Reconstruction

During this operation, the surgeon removes your bladder and uses a section of your bowel to form a new pouch to hold urine. This pouch will be connected to your ureters and to your urethra so that you can pass urine normally after the operation.

This creation of your new bladder takes place during the same operation as the removal of your bladder, making this very long and complex surgery.
What the surgery entails

After removing your bladder, pelvic lymph glands and urethra, your surgeon will separate a two-foot long piece of your small bowel. This will be connected to your ureters. The other end of the small bowel will then be joined to your urethra. This effectively recreates your urinary system, enabling you to go to the toilet normally after the operation.

If you are a woman, the surgeon will usually remove your uterus (womb), both ovaries and the upper part of your vagina, as well as your bladder. This is to prevent the risk that the cancer could spread to these organs. Most of the vagina will be left in place, which means that you should still be able to have sex.

If you are a man, the prostate and sperm sacs (seminal vesicles) and, in some cases, the urethra will also be removed. Your surgeon will try and preserve the nerves which control erections, which run very close to the prostate, but it is likely they will suffer some damage during the operation. We will talk to you about this in detail before you have surgery, and will
explain the treatments we will be able to give you which may help.
Recovery - reconstruction

In hospital

When you wake up after the operation, you will have one drip in your arm, another in a vein in your neck and a catheter draining urine from your new bladder. This will stay in place for up to three weeks to give your new bladder time to heal.

Our highly experienced team of nursing staff and physiotherapists we will help you to get out of bed and start moving as early as possible. This will reduce the risk of blood clots forming in your legs and lungs and will also help prevent chest infections. It will also encourage your bowel to start working, which normally takes a few days.

As your new bladder is made from bowel tissue, it will produce thick white mucus. We will show you how to flush your neobladder to remove this mucus, as it can sometimes block the urinary stream. We will also teach you how to empty your new bladder and increase its capacity over time.

You will need to stay in hospital for around 21 nights after your operation so that our doctors and nurses can carefully monitor your recovery. You should be able to drive six weeks after surgery but a full recovery will take between three to six months.

Going home

When you leave hospital, you will be given a discharge summary which gives important information about your inpatient stay and operation. If you need to call your GP or go to another hospital for any reason in the first few weeks after your discharge, you should take this summary with you so that the doctor can see details of your treatment.

The results of any biopsies taken during your surgery will be available after around ten days and will be discussed in detail by the multi-disciplinary team before any decisions on further treatment are made. We will let you and your GP know the results after the MDT has met to discuss your care.

After the operation, you will feel like you don’t have much energy, and will need help with lots of the daily activities which you normally take for granted. This is to be expected after major surgery; you will gradually find things easier to do as you recover over time.
You will need to continue training your new bladder to increase its capacity. You’ll be given lots of advice on what to do before you leave hospital, and are welcome to contact our specialist nurses with any questions you may have when you do go home. Initially, you’ll need to go to the toilet every two hours, which will gradually increase to four hours. On average, it takes between three and six months for your bladder activity to return to normal, although you may need to continue the training for 12 months.

For the first few months after surgery, it is likely that your bowel will be disturbed. If this continues, please let us know as you may need treatment to help it settle.

**Check up**

Around six weeks after your operation, you will need to come back to Addenbrooke’s to have a scan to make sure your new urinary system is working correctly. We will also check on your progress and discuss the results of your surgery. If you do need any further treatment, we will also be able to make appointments for you.
Side effects

The majority of patients don’t suffer any side effects following a bladder cancer reconstruction operation. However, you should make sure you are aware of the complications which could occur so that you can ask for extra medical help if you start to feel unwell.

You should contact your doctor immediately if you develop a fever or vomiting, especially if you also have unexpected pain in your abdomen. If you are unable to pass urine and can’t pass a catheter, you should go to your nearest A&E department as quickly as possible. Your specialist nurse will be able to help if you have problems training the bladder or get repeated urinary tract infections.

Common side effects

You have around a one in ten chance of developing one of these side effects. Men should also be aware that won’t be able to ejaculate or have children after the operation as their sperm sacs will have been removed.

Common side effects include:

- the cancer has not been cured
- you may find it difficult to clear your bowel in the first few weeks after your operation (this may continue in the long term for five to 10% of patients)
- difficulty emptying the reconstructed bladder properly, which could lead to long term self-catheterisation or wearing pads
- for women:
  - discomfort or difficulty having sex
  - menopause may occur if the ovaries have been removed
- for men:
  - a high risk of impotence (lack of erections)
  - one in three chance of unsuspected prostate cancer being found

Occasional side effects

There is between a one in ten and one in 50 chance that you may develop one of these side effects.
Occasional side effects include:

- a reaction to the anaesthetic, or cardiovascular problems which may need intensive care
- infection in the abdominal cavity or in the wound
- blood loss which needs repeat surgery
- developing a hernia which needs further treatment
- a decrease in kidney function over time
- scarring of the bowels or ureters which needs further surgery

**Rare side effects**

You have a less than one in 50 chance of developing one of these side effects.

Rare side effects include:

- diarrhoea or a vitamin deficiency (due to the shortened bowel)
- bowel and urine leakage
- scarring of the bowel or ureters
- accidental injury to the rectum during surgery, which would need a colostomy bag
- inability to create a reconstructed bladder, in which case we will need to create a urinary diversion and stoma
- (in men) need to remove the urethra as part of the procedure
Living with a reconstruction

Most people who have a bladder reconstruction are able to return to a normal life. However the first few months after surgery can be very difficult. You will need to learn how to empty your reconstructed bladder and to recognise the changed sensations which mean that it is full. In addition, you will have had major surgery and will be dealing with changes affecting, for instance your sex life and ability to have children.

We will teach you how to empty your reconstructed bladder by relaxing the muscles in your pelvis while at the same time tightening the muscles in your abdomen. Most people quickly get used to this technique and find it quite comfortable.

If you are having difficulty emptying your reconstructed bladder or are not able to empty it completely at first, you may have to use a catheter to drain urine. We will teach you how to do this if it is necessary.

For the first weeks, your reconstructed bladder will not hold as much urine as a normal adult bladder. This means that you will need to empty it more frequently. As your bladder stretches over time, this will improve, but you will still need to wake up once or twice a night to go to the toilet.

As your reconstructed bladder will not contain the same types of nerve endings as a real bladder, you will not get the same sensation when you need to go to the toilet. Instead, you may feel like your abdomen is full or you need to pass wind.

Because of the loss of nerve function, around 25% of people who have a bladder reconstruction will have some problems with incontinence. This usually happens during the night while you are asleep. To help with this, you may find it useful to go to the toilet at set times during day, including before you go to bed.

Our specialist nurses will be able to give you help and support if you are having any specific problems.

It is not unusual to feel quite depressed in the weeks immediately after surgery. It's important to know that there many lines of support open to you to help you overcome the difficulties you may experience. These include:

- your specialist nurse
• buddies - other patients who have been through the same experiences