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

This patient information leaflet is drawn from the consensus panels of many worldwide urological societies, as a supplement to any advice that you may already have been given. Alternative treatments are outlined below and can be discussed in more detail with Dr Campbell.

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.

Before the procedure

Please be sure to inform Dr Campbell in advance of your procedure if you have any of the following:

- ~An artificial heart valve
- ~A coronary artery stent
- ~A heart pacemaker or defribrillator
- ~An artificial blood vessel graft
- ~A neurosurgical shunt
- ~ Any other implanted foreign body
- ~ Mesh hernia repair
- ~ Previous abdominal surgery
- ~Angina
- $\sim {\rm Hypertension}$
- ~ Diabetes
- ~ Recent heart attack

- \sim Blood thinning medications, particularly
 - ~Asasantin
 - ~Aspirin
 - ~ Fish oil
 - ~ Iscover
 - ~ Persantin
 - ~ Plavix
 - ~ Warfarin

You will usually be admitted on the day of surgery. You may be asked to attend a pre-admission clinic 5-10 days before the procedure to assess your general fitness and to perform some baseline investigations.

If you are taking warfarin, Clopidogrel, iscover, asaantin, or persantin on a regular basis, you must discuss this with Dr Campbell because these drugs can cause increased bleeding after surgery. There may be a balance of risk where stopping them will reduce the chances of bleeding but this can result in increased clotting, which may also carry a risk to your health. This will, therefore, need careful discussion with regard to risks and benefits.

From the day before your operation you will need to only have fluids by mouth.

You will be asked not to eat or drink for 6 hours before surgery. Immediately before the operation, you may be given a pre-medication by the anaesthetist which will make you dry mouthed and pleasantly sleepy.

You will be given an injection under the skin of a drug (heparin), that along with the help of elasticated stockings fitted on admission, will help prevent thrombosis (clots) in the veins of the legs. An enema will be given approximately 2 hours prior to the operation.

After admission, you will be seen by members of the urological team which may include not only Dr Campbell, but the specialist registrar's, the intern, your named nurse, the stoma nurse specialist, and the physiotherapist. The specialist registrar may perform the operation in conjunction with Dr Campbell and with your permission.

Where do I go for my procedure?

The admissions section of the hospital at the appointed time, on the appointed day. The admissions section of the particular hospital will give you instructions well in advance of the operation.

If no contact has been made telephone Dr Campbell's secretary on (07) 3367 1608, and the problem will be addressed.

Do I need to do anything special before my procedure?

You will need to not drink or eat anything for 6 hours prior to the procedure and to have an enema at least 2 hrs prior to the operation.

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.

The operation takes approximately 6-8 hours to complete.

Immediately after the procedure

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 and these are outlined below. Please use the check circles to tick off individual items when you are happy that they have been discussed to your satisfaction:

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
- \sim MRSA wound infection (1 in 10 risk)

Occasional (between 1 in 10 & 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

General side-effects of any procedure

Any operative procedure that involves regional (spinal) or general anaesthetic can have side-effects. These are explained in the leaflet on anaesthesia.

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 1,250)

(These rates 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?

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 and the stoma nurse will 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.

When you leave hospital, a discharge summary of your admission will be sent to your family doctor. This holds important information about your inpatient stay and your operation.

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 family doctor or contact with Dr Campbell.

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

For after hours emergencies Dr Campbell can be contacted on $(o_7) 336_7 1608$.

The Wesley Hospital Emergency Centre (07) 3232 7333, and The Greenslopes Private Hospital Emergency Centre (07) 3394 7111 are other resources that are also available.

If you are unable to pass urine and cannot pass a catheter, you should attend the Emergency Centre 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 selfcatheterisation 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 specific points?

It will be at least 5–7 days before the pathology results on the tissue removed are available. You and your family doctor will be informed of the results.

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 a follow-up clinic after 6 weeks to check your progress and to discuss the results of your surgery. If further treatment is required, the necessary appointments will be made for you at this stage.

Is there any research being carried out in this field?

There is no specific research in this area at the moment but all operative procedures performed are subject to rigorous audit at monthly Audit & Clinical Governance meetings.

Who can I contact for more help or information?

Dr Peter Campbell

Suite 9, level 9, Evan Thomson Building, The Wesley Hospital, Chasely St, Auchenflower, QLD 4066 (07) 3367 1608, www.campbellurology.com.au

The Wesley Hospital, Urology Ward

451 Coronation Drive, Auchenflower, QLD 4066 (07) 3232 7168 www.uhc.com.au/wesley

The Wesley Emergency Centre 451 coronation Drive,

Auchenflower, QLD 4066 (07) 3232 7333

Greenslopes Private Hospital, Continence Advisor

Newdgate St, Greenslopes, QLD 4120 (07) 3394 7978 www.greenslopesprivate.com.au

Greenslopes Private Hospital Urology Ward

Newdgate St, Greenslopes, QLD 4120 (07) 3394 7261 www.greenslopesprivate.com.au

Greenslopes Private Hospital Emergency Centre

Newdgate St, Greenslopes, QLD 4120 (07) 3394 6777 www.greenslopesprivate.com.au **The Queen Elizabeth II Jubilee Hospital, Urodynamics Department** Kessels Rd, Coopers plains, QLD 4108 (07) 3275 6346

American Urological Association Foundation 1000 Corporate Blvd, Suite 410, Linthicum, MD 21090 1800 828 7866 www.UrologyHealth.org

Thank you for taking the trouble to read this information sheet. If you are satisfied with the explanation of the test, please sign below and this leaflet will be filed in your chart.

If you wish to retain a copy for you own records, one will be provided.

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

Signature

Date