

### SIMPLE CYSTECTOMY with FORMATION of an ILEAL CONDUIT Information about your procedure from The British Association of Urological Surgeons (BAUS)

This leaflet contains evidence-based information about your proposed urological procedure. We have consulted specialist surgeons during its preparation, so that it represents best practice in UK urology. You should use it in addition to any advice already given to you.

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http://rb.gy/2oid5

# **KEY POINTS**

- Simple cystectomy is performed for severe bladder problems but is a different procedure from radical cystectomy for bladder cancer
- Most patients will have a urostomy an opening on the abdomen (tummy) that constantly drains into a bag
- Some patients will have a neobladder (new bladder) made either connected to your urethra (waterpipe) or a created channel, so that they can store urine inside; this avoids the need for a urine bag
- Although simple cystectomy successfully relieves the constant desire you may have to pass urine, it may not relieve chronic bladder pain
- It is a major procedure with a significant risk of complications and after-effects

# What does this procedure involve?

Removal of your bladder through an incision in the lower part of your abdomen (tummy) or with keyhole surgery (e.g. laparoscopic or robotic surgery). Most patients need diversion of their urine into a stoma on the abdominal wall (ileal conduit, also known as an urostomy). The urine is collected in a bag. Sometimes, we make a new bladder (neobladder) out of your bowel, so that urine can be stored inside the body. You may need to drain your neobladder several times a day, using a disposable catheter, either through your urethra or a created channel, but you do not need a urine bag all the time.

Sometimes we remove the prostate gland in men and, in women, the uterus (womb), ovaries and vagina may be left intact.

This operation is used in patients with severe bladder symptoms, unrelated to bladder cancer, who cannot manage their symptoms in any other way. It is also used in a small group of patients who experience chronic bladder pain and a constant desire to pass urine. Removal of your bladder in this situation does not always resolve your pain.

# What are the alternatives?

Incontinence and bladder pain can often be treated without having an operation. Cystectomy will only be discussed with you if all other treatments have failed or are not appropriate for you. It is a last resort and cannot be reversed. The main alternatives for patients with this type of severe bladder problems include:

- Incontinence pads
- Urethral or suprapubic catheterisation
- Pain relief medication & pain management programmes
- Specific treatments targeting bladder pain
- Enterocystoplasty using a piece of bowel to enlarge your bladder may be used in some patients

# What happens on the day of the procedure?

You will be seen by the surgeon and the anaesthetist who will go through the plans for your operation with you.

We may provide you with a pair of TED stockings to wear, and we may give you an injection to thin your blood. These help to prevent blood clots from developing and passing into your lungs. Your medical team will decide whether you need to continue these after you go home.

Before your procedure, we will arrange for you to see a **Stoma Nurse Specialist**. Their job is to help you decide on the ideal site for your stoma. They will mark this on your skin with a pen. The surgeon needs to see this mark during the procedure, so it is important not to wash it off.

## Details of the procedure

- we use a general anaesthetic for the procedure
- your anaesthetist may also use an epidural or spinal anaesthetic to minimise any post-operative pain
- you will usually be given an injection of antibiotics before the procedure, after you have been checked for any allergies
- we normally perform the procedure through an incision in your lower abdomen (tummy) or using a laparoscopic ("keyhole") approach with or without robotic assistance
- we will remove your bladder (in some men we also remove your prostate gland)
- we usually stitch the ureters (the tubes which drain urine from the kidneys to the bladder) to a separated piece of small bowel and bring this out on the surface of your abdomen as a **urostomy** (ileal conduit)



- occasionally, you may have a neobladder (new bladder) made out of your bowel so that urine is stored inside the new bladder
- if you have a urostomy, there will be stents (small plastic tubes) coming out of your stoma to help everything to heal and prevent urine leaks (pictured)
- we re-join the ends of the small bowel from which the urostomy has been made
- we close the wound with stitches or clips
- we attach a drainage bag to your urostomy

You should normally expect to be in hospital for seven to 14 days.

We normally remove your drains when they have stopped draining. The stents in your stoma are usually removed 10 to 14 days after the procedure.



### Are there any after-effects?

The possible after-effects and your risk of getting them are shown below. Some are self-limiting or reversible, but others are not. We have not listed very rare after-effects (occurring in less than 1 in 250 patients) individually. The impact of these after-effects can vary a lot from patient to patient; you should ask your surgeon's advice about the risks and their impact on you as an individual:

After-effect	Risk
In men, inability to ejaculate (or father children) because your sperm-carrying mechanism has been removed	All male patients
In men, inability to get an erection (impotence)	Almost all male patients (unless the nerves can be preserved)
In patients with neobladders, the need for self-catheterisation to wash out & empty the new bladder (this becomes less of a problem with time)	Almost all patients
Recurrent urinary infections	Between 1 in 2 & 1 in 10 patients
Mucus in your urine	Between 1 in 2 & 1 in 10 patients
Failure to improve your bladder pain	Between 1 in 2 & 1 in 10 patients
Need for blood transfusion	Between 1 in 2 & 1 in 10 patients
In neobladders Incontinence of urine is common in the early weeks and improves in most but can persist, especially at night	Between 1 in 3 & 1 in 7 patients (15 to 30%)

Paralytic ileus (failure of your bowel to work) for several days which causes nausea, bloating & vomiting, and needs an intravenous drip and a stomach drainage tube through your nose until it recovers	Between 1 in 2 & 1 in 10 patients
An imbalance in the salt or acid levels in your blood	Between 1 in 10 & 1 in 50 patients
Scarring, narrowing or hernia formation around your urostomy requiring revision	Between 1 in 10 & 1 in 50 patients
Hernia of the incision (or keyhole ports) requiring further surgical repair	Between 1 in 10 & 1 in 50 patients
Stricturing (scarring) of the ureters requiring further surgery	Between 1 in 10 & 1 in 50 patients
Anaesthetic or cardiovascular problems possibly requiring intensive care (including chest infection, pulmonary embolus, stroke, deep vein thrombosis, heart attack and death)	Between 1 in 10 & 1 in 50 patients (your anaesthetist can estimate your individual risk)
Bladder stones may form in neobladders	Between 1 in 10 & 1 in 50 patients
Need to abandon a keyhole procedure and convert to open surgery because of operative difficulties	Between 1 in 10 & 1 in 50 patients
Long-term recurrent urinary infections	Between 1 in 10 & 1 in 50 patients
In neobladders, biochemical imbalance may occur due to reabsorption of acid from your	Between 1 in 10 & 1 in 50 patients

neobladder requiring regular treatment with bicarbonate tablets	
Need for return to theatres for re-operation due to bleeding, bowel leakage, urine leakage or bowel obstruction	Between 1 in 50 & 1 in 250 patients
Hernia of the incision (or keyhole ports) requiring further surgical repair	Between 1 in 50 & 1 in 250 patients
Scarring, narrowing or hernia formation around your urostomy requiring revision	Between 1 in 50 & 1 in 250 patients
Diarrhoea/vitamin deficiency due to shortened bowel requiring specific dietary supplements or other treatment	Between 1 in 50 & 1 in 250 patients
Late stricturing (scarring) of the bowel or ureters requiring further surgery	Between 1 in 50 & 1 in 250 patients
Rectal injury at the time of surgery requiring a temporary colostomy (bowel opening on your abdomen)	Between 1 in 50 & 1 in 250 patients
Spontaneous rupture of your neobladder with urinary leakage requiring further surgery	Between 1 in 50 & 1 in 250 patients
Decrease in kidney function over time	Between 1 in 50 & 1 in 250 patients
The risk of death as the result of complications	Between 1 in 50 & 1 in 250 patients

## What is my risk of a hospital-acquired infection?

Your risk of getting an infection in hospital is between 4 & 6%; this includes getting *MRSA* or a *Clostridium difficile* bowel infection. Individual hospitals

Published: Jan 2025 Review due: Jul 2026 may have different rates, and the medical staff can tell you the risk for your hospital. You have a higher risk if you have had:

- long-term drainage tubes (e.g. catheters);
- bladder removal;
- long hospital stays; or
- multiple hospital admissions.

## What can I expect when I get home?

- we will arrange for the stitches or clips in your wound to be removed after a week or two
- if you get a fever or start vomiting, especially if associated with unexpected pain in your abdomen, you should contact your GP immediately
- you will be given advice about your recovery at home
- you will be given a copy of your discharge summary and a copy will also be sent to your GP
- any antibiotics or other tablets you may need will be arranged & dispensed from the hospital pharmacy
- you will feel tired for several weeks

# General information about surgical procedures

#### Before your procedure

Please tell a member of the medical team if you have:

- an implanted foreign body (stent, joint replacement, pacemaker, heart valve, blood vessel graft);
- a regular prescription for a blood thinning agent (e.g. warfarin, aspirin, clopidogrel, rivaroxaban, dabigatran);
- a present or previous MRSA infection; or
- a high risk of variant-CJD (e.g. if you have had a corneal transplant, a neurosurgical dural transplant or human growth hormone treatment).

#### Questions you may wish to ask

If you wish to learn more about what will happen, you can find a list of suggested questions called <u>"Having An Operation"</u> on the website of the Royal College of Surgeons of England. You may also wish to ask your surgeon for his/her personal results and experience with this procedure.

#### Before you go home

We will tell you how the procedure went and you should:

- make sure you understand what has been done;
- ask the surgeon if everything went as planned;
- let the staff know if you have any discomfort;
- ask what you can (and cannot) do at home;
- make sure you know what happens next; and
- ask when you can return to normal activities.

We will give you advice about what to look out for when you get home. Your surgeon or nurse will also give you details of who to contact, and how to contact them, in the event of problems.

#### Smoking and surgery

Ideally, we would prefer you to stop smoking before any procedure. Smoking can worsen some urological conditions and makes complications more likely after surgery. For advice on stopping, you can:

- contact your GP;
- access your local NHS Smoking Help Online; or
- ring the Smoke-Free National Helpline on **0300 123 1044**.

#### Driving after surgery

It is your responsibility to make sure you are fit to drive after any surgical procedure. You only need to <u>contact the DVLA</u> if your ability to drive is likely to be affected for more than three months. If it is, you should check with your insurance company before driving again.

## What should I do with this information?

Thank you for taking the trouble to read this information. Please let your urologist (or specialist nurse) know if you would like to have a copy for your own records. If you wish, the medical or nursing staff can also arrange to file a copy in your hospital notes.

## What sources have we used to prepare this leaflet?

This leaflet uses information from consensus panels and other evidencebased sources including:

- the <u>Department of Health (England);</u>
- the <u>Cochrane Collaboration</u>; and
- the National Institute for Health and Care Excellence (NICE).

It also follows style guidelines from:

• the Royal National Institute for Blind People (RNIB);

- the Information Standard;
- the Patient Information Forum; and
- the <u>Plain English Campaign</u>.

#### DISCLAIMER

Whilst we have made every effort to give accurate information, there may still be errors or omissions in this leaflet. BAUS cannot accept responsibility for any loss from action taken (or not taken) as a result of this information.

**PLEASE NOTE:** the staff at BAUS are not medically trained, and are unable to answer questions about the information provided in this leaflet. If you have any questions, you should contact your Urologist, Specialist Nurse or GP in the first instance.