Urology department

Radical removal of the bladder and formation of a bladder substitute with bowel (female)

What is the evidence base for this information?
This leaflet 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 practice in the UK. It is intended to supplement any advice you may already have been given by your urologist or nurse specialist as well as the surgical team at Addenbrooke’s. 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 (ie 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 (ie 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.

The plan for your hospital stay will be discussed in detail with you before admission, including coming into hospital on the morning of the operation, having carbohydrate drinks the night before surgery and early on the morning of surgery, and being given a small enema after arriving in hospital on the morning of surgery.

Your stay is expected to be 21 nights in hospital if all goes as anticipated. You will receive an appointment for pre assessment, before your admission, 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 including the consultant, specialist registrar, junior doctors and urology nurse practitioner.

After your operation, you may be given an injection under the skin of a drug (dalteparin) that, along with the help of elasticated stockings provided by the ward, will help prevent thrombosis (clots) in the veins.
You will be seen by a urology specialist nurse before your operation to mark the site where a stoma will be positioned, if it is not possible to make a bladder substitute at the time of your operation. If you wish, you will be given the opportunity to meet someone who has previously had this procedure.

Please be sure to inform your urologist 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 prescription for Warfarin, Aspirin, Rivaroxaban, Dabigatran, Apixaban, Edoxaban or Clopidogrel, Ticagrelor or blood thinning medication
- a previous or current MRSA infection
- high risk of variant CJD (if you have received a corneal transplant, a neurosurgical dural transplant or previous injections of human derived growth hormone)

**What happens during the procedure?**

A full general anaesthetic will be used and you will be asleep throughout the procedure. There will be an epidural anaesthetic to minimise post operative pain.

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

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?
After your operation, you are likely to go to the special recovery area of the operating theatre, rather than high dependency or intensive care, before returning to the ward. 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 two 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 seven days. You will have a tube drain in your abdomen. 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.

You will be helped to recover mobility after the operation, so that you are able to walk up and down the length of the ward (100m) and to do a flight of stairs before you go home. Driving and heavy lifting should be possible at six weeks after surgery. It will, however, take at least three to six months, and possibly longer, for you to recover fully from this surgery.

The expected hospital stay is 21 nights.

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.

Please use the check boxes to tick off individual items when you are happy that they have been discussed to your satisfaction:

Common (greater than one in 10)

- ☐ The cancer may not be cured by the operation (this will be discussed with you before the operation)
- ☐ Difficulty re-establishing normal bowel movements in the first few weeks after your operation. This can persist in the long term in 5-10% of patients
- ☐ Temporary insertion of a stomach tube through the nose, a drain and ureteric stents
- ☐ Discomfort or difficulty with sexual intercourse due to narrowing or shortening of vagina
- ☐ In the event of removal of the ovaries, menopause may occur
- ☐ Difficulty emptying the bladder substitute adequately, requiring long term self-catheterisation, or wearing pads.

Occasional (between one in 10 and one 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 in the abdominal cavity or in the wound
Blood loss requiring repeat surgery
- Hernia of the incision requiring further treatment
- Decrease in kidney function with time
- Scarring, narrowing or hernia formation around the stomal opening requiring revision

Rare (less than one in 50)
- Diarrhoea/ vitamin deficiency due to shortened bowel requiring treatment
- Bowel and urine leakage from the anastomosis requiring re-operation
- Scarring of the bowel or ureters requiring further surgery
- Intra-operative rectal injury requiring colostomy
- MRSA wound infection (one in 10 risk)

What should I expect when I get home?
When you leave hospital, you will be given a discharge summary of your admission. This holds important information about your inpatient stay and your operation. If, in the first few weeks after your discharge, 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 two hours but this will gradually increase to four 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 two and four 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 and 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 10 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 multidisciplinary 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 six 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 three 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.

**Privacy & dignity**

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high tech equipment and/or specialist one to one care is required.

**Hair removal before an operation**

For most operations, you do not need to have the hair around the site of the operation removed. However, sometimes the healthcare team need to see or reach your skin and if this is necessary they will use an electric hair clipper with a single-use disposable head, on the day of the surgery. Please do not shave the hair yourself or use a razor to remove hair, as this can increase the risk of infection. Your healthcare team will be happy to discuss this with you.

**References**

NICE clinical guideline No 74: Surgical site infection (October 2008); Department of Health: High Impact Intervention No 4: Care bundle to preventing surgical site infection (August 2007)

**Is there any research being carried out in this field at Addenbrooke’s Hospital?**

Yes. As part of your operation, various specimens of tissue will be sent to the pathology department so that we can find out details of the disease and whether it has affected other areas. This information sheet has already described to you what tissue will be removed.
We would also like your agreement to carry out research on that tissue which will be left over when the pathologist has finished making a full diagnosis. Normally, this tissue is disposed of or simply stored. What we would like to do is to store samples of the tissue, both frozen and after it has been processed. Please note that we are not asking you to provide any tissue apart from that which would normally be removed during the operation.

We are carrying out a series of research projects which involve studying the genes and proteins produced by normal and diseased tissues. The reason for doing this is to try to discover differences between diseased and normal tissue to help develop new tests or treatments that might benefit future generations. This research is being carried out here in Cambridge but we sometimes work with other universities or with industry to move our research forwards more quickly than it would if we did everything here.

The consent form you will sign from the hospital allows you to indicate whether you are prepared to provide this tissue. If you would like any further information, please ask the ward to contact your consultant.

**Who can I contact for more help or information?**

**Oncology nurses**

*Uro-oncology nurse specialist*

01223 586748

*Bladder cancer nurse practitioner (haematuria, chemotherapy and BCG)*

01223 274608

*Prostate cancer nurse practitioner*

01223 274608 or 216897 or bleep 154-548

*Surgical care practitioner*

01223 348590 or 256157 or bleep 154-351

**Non-oncology nurses**

*Urology nurse practitioner (incontinence, urodynamics, catheter patients)*

01223 274608 or 586748 or bleep 157-237

*Urology nurse practitioner (stoma care)*

01223 349800

*Urology nurse practitioner (stone disease)*

01223 349800 or bleep 152-879
Patient Information

Patient advice and liaison service (PALS)
Telephone:
01223 216756 or 257257
01223 274432 or 274431
PatientLine: *801 (from patient bedside telephones only)
email: pals@addenbrookes.nhs.uk
Mail: PALS, Box No 53
Addenbrooke’s Hospital
Hills Road, Cambridge, CB2 2QQ

Chaplaincy and multi faith community
Telephone: 01223 217769
email: chaplaincy@addenbrookes.nhs.uk
Mail: The Chaplaincy, Box No 105
Addenbrooke’s Hospital
Hills Road, Cambridge, CB2 2QQ

MINICOM System ("type" system for the hard of hearing)
Telephone: 01223 217589

Access office (travel, parking and security information)
Telephone: 01223 596060

What should I do with this leaflet?

Thank you for taking the trouble to read this patient information leaflet. 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 leaflet to be filed in your hospital records for future reference, please let your urologist or specialist nurse know. If you do, however, decide to proceed with the scheduled procedure, you will be asked to sign a separate consent form which will be filed in your hospital notes and you will, in addition, be provided with a copy of the form if you wish.

I have read this patient information leaflet and I accept the information it provides.

Signature......................................................Date..........................................
We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site.
For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:
If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team:
patient.information@addenbrookes.nhs.uk.
Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history
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