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.

To view the online version of this leaflet, type the text below into your web browser:

### Key Points

- The aim of cystectomy is to remove your bladder and the cancer that it contains
- This usually involves removal of your uterus (womb), ovaries, part of your vagina and local lymph glands to give us the best chance of removing all the cancer
- Once we have removed your bladder, we divert your urine, using an isolated section of bowel, on to your abdominal (tummy) wall as a urostomy (ileal conduit)

### What does this procedure involve?

Removal of your bladder, uterus, ovaries, upper part of your vagina and local lymph nodes. Your urine is then diverted into a section of bowel which is brought to the skin surface as a stoma (usually an ileal conduit, also known as a urostomy).

Most of your vagina is left in place and, for women who are still sexually active, intercourse should be possible. Your surgeon can give you more details about this.

### What are the alternatives?

- [Radical radiotherapy](#) – if, for any reason, a decision has been made that you should not undergo surgery
• **BCG instillation into the bladder** – only indicated for high-grade non-muscle invasive cancer; not for muscle-invasive disease

• **Radical cystectomy with formation of a neobladder** or **construction of a catheterisable pouch** – radical bladder removal but without an external urostomy

• **Systemic chemotherapy** – drugs given by mouth or into your bloodstream; sometimes used before radiotherapy or radical cystectomy

**What happens on the day of the procedure?**

Your urologist (or a member of their team) will briefly review your history and medications, and will discuss the surgery again with you to confirm your consent.

An anaesthetist will see you to discuss the options of a general anaesthetic or spinal anaesthetic. The anaesthetist will also discuss pain relief after the procedure with you.

We may provide you with a pair of TED stockings to wear, and we may give you a heparin 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.

Some urology units admit you the day before your procedure to administer laxatives to clear your bowel; others will admit you on the day of surgery and will not use laxatives. Your urologist will advise on which protocol will be used.

**Will I have any say in where my urostomy is sited?**

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 then mark this on the skin of your abdomen. The surgeon needs to see this mark during the procedure, so it is important not to wash it off. If you wish, we will give you the opportunity to meet someone who already has a urostomy.
Details of the procedure

- we normally 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, uterus, both ovaries and the upper part of your vagina
- we may be able to preserve the nerves which control sexual function but this is not always possible; you should discuss this with your urologist before the procedure
- we 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 the abdomen as a urostomy (usually an ileal conduit)
- we re-join the ends of the small bowel from which the urostomy has been made
- we close the wound with stitches or staples
- we normally place one or more drains where the bladder has been removed and leave two small splints in the ureters, protruding from the end of your urostomy (pictured)
- we attach a drainage bag to your urostomy
- the procedure can take anything from two to six hours to perform, depending on how complex the procedure is and what approach (open or keyhole) is used
- you should expect to be in hospital for seven to 14 days.

Following radical cystectomy, some urology units have introduced Enhanced Recovery Pathways. These actually start before you are admitted to hospital. After your surgery, they are designed to speed your recovery, shorten your time in hospital and reduce your risk of re-admission.

We will encourage you to get up and about as soon as possible. This reduces the risk of blood clots in your legs and helps your bowel to start
working again. You will sit out in a chair shortly after the procedure and be shown deep breathing/leg exercises. We will encourage you to start drinking and eating as soon as possible.

We normally remove your drains when they have stopped draining. The splints in your stoma will be removed 10 to 14 days after the procedure, sometimes after an X-ray along the splints shows that the ureters and bowel have been joined securely.

**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:

<table>
<thead>
<tr>
<th>After-effect</th>
<th>Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discomfort or difficulty with sexual intercourse due to narrowing or shortening of your vagina</td>
<td>Almost all patients</td>
</tr>
<tr>
<td>Menopausal symptoms because your ovaries have been removed</td>
<td>Almost all patients</td>
</tr>
<tr>
<td>Your cancer may not be cured by the procedure (this possibility will have been discussed with you before the operation)</td>
<td>Between 1 in 2 &amp; 1 in 10 patients</td>
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<tr>
<td>Blood transfusion</td>
<td>Between 1 in 2 &amp; 1 in 10 patients</td>
</tr>
<tr>
<td>Paralytic ileus (failure of your bowel to work) for several days causing nausea, bloating &amp; vomiting, and requiring an intravenous drip and stomach drainage tube through your nose until it recovers</td>
<td>Between 1 in 2 &amp; 1 in 10 patients</td>
</tr>
<tr>
<td>Infection in your wound or an abscess in your abdominal (tummy) cavity</td>
<td>Between 1 in 10 &amp; 1 in 50 patients</td>
</tr>
<tr>
<td>Condition</td>
<td>Risk Category</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Anaesthetic or cardiovascular problems possibly requiring intensive care</td>
<td>Between 1 in 10 &amp; 1 in 50 patients (your anaesthetist can estimate your individual risk)</td>
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<tr>
<td>Decrease in kidney function over time</td>
<td>Between 1 in 10 &amp; 1 in 50 patients</td>
</tr>
<tr>
<td>Need to abandon a keyhole procedure and convert to open surgery because of</td>
<td>Between 1 in 10 &amp; 1 in 50 patients</td>
</tr>
<tr>
<td>operative difficulties</td>
<td></td>
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<tr>
<td>Need to remove your urethra (waterpipe) as part of the procedure</td>
<td>Between 1 in 10 &amp; 1 in 50 patients</td>
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<tr>
<td>Need for return to theatres for re-operation due to bleeding, bowel leakage, urine leakage or bowel obstruction</td>
<td>Between 1 in 50 &amp; 1 in 250 patients</td>
</tr>
<tr>
<td>Hernia of the incision (or keyhole ports) requiring further surgical repair</td>
<td>Between 1 in 50 &amp; 1 in 250 patients</td>
</tr>
<tr>
<td>Scarring, narrowing or hernia formation around your urostomy requiring revision</td>
<td>Between 1 in 50 &amp; 1 in 250 patients</td>
</tr>
<tr>
<td>Diarrhoea/vitamin deficiency due to shortened bowel requiring specific dietary supplements or other treatment</td>
<td>Between 1 in 50 &amp; 1 in 250 patients</td>
</tr>
<tr>
<td>Late stricturing (scarring) of the bowel or ureters requiring further surgery</td>
<td>Between 1 in 50 &amp; 1 in 250 patients</td>
</tr>
<tr>
<td>Rectal injury at the time of surgery requiring a temporary colostomy (bowel opening on your abdomen)</td>
<td>Between 1 in 50 &amp; 1 in 250 patients</td>
</tr>
</tbody>
</table>

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

Your risk of getting an infection in hospital is approximately 8 in 100 (8%); this includes getting *MRSA* or a *Clostridium difficile* bowel infection. This
figure is higher if you are in a “high-risk” group of patients such as patients who 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?**

- 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
- by the time you get home, you should be able to perform “daily living” activities such as making a cup of tea, preparing food and emptying your stoma bag
- you will feel tired for several weeks and may need to take regular “cat naps” during the day
- we will arrange for the stitches or clips in your wound to be removed after 10 to 12 days
- if you get a fever or start vomiting, especially if associated with unexpected pain in your abdomen, you should contact your GP immediately
- a follow-up appointment will be made for you six to 12 weeks after your surgery

**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 (warfarin, aspirin, clopidogrel, rivaroxaban or 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 “Having An Operation” 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.

BAUS runs a national audit and collects data from all urologists undertaking this surgery. There are two reasons for this. First, surgeons are required by the Department of Health to look at how well the surgery is being done under their care and, second, to look at national trends for the procedure.

Some basic patient data (e.g. name, NHS number and date of birth) are entered and securely stored. This is required so that members of the clinical team providing your care can go back to the record and add follow-up data such as length of stay or post-operative complications. This helps your surgeon to understand the various outcomes of the procedure.

Although BAUS staff can download the surgical data for analysis, they cannot access any patient identifiable data. This information is used to generate reports on individual surgeons and units; these are available for the public to view in the Surgical Outcomes Audit section of the BAUS website.

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 cause bladder cancer, increase the risk of cancer recurrence and make complications more likely after surgery. We strongly advise anyone with bladder cancer to stop smoking. For advice on stopping, you can:

- contact your GP;
- access your local NHS Smoking Help Online; or
- ring the free NHS Smoking Helpline on 0800 169 0 169.
**Driving after surgery**
It is your responsibility to make sure you are fit to drive after any surgical procedure. You only need to contact the DVLA 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 evidence-based sources including:

- the [Department of Health (England)](https://www.gov.uk);
- the [Cochrane Collaboration](https://www.cochrane.org);

It also follows style guidelines from:

- the [Royal National Institute for Blind People (RNIB)](https://www.rnib.org.uk);
- the [Information Standard](https://www.informationstandard.org);
- the [Patient Information Forum](https://www.patientinformationforum.org);
- the [Plain English Campaign](https://www.plainenglishcampaign.org).

**Disclaimer**
We have made every effort to give accurate information but 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.

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**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 do have any questions, you should contact your urologist, specialist nurse or GP.