



RADICAL CYSTECTOMY (IN WOMEN) WITH BLADDER SUBSTITUTION

Procedure Specific Information

What is the evidence base for this information?

This publication includes advice from consensus panels, the British Association of Urological Surgeons, the Department of Health and evidence-based sources. It is, therefore, a reflection of best urological practice in the UK. It is intended to supplement any advice you may already have been given by your GP or other healthcare professionals. Alternative treatments are outlined below and can be discussed in more detail with your Urologist or Specialist Nurse.



What does the procedure involve?

This involves removal of the bladder, pelvic lymph nodes and, usually, remaining female organs (i.e. ovaries, uterus and a portion of vagina) with formation of a bladder substitute using a segment of bowel

What are the alternatives to this procedure?

Instillation treatment into the bladder, radiotherapy treatment to the bladder, removal of the bladder without construction of a bladder substitute (i.e. construction of a stoma), systemic chemotherapy (into the bloodstream) may be used but is not suitable for everyone

What should I expect before the procedure?

Before the operation, you will have been counselled about the bladder substitute and what to expect. If you wish, you will be given the opportunity to meet someone who has previously had this procedure.

You will come into hospital 1 day before the surgery. Sometimes you will be given laxatives so that your bowel can be prepared. Your stay will last approximately 18 days. You will normally receive an appointment for pre-assessment to assess your general fitness, to screen for the carriage of MRSA and to perform some baseline investigations.

After admission, you will be seen by members of the medical team which may include the Consultant, Specialist Registrar, House Officer and the Urology Nurse Practitioner who will mark a stoma site on your abdomen.

From the day before your operation you will have only fluids by mouth; you should take nothing by mouth for the 6 hours before surgery. You will also be given an enema to ensure that you pass a bowel motion on the morning of surgery.



You will be given an injection under the skin of a drug (Clexane), that, along with the help of elasticated stockings provided by the ward, will help prevent thrombosis (clots) in the veins.

Please be sure to inform your surgeon in advance of your surgery if you have any of the following:

- an artificial heart valve
- a coronary artery stent
- a heart pacemaker or defibrillator
- an artificial joint
- an artificial blood vessel graft
- a neurosurgical shunt
- any other implanted foreign body
- a regular prescription for Warfarin, Aspirin or Clopidogrel (Plavix®)
- a previous or current MRSA infection
- a high risk of variant-CJD (if you have received a corneal transplant, a neurosurgical dural transplant or previous injections of human-derived growth hormone)

At some stage during the admission process, you will be asked to sign the second part of the consent form giving permission for your operation to take place, showing you understand what is to be done and confirming that you wish to proceed. Make sure that you are given the opportunity to discuss any concerns and to ask any questions you may still have before signing the form.

Fact File 1 • The NHS Constitution Same-Sex Accommodation

As a result of the new NHS constitution, the NHS is committed to providing same-sex accommodation in hospitals by April 2010. This is because feedback from patients has shown that being in mixed-sex accommodation can compromise their privacy. The NHS pledges that:

- sleeping and washing areas for men and women will be provided
- the facilities will be easy to get to and not too far from patients' beds

To help accomplish this, the Department of Health has announced specific measures designed to "all but eliminate mixed-sex accommodation" by 2010. These include:

- more money for improvements in hospital accommodation
- providing help and information to hospital staff, patients and the public
- sending improvement teams to hospitals that need extra support
- introducing measures so that the Department can see how hospitals are progressing

What happens during the procedure?

A full general anaesthetic will be used and you will be asleep throughout the procedure. In some patients, the anaesthetist may also use an epidural anaesthetic which improves or minimises post-operative pain.

In the operation, the bladder and its lymph nodes will be removed. The ureters (the tubes which drain urine from the kidneys to the bladder) are then sewn to an separated piece of small bowel which is fashioned into a bladder substitute and joined to the water pipe (urethra). Alternatively, a catheterisable pouch (or reservoir) may be constructed.

As part of the operation, it is usual to remove the uterus (womb), both ovaries and the upper part of the vagina. Most of the vagina is left in place and, for women who wish to be sexually active, this should be possible. The precise details of this aspect of your operation can be discussed in detail if you wish.

What happens immediately after the procedure?

In general terms, you should expect to be told how the procedure went and you should:

- ask if what was planned to be done was achieved
- let the medical staff know if you are in any discomfort
- ask what you can and cannot do
- feel free to ask any questions or discuss any concerns with the ward staff and members of the surgical team
- ensure that you are clear about what has been done and what is the next move



After your operation, you may be in the Intensive Care Unit or the Special Recovery area of the operating theatre before returning to the ward; visiting times in these areas are flexible and will depend on when you return from the operating theatre. You will have a drip in your arm and a further drip into a vein in your neck.

You will be encouraged to mobilise as soon as possible after the operation because this encourages the bowel to begin working. We will start you on fluid drinks and food as soon as is possible.

You will usually have a catheter in the urethra and a second catheter passing through the abdominal wall to the bladder; these catheters are normally removed after 2 weeks. Small tube drains will pass from the kidneys through the bladder substitute to a bag on the abdominal wall; these drains collect urine until they are removed after 7 days. An additional drain is usually placed in the abdomen itself and is removed after 4-5 days.. Normally, we use injections and elastic stockings to minimise the risk of a blood clot (deep vein thrombosis) in your legs. A physiotherapist will come and show you some deep breathing and leg exercises, and you will sit out in a chair for a short time soon after your operation. It will, however, take at least 3-6 months, and possibly longer, for you to recover fully from



this surgery.

The average hospital stay is 18 days.

Are there any side-effects?

Most procedures have a potential for side-effects. You should be reassured that, although all these complications are well-recognised, the majority of patients do not suffer any problems after a urological procedure.

Common (greater than 1 in 10)

- Need to self-catheterise If bladder substitute fails to fully empty
- Temporary insertion of a stomach tube through the nose, a drain and ureteric stents
- Pain or difficulty with sexual intercourse due to narrowing or shortening of vagina
- In the event of removal of the ovaries, menopause may occur
- Recurrent urinary tract infection requiring antibiotic treatment and/or bladder substitute washing
- Cancer may not be cured with removal of bladder alone
- Passing of mucus in the urine which can cause intermittent blockage of the urinary stream
- MRSA wound infection (1 in 10 risk)

Occasional (between 1 in 10 and 1 in 50)

- Anaesthetic or cardiovascular problems possibly requiring intensive care admission (including chest infection, pulmonary embolus, stroke, deep vein thrombosis, heart attack and death)
- Infection or hernia of incision requiring further treatment
- Blood loss requiring repeat surgery
- Incontinence of urine
- Decreased kidney function with time

Rare (less than 1 in 50)

- Diarrhoea/vitamin deficiency due to shortened bowel requiring treatment
- Bowel and urine leakage from anastomosis requiring re-operation
- Scarring to the bowel or ureters requiring operation in future
- Urethral recurrence of the cancer
- Technical failure to create a bladder substitute, requiring formation of a urinary stoma (bag)
- Intra-operative rectal injury requiring colostomy

Hospital-acquired infection

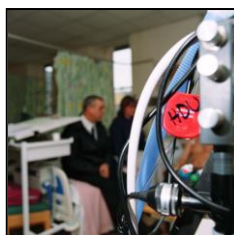
- Colonisation with MRSA (0.9% - 1 in 110)
- Clostridium difficile bowel infection (0.2% - 1 in 500)
- MRSA bloodstream infection (0.08% - 1 in 1250)

The rates for hospital-acquired infection may be greater in high-risk patients e.g. with long-term drainage tubes, after removal of the bladder for cancer, after previous infections, after prolonged hospitalisation or after multiple admissions.

What should I expect when I get home?

By the time of your discharge from hospital, you should:

- be given advice about your recovery at home
- ask when to resume normal activities such as work, exercise, driving, housework and sexual intimacy
- ask for a contact number if you have any concerns once you return home
- ask when your follow-up will be and who will do this (the hospital or your GP)
- ensure that you know when you will be told the results of any tests done on tissues or organs which have been removed



When you leave hospital, you will be given a “draft” discharge summary of your admission. This holds important information about your inpatient stay and your operation. If you need to call your GP for any reason or to attend another hospital, please take this summary with you to allow the doctors to see details of your treatment. This is particularly important if you need to consult another doctor within a few days of your discharge.

You will find that your energy levels are low when you get home and you will require assistance with many of the daily activities you normally take for granted. The wound clips will be removed in hospital or by the District Nurse who will also help with any other problems which may develop.

You will need to continue training your bladder substitute to increase its capacity once you get home. Initially, you will pass urine every 2 hours but this will gradually increase to 4-hourly by day and night. Bladder training may take up to 12 months to complete.

The time taken to return to normal activity is between 2 and 4 months.

What else should I look out for?

There are a number of complications which may make you feel unwell and may require consultation with your GP or contact with the Urology Department.

If you experience fever or vomiting, especially if associated with unexpected pain in the abdomen, you should contact your doctor immediately for advice.

If you are unable to pass urine and cannot pass a catheter, you should attend the Accident & Emergency Department as quickly as possible. If you have problems relating to recurrent urinary tract infection or bladder re-training, you should contact the Specialist Nurse.



Occasional blocking of the urinary stream with a plug of mucus from the bowel lining is common. It usually clears on its own but you may need to carry out clean intermittent self-catheterisation for this to ensure that the bladder is emptying completely.

Your blood acid content will be monitored since this can become altered with a bladder substitute. Your urologist may prescribe medication to alter the acid levels depending on the results. Symptoms of an abnormal acid level include fatigue, tiredness and weakness.

Are there any other important points?

It will be at least 14-21 days before the pathology results on the tissue removed are available. It is normal practice for the results of all biopsies to be discussed in detail at a multi-disciplinary meeting before any further treatment decisions are made. You and your GP will be informed of the results after this discussion.

You will be brought back to the Hospital for a special scan to check that the kidneys are draining into the bowel correctly and you will be seen in the outpatient clinic after 6 weeks to check your progress and to discuss the results of your surgery. If the doctors decide that further treatment is required, the necessary appointments will be made for you at this stage.

Driving after surgery

It is your responsibility to ensure that you are fit to drive following your surgery. You do not normally need to notify the DVLA unless you have a medical condition that will last for longer than 3 months after your surgery and may affect your ability to drive. You should, however, check with your insurance company before returning to driving. Your doctors will be happy to provide you with advice on request.

Is there any research being carried out in this area?



Before your operation, your surgeon or Specialist Nurse will inform you about any relevant research studies taking place, and, in particular, if any surgically-removed tissue may be stored for future study. If this is the case, you will be asked if you wish to participate and, if you agree, to sign a special form to consent to this.

All surgical procedures, even those not currently the subject of active research, are subjected to rigorous clinical audit so that we can analyse our results and compare them with those of other surgeons. In this way, we can learn how to improve our techniques and our results; this means that our patients will get the best treatment available.

Who can I contact for more help or information?

For further information on the internet, here are some useful sites to explore:

[Best Health](#) (prepared by the British Medical Association)

[NHS Clinical Knowledge Summaries](#) (formerly known as Prodigy)



[NHS Direct](#)

[Patient UK](#)

[Royal College of Anaesthetists](#) (for information about anaesthetics)

[Royal College of Surgeons](#) (patient information section)

What should I do with this information?

Thank you for taking the trouble to read this publication. If you wish to sign it and retain a copy for your own records, please do so below.

If you would like a copy of this publication to be filed in your hospital records for future reference, please let your Urologist or Specialist Nurse know. However, if you do agree to proceed with the scheduled procedure, you will be asked to sign a separate consent form which will be filed in your hospital record. You will, if you wish, be provided with a copy of this consent form.

I have read this publication and I accept the information it provides.

Signature..... Date.....



How can I get information in alternative formats?

Please ask your local NHS Trust or PALS network if you require this information in other languages, large print, Braille or audio format.



Most hospitals are smoke-free. Smoking increases the severity of some urological conditions and increases the risk of post-operative complications. For advice on quitting, contact your GP or the **NHS Smoking Helpline** free on **0800 169 0 169**

Disclaimer

While every effort has been made to ensure the accuracy of the information contained in this publication, no guarantee can be given that all errors and omissions have been excluded. No responsibility for loss occasioned by any person acting or refraining from action as a result of the material in this publication can be accepted by the British Association of Urological Surgeons Limited.

Fact File 2 • The NHS Constitution Patients' Rights & Responsibilities

The constitution, as a result of extensive discussions with staff and the public, sets out new rights for patients which will help improve their experience within the NHS. These new rights include:

- a right to choice and a right to information that will help them make that choice
- a right to drugs and treatments approved by NICE when it is considered clinically appropriate
- a right to certain services such as an NHS dentist and access to recommended vaccinations
- the right that any official complaint will be properly and efficiently investigated, and that they be told the outcome of the investigations
- the right to compensation and an apology if they have been harmed by poor treatment

The constitution also lists patient responsibilities, including:

- providing accurate information about their health
- taking positive action to keep themselves and their family healthy
- trying to keep appointments
- treating NHS staff and other patients with respect
- following the course of treatment that they are given
- giving feedback, both positive and negative, after treatment