

Bladder removal (cystectomy) and bladder reconstruction (neo-bladder)

Department of Urology

Your doctor has recommended that you have your bladder removed. During this operation, you may be suitable to have your bladder reconstructed out of bowel tissue (neo-bladder). This leaflet explains what is involved in bladder reconstruction and the risks, benefits and alternatives to this surgery. If you have any questions or concerns, please speak to a member of staff caring for you.

What does a cystectomy involve?

A cystectomy involves removing the bladder and often other organs, such as the prostate gland in men and the uterus (womb) and part of the vagina in women. It aims to remove all your bladder cancer cells.

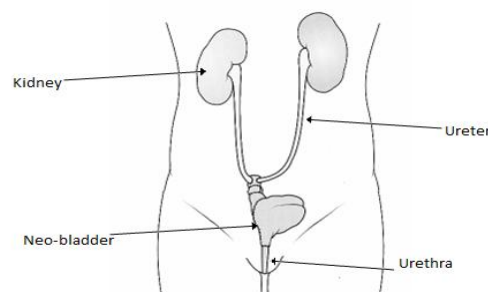
What is a neo-bladder?

A neo-bladder is where a new bladder is created from a section of your bowel and reconnected to your urethra (water pipe), so you can collect urine in an internal reservoir.

What are the benefits of having a neo-bladder?

It allows you to pass urine in much the same way as you would with a normal bladder, so it can improve the quality of your life after your cystectomy. However, not everyone needing a cystectomy is suitable for this surgery. This is especially the case if you have had radiotherapy to your pelvis or a history of bowel abnormalities.

What happens in a bladder reconstruction?



Neo-Bladder

This operation can be carried out in several ways but generally involves using a section of the small bowel approximately 60cm long. This piece of bowel is isolated from the main intestine and used to make the new reservoir or pouch that replaces your existing bladder. The ureters (tubes linking the kidneys and bladder) are implanted into this new reservoir, which is then sewn onto the urethra. A catheter is placed into the new bladder through the urethra and left in place for 2 -4 weeks, while the new joins heal. The catheter is then removed after this.

What are the alternatives?

If you decide not to have a neo-bladder, or are not suitable for the surgery, then you will need to have a stoma created at the same time that your bladder is removed.

A stoma - or urostomy - is an artificial opening on your abdomen that can be used to collect waste from your bladder or bowel. As you are having your bladder removed, it is used to collect urine.

If you have a stoma, the tubes connecting your kidneys and bladder (the ureters), are disconnected. They are then connected to a smaller segment of your bowel that's been isolated from your intestine. This segment is then brought to the skin surface, usually on the right hand side of your abdomen. Your urine then empties through this stoma into a small bag attached to the skin.

Limitations of surgery

Sometimes during the surgery, it may not be possible to create a neo-bladder. It is then necessary to create a stoma.

The stoma nurse will see you before your surgery to mark a site on your abdomen where your stoma should be. If your surgeon has to create a stoma, this mark shows him where to put it.

How will this surgery affect me?

This surgery permanently changes your body in several ways. It can affect:

- how you pass urine
- how you have sex
- your ability to have children
- your bowel function.

Your surgeon will discuss with you in more detail how your operation will affect you. Please ask questions if you are uncertain.

Passing urine

After the operation, your kidneys will produce urine in the normal way and the ureters will drain urine into your new bladder. Your new bladder will store urine until you decide to empty it. However, your bladder will not feel full in the same way as it used to. Some people say that they get a full sensation in the abdomen; others say that it feels a bit like having "wind". If you are unsure about when your bladder is full, you will have to keep an eye on the time and empty your bladder at regular intervals.

Many people who have had this operation will need to relax their pelvic floor muscles and use some abdominal pressure or strain to empty their new bladder. At first, the amount of urine the new bladder can hold will be less than a normal bladder. This will increase over time. You will need to empty your bladder every one to three hours at first until your bladder reaches its full capacity. After about three to six months, it should hold around a pint of urine (similar to the capacity of a normal bladder).

At night we recommend that you get up at least once to empty your new bladder before it becomes full. This is important, as control may be difficult when you are asleep if your bladder is full.

Most patients will experience leakage at night over the first couple of months. However, with pelvic floor exercises and bladder training, this should improve over time. Also, as the new bladder stretches it will be able to hold more urine, so you will not need to empty it as often.

Pelvic floor exercises will help to restore tone to the muscles in the pelvis. These muscles help you to control leakage. We will teach you how to do these exercises before you come into hospital for your surgery. For more information, please ask for a copy of our leaflet, **Pelvic floor exercises for men/women**.

We will teach you how to pass a catheter into your new bladder before your surgery. We will do this because you may occasionally need to use a catheter after you have emptied your bladder to make sure no urine has been left behind. If a large amount of urine is left behind in your bladder, it could cause infection, difficulty controlling urine leakage and problems with your kidneys.

How often you need to pass a catheter depends on how often and how much urine you are passing. Your consultant or specialist nurse will tell you what to do. About 30 per cent of people having this type of operation will need to insert a catheter once or twice a day in the long-term. If you do need to use a catheter to help empty your bladder, don't worry.

Learning to pass a catheter is not as difficult as it sounds and it doesn't take long to become an expert. It is a safe procedure as long as it is done under clean conditions and can be carried out almost anywhere, with very little fuss. The catheters are available on prescription and you can collect them from your local chemist or get them delivered to your home.

Having sex and the ability to have children

As mentioned earlier, the aim of the cystectomy is to remove all of your bladder cancer cells. This means other tissues that touch or lie close to your bladder are usually removed during the operation. These other organs and tissues affect your sexual function.

- **In men** - the prostate, which sits directly below the bladder, is removed during the operation. The nerves responsible for achieving an erection touch the prostate gland and so are also removed. In some cases, it may be possible to preserve the nerves on one side of your prostate, to increase the chances of restoring your erectile function (the ability to get an erection) with the use of tablets and/or injections. We will discuss this in more detail at your follow-up appointment.

- **In women** - there is an area of tissue between a section of the bladder and the vagina that has shared blood supply. This means that when this tissue is removed, a strip of the front wall of the vagina is also taken away. The result of this means that there may be some shortening of your vagina and full intercourse may not be possible for some patients. You should wait several weeks after your surgery before attempting to have intercourse and we advise you to use a lubricant such as KY jelly to help. Your uterus (womb) is usually removed.

Bowel function

After this operation, some people notice a change in their bowel habit. You may go to the toilet more frequently or notice that your bowel movements are more "loose" than before. This is because your bowel has been shortened by removing a section to make your new bladder.

This should improve within the first couple of months after your surgery. If it doesn't, medicines are available that bulk up your stool. This can be discussed with you in more detail if it applies to you.

Asking for your consent

If you decide to go ahead with the surgery, you will be asked to sign a consent form. This is to confirm that you agree to have the procedure and understand what it involves. It is your right to have a copy of this form.

Coming to hospital

What happens before the operation?

Before your operation you will be asked to attend the Pre-Admission Clinic. This is to check that you are fit for your operation. You will be asked questions about your general health and will have some or all of the following tests: blood and urine tests, chest x-ray and ECG (heart tracing). These are routine tests before an operation. You will also have the opportunity to ask any questions.

The day you come to hospital

- You will come into hospital the day before or the day of the operation and should expect to stay about 12 days.
- You will meet the nursing and medical staff who will be looking after you on one of our urology wards. You will also meet the anaesthetist who will take part in your care.

Additional Treatment

After your operation you will be started on daily subcutaneous injections of Fragmin (Daletparin), this also helps reduce your risk of blood clots. The nurse on the ward will teach you how to do this yourself as this treatment needs to be continued for 4 weeks. Current evidence from the National Institute of Clinical Health Excellence (NICE) recommends this treatment for patients undergoing major cancer surgery to reduce their risk of developing deep vein thrombosis (DVT) or pulmonary embolism (PE).

The Day of your Operation

If you have prescription medicines, you can take these with a small sip of water. The anaesthetist will discuss with you exactly which tablets you will be able to take.

- You should stop eating and drinking the night before the operation. You will be given a laxative suppository just before surgery. This will clear your lower bowel, which is necessary before you have your surgery.

After your operation

After you come out of theatre you will spend some time in the recovery area. When you are well enough you will be taken back to the Urology ward. Occasionally we take patients to the high dependency unit. This allows us to monitor your blood pressure, heart rate and fluid levels using very accurate equipment.

To reduce the pain in your abdomen after the operation we will give you painkillers. There are different options for pain relief, which the anaesthetist will discuss with you. You can either have:

- a painkiller device that you control (patient-controlled analgesia or PCA).
- This releases painkillers into your blood stream via a drip
- an epidural, where painkillers and local anaesthetic are given directly into your spinal nerve system. This involves inserting a very fine plastic tube into your back.

After about two days you will generally need less pain relief and will be given tablets or injections to relieve your pain instead.

You may also have:

- a drip running into a vein in your neck to give you fluids until you are able to drink normally. You will be able to drink fluids on your first post-operative day and sloppy food on the second. We encourage you to eat only when you feel hungry.
- 2 catheters draining urine from your new bladder. One coming down your water pipe, the other through a small incision in your tummy. To prevent a build-up of mucus, (which continues to be made by the bowel making up your new bladder), we will need to flush these catheters every 2 hours after your operation. As soon as you are able we teach you to do this yourself. These will drain your urine, so that the new bladder does not fill until it has had time to heal. They will be removed about two to four weeks after your surgery
- a small plastic tube from your abdomen that will stay in place for about five to seven days to drain any excess fluid surrounding the reconstruction.
- two fine tubes exiting one hole in your skin. These are draining urine directly from your kidneys and are removed 7 – 9 days after your operation.

Your recovery

The nursing staff will help you to get out of bed on the first or second day after your operation and help you to start walking soon after this. Patients are usually up and about independently around four to five days after their surgery. The nurses on the ward will teach you how to care for yourself. This is essential, as it is important that the catheters do not become blocked. Your new bladder will take around 10 days to heal. During this time the catheters will remain in place to drain away your urine.

Having a cystogram

About 10 days after your surgery, you will have a test called a cystogram. This test involves inserting dye into one of the catheters in your bladder, to check there are no leaks from your new bladder.

Once the test confirms this, your tummy catheter will be removed on the ward. 48 hours later your water pipe catheter is removed. Immediately after the catheter is removed you will find you need to empty your bladder very frequently, but this will improve, as explained previously.

Continue your Fragmin injections until the 4 week course finishes.

Getting back to normal

- Recovery time after abdominal surgery varies but generally, you should feel improvements after 6 to 12 weeks.

- Do not attempt to drive a car during the first six weeks after your surgery. Before you begin again, make sure you feel able to do an emergency stop and check with your insurance provider.
- Do not attempt to lift or move heavy objects, start digging the garden or do housework for the first six weeks after your surgery. Build up your activities slowly after this and only do as much as you feel able to.
- When you can return to work depends on the type of job you do.
- Please ask your surgeon if you are unsure. The ward clerk can give you a sick note for the time that you are in hospital. Your GP can then supply you with any further sick forms that you may need for your employer.

What are the potential risks of this operation?

There are potential complications from your bladder reconstruction, which your consultant will discuss with you in more detail before asking you to sign a consent form.

Possible early complications of a major operation

Problems that can occur while you are in hospital recovering are similar to those for any major operation. These include:

- a chest infection
- blood clots in your lower leg, which could pass to your lung
- wound infection
- bruising around your wound
- poor wound healing or weakness in the wound site
- bleeding and the need for a blood transfusion
- injury to nearby nerves or tissues.

Possible longer-term complications

- There is about a five per cent risk that the junction between your ureters (tubes from the kidneys) and your new bladder will narrow. You may need an operation to correct this if it interferes with the function of your kidneys.
- Urine leakage from your new bladder. This usually settles down as your bladder stretches, but in rare circumstances you may need further treatment for this.

- Very occasionally, stones may occur in your new bladder and you may need treatment to remove them.

Managing in the long-term

We have specially trained staff to help you make adjustments to your new lifestyle. They are there to offer support and someone to talk to. They are also there to help you to regain your independence.

Your follow-up appointment

Depending on your recovery time, we will see you two to three weeks after your surgery in the outpatient clinic for your first post-surgery check-up. About three months afterwards, we will ask you to come to this hospital for routine tests on your kidneys and urinary system. This will involve blood tests, x-rays and scans. Some of these tests will be repeated each year after your operation. You will also have regular blood tests as the minerals and salts in the blood can be affected by the changes in digestion and absorption that occur when bowel tissue has been used to form a bladder.

If you have any questions or concerns, please find below contact numbers for the Urology nurses:-

Urology Wards

Julia Simpson, Uro-oncology Specialist Nurse on:-
Tel. No:- 01633 – 238976 / 01873 – 732081

Sian Lewis, Uro-oncology Specialist Nurse on:-
Tel. No:- 01633 – 238976

Continence Nurse Advisors –

Paulette Hussein, Kath Connor Middleton or Coral Seymour:-
01633 - 234976

Further information

The following charities provide further written information and help lines for patients diagnosed with cancer.

Action on Bladder Cancer

Action on Bladder Cancer (ABC)

c/o ABC Secretariat

Right Angle Communications

Barley Mow Centre, 10 Barley Mow Passage, London W4 4PH

Tel: 020 3142 6491

www.actiononbladdercancer.org

Macmillan Cancer Support

89 Albert Embankment, London SE1 7UQ
Tel: 0808 808 0000 (Mon-Fri 0900-2000)
Web Address: www.macmillan.org.uk

Cancer Research UK

Angel Building, 407 St John Street, London EC1V 4AD
Tel: (Supporter Services) 0300 123 1861
(Switchboard) 020 7242 0200
Web Address: www.cancerresearchuk.org

St David's Foundation

Cambrian House, St John's Road, Newport NP19 8GR
Tel: 01633 270980
Email: enquiries@stdavidsfoundation.co.uk
Web Address: www.stdavidsfoundation.co.uk

Age Concern - Help and support for the over 60s

Age Cymru, Ty John Pathy, 13/14 Neptune Court, Vanguard Way, Cardiff CF 24 5PJ
Tel: 02920-431555/0800 169 6565
Web address: www.ageuk.org.uk/cymru

Smoking Cessation Service

Tel: 0800 085 2219

**"This document is available in Welsh /
Mae'r ddogfen hon ar gael yn Gymraeg".**