma as the new bladder reaches full capacity. We suggest that you catheterise approximately every three hours at first. As the capacity of the new bladder increases, the number of times you need to catheterise will decrease.

You will be advised to catheterise at timed intervals. Remember that at first you will need to get up at least once in the night to empty your new bladder. An alarm clock should be used at first to wake you.

You should drink about 2 litres (3-4 pints) per day, reducing your fluid intake in the evening.

You will be given a supply of catheters when you go home and details of how to get a prescription from your GP. The catheters are essential pieces of equipment for your new lifestyle and because of this you may be exempt from prescription charges. Ask your GP about an ‘Exemption from Charges’ form.

Occasionally you may have difficult with inserting a catheter into your stoma. If this is the case you may need to come into hospital for appropriate management.

How do I wash out my new bladder?

Mucus will collect in the new bladder. This is normal, it is being produced by the piece of bowel which was used to make your new bladder. Sometimes the mucus collects together and forms stones within your new bladder. To help to avoid these problems, we will teach you how to wash the new bladder out using cooled, boiled salt water and a syringe that attaches to the end of the catheter. The ward staff will give you a supply of syringes when you go home. Further supplies of these syringes can be obtained from your district nurse, continence nurse or home delivery service.

Urine infection

The mucus from the new bladder may make your urine look cloudy or as if you have an infection. Your urine may have some organisms in it because your new bladder was made out of bowel tissue. Cloudy urine and the presence of these organisms does not necessarily mean you have a urine infection. You will not need antibiotics unless you are feeling unwell or have a temperature.

Getting back to normal

Exercise
You should go for short gentle walks in order to reduce the risk of clots in your legs, but avoid too much exercise for a few weeks. Expect to feel tired for a few weeks and take an afternoon rest if necessary.

Driving
Do not drive for 4-6 weeks.

Return to work
Your consultant will advise you about going back to work.

Further information

This booklet has been designed to answer many of your questions, but of course there may be others.

If you have any questions you would like to ask, you can contact your specialist nurse. See details below.

Further treatment

You will be seen in outpatients about two months after your operation. Some patients receive further treatment following surgery and this will be discussed with you at your outpatient visit.

You may wish to bring someone with you to this appointment.

Leicester Bladder Cancer Support Group

This group meets every month in Leicester. Please ask your nurse specialist (key worker) for more information.

For further information please contact:

Urology Nurse Specialists / Continence Nurse

Monday to Friday 9:00 am to 5:00 pm

Telephone: 0116 258 4635

Urology Oncology Nurse Specialists (Key Workers)

Monday to Friday 9:00 am to 5:00 pm

Telephone: 0116 258 4637

Outside these hours:

Urology Unit (24 hours):

Telephone: 0116 258 4247

Further sources of help

Macmillan Information and Support Centre
Osborne Building, Leicester Royal Infirmary, Leicester LE1 5WW

Telephone:	0116 258 6189
Email:	cancerinfo@uhl-tr.nhs.uk
Website:	www.leicestershospitals.nhs.uk/cancerinfo

Macmillan Cancer Support
For information and support from cancer support specialists.

Freephone:	0808 808 00 00
Website:	www.macmillan.org.uk

Cancer Research UK
Ask specialist nurses about anything to do with cancer.

Freephone: 0808 800 4040

Website: www.cancerresearchuk.org

Action Bladder Cancer UK

Website: www.actionbladdercanceruk.org

Fight Bladder Cancer

Website: www.fightbladdercancer.co.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
علی هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk

LEICESTER'S RESEARCH

Leicester's Hospitals is a research active trust so you may find research happening on your ward or in your clinic. To find out about the benefits of research and become involved yourself, speak to your clinician or nurse, call 0116 258 8351 or visit www.leicestersresearch.nhs.uk/patient-and-public-involvement