

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

Your doctor has recommended removal of your bladder (cystectomy). During this operation, it may be possible for you to have a new bladder (neo-bladder) reconstructed using part of your bowel. 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), ovaries and part of the vagina in women.

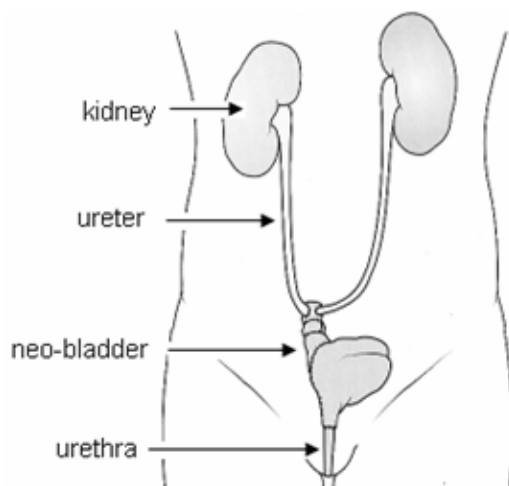
## What is a neo-bladder?

A neo-bladder is a replacement for your original bladder and is created from a section of your bowel and reconnected to your urethra (water pipe), with the aim of collecting 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 by avoiding the need for an external device to collect your urine 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, or if cancer extends to the water pipe. Surgeons will only go ahead with the procedure if there is no evidence of cancer on tissue examination during the operation.

## What happens during a bladder reconstruction?



Orthotopic or neo-bladder.  
Source Christie Hospital.

This operation can be carried out in several ways. The different types of reconstruction are usually named after the surgeon who developed them.

At Guy's Hospital, patients usually have a Studer pouch reconstruction. This involves using a section of the small bowel between 45 and 60cm long. This piece of bowel is 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 four 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 will be used to collect urine.

If you have a stoma, the tubes connecting your kidneys and bladder (the ureters), are disconnected from your bladder. They are then connected to a 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.

## **Limitations of surgery**

Sometimes during the surgery, it may not be possible to create a neo-bladder because of the length of your bowel or urethra. 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
- sexual function
- 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 sensation of fullness in the abdomen; others say that it feels a bit like having 'wind'. If you are unsure about when your bladder is full, keep an eye on the time and empty your bladder at regular intervals of three to four hours.

Many people who have had this operation will need to relax their pelvis 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 or twice to empty your new bladder before it becomes full, using an alarm clock to wake yourself up. 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 when you come into hospital for your surgery. For more information, please ask for a copy of our leaflet called Pelvic floor exercises for men/women.

We will need to teach you how to pass a catheter into your new bladder before your surgery. This is 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 including keeping a diary of your urine output for the first couple of months to work out what is going to be best for you as all patient outcomes are individual. However, approximately 30–40 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 pharmacy 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 to bulk up your stool. This can be discussed with you in more detail if it applies to you.

These are all major changes for you. It is important to us that you are able to return to as active a lifestyle as possible after this operation. This depends on how you feel mentally as well as physically. There are people you can talk to at the hospital. Some patients who have had this type of surgery are also willing to answer questions that you might have. Please ask your doctor or nurse specialist for more details. Alternatively, there is a **Bladder Cancer Support Group** held every month where you can meet other people with bladder cancer. Ask the nurse specialist for details.

## **Asking for your consent**

We want to involve you in all the decisions about your care and treatment. If you decide to go ahead with the surgery, you will be asked to sign a consent form that says you have agreed to the treatment and that you understand the benefits, risks and alternatives. If there is anything you don't understand or you need more time to think about it, please tell the staff caring for you.

Remember, it is your decision. You can change your mind at any time, even if you have signed the consent form. Let staff know immediately if you change your mind. Your wishes will be respected at all times. If you would like to read our consent policy, please tell a member of staff.

## **Pre-operative preparation**

You will have a pre-operative assessment **or** an appointment with the Proactive Care of Older People Undergoing Surgery (POPS) team before your surgery. It is important that you come to this appointment, as this is when we will assess your suitability for surgery and the anaesthetic. We will also make sure you have had the relevant tests and examinations. If you do not come to this appointment, we may have to cancel your surgery.

If you take any medicines that thin your blood, such as aspirin, warfarin, clopidogrel or rivaroxaban please tell your doctor or the nurse in pre-assessment/POPS. They will give you special instructions. If you take high doses of these medicines, you may need to come into hospital earlier. This will be arranged at your pre-admission clinic appointment if it is needed.

**Please continue to take all your medicines unless you are told otherwise and remember to bring them into hospital with you.**

The urology department currently runs an Enhanced Recovery Programme (ERP) for patients undergoing cystectomy and neo-bladder construction. This programme aims to help you recover from your surgery and regain your independence as quickly as possible. There is researched evidence that eating, drinking, moving around soon after your operation and having good control of your pain helps with, and speeds up, your recovery. Therefore, the programme emphasises these aspects of your recovery and focuses on how you can help yourself after your surgery. Please ask staff for more details.

As part of the ERP you will also come to a pre-cystectomy preparation clinic where you will meet one of the Clinical Nurse Specialists (CNS) for bladder cancer, the stoma nurse, the dietician and the physiotherapist.

The Specialist nurse for bladder cancer will prepare you for your surgery and your hospital stay, answering any questions you may have and talk you through the ERP pathway.

The dietician will give you instructions on what you are allowed to eat and drink prior to your admission for surgery. He/she will also give you some nutritional supplement drinks to have at home prior to your admission and morning of surgery.

The physiotherapist will focus on two elements. The first will be your physical function before your operation and the second will be what to expect physically after it. He or she will provide you with advice on your physical preparation for surgery as well as their role in helping your recovery after your surgery. They will also discuss what is available after your surgery to help in your recovery.

The stoma nurse specialist will help prepare you for the formation of your urostomy/stoma if the surgeon is unable to create a new bladder. She will also make a mark on your tummy to help guide the surgeon as to the most suitable place for your stoma if one needs to be sited. This is usually away from skin creases when you sit, away from previous operation scars and somewhere that you can see easily. She will answer any questions you have regarding the stoma and stoma care and will provide you with some written information.

If you smoke, you should try to stop smoking, as this increases the risk of developing a chest infection or deep vein thrombosis (DVT), explained in the risks section. Smoking can also delay wound healing. For help giving up smoking, please speak to your nurse, or call the Trust stop smoking service on 020 7188 0995 or the NHS Smoking Helpline on **0800 169 0169**.

## **Coming to hospital**

Generally, you will come into hospital on the day of your operation and will be admitted via the Surgical Admissions Lounge (SAL). On admission you will be asked for a urine sample. Some patients will need to be admitted via a ward the day before. We will let you know if this is the case for you. You should expect to stay for about seven to 10 days after your surgery.

### **The day before the operation**

- **Drink 2 fortisip compact and 2 fortijuice the day before. A low fibre diet until 6 hours pre-surgery. The dietician will give you these drinks in your preassessment appointment and information on a low fibre diet.**

### **On the day of your surgery**

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

- **2 pre-op drinks 2 hours prior to surgery.**
- **Nil by mouth after**

## After your operation

After you come out of theatre, we will transfer you to the critical care unit where you will stay overnight for close monitoring. You will return to the ward the following day. Staying in the critical care unit will allow 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 pain relieving 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. Please tell the staff looking after you if you are still in pain or discomfort.

You will also have:

- two small tubes called stents that aid the urine draining from your kidney through the ureters into a stoma bag attached to your abdomen for approx. 8 days.
- a fine plastic tube inserted through your nose into your stomach to stop you from being sick. This tube is usually removed a day or two after your operation
- a catheter in your new bladder. This will drain your urine, so that the new bladder does not fill until it has had time to heal. It will be removed about four weeks after your surgery
- sometimes the surgeon will also place a catheter into your new bladder through your tummy. This is called a suprapubic catheter. This allows the new bladder to heal with another entry for draining urine and flushing the mucus if necessary. This will usually be removed within two weeks
- 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.

## Your recovery

After your surgery the urethral catheter (tube from your new bladder draining urine) will be flushed six hourly with 30–50mls of saline to help clear your new bladder of mucus, which is produced by the bowel. You will be taught how to do this yourself whilst you are in hospital as you will need to flush the urethral catheter when you are discharged home. This is essential as you go home with the catheter in and it is important the catheter does not become blocked. Your new bladder will take around four weeks to heal. During this time the catheter will remain in place to drain away your urine. We will arrange a discharge date for when you feel confident you will be able to cope by yourself. This is usually two weeks after your surgery. A cystogram will be arranged three to four weeks after the surgery. The cystogram is to make ensure that there are no leaks in your new bladder.

The urine is absorbed by the new bladder (bowel). To neutralise this process you will need to take a sodium bicarbonate supplement for six weeks after the ureteric stents are removed. Your doctor will explain when, how much and how often you need to take this. Regular blood tests will enable us to ensure that everything is within the normal range and your new bladder is working well.

### **Before you leave hospital**

- the ward nurses will arrange for a district nurse to visit you while you are recovering
- we will give you a letter for your GP and a week's supply of any medication that you have been prescribed
- we will give you a date for a cystogram.
- We will also arrange for you to go home with 28 days of medicine (injections) to prevent blood clots. You will be taught how to self administer these or the District Nurse will do it for you.

### **Having a cystogram**

About three or four weeks after your surgery you will come to the diagnostic radiology department for a test called a cystogram. This test involves inserting dye into the catheter in your bladder, to check there are no leaks from your new bladder.

Once the test confirms this, your catheter will be removed. This usually takes place in the urology outpatient centre. Immediately after the catheter is removed you will find you need to empty your bladder very frequently, as mentioned in passing urine section, but this will improve with pelvic floor exercises. You will be given voiding instructions from your specialist nurse.

### **Getting back to normal**

Recovery time after abdominal surgery varies but generally, you should feel improvements after six to twelve 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 (between 1 in 10 and 1 in 50)**

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.

### **Specific risks for a cystectomy and neo-bladder formation include (between 1 in 10 and 1 in 50) :**

- Paralytic ileus – this is when the bowel stops working causing bloating and nausea/vomiting. You may need to have a tube inserted into your nose to your stomach to drain off any excess fluid.
- Leakage or narrowing of your intestine where the section of the bowel was removed causing obstruction which could require additional surgery.
- 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.
- Damage to your rectum requiring surgical repair and/or colostomy formation (additional temporary stoma for faeces).
- The operation may not remove all of your cancer (if this was the reason for your surgery).
- You may have recurrence of the cancer in your urethra.
- Your sexual function may be affected.
- There is a small risk of dying from this surgery (1–2 per cent).

## **Your follow-up appointment**

Depending on your recovery time, we will see you one to two 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. Regular blood tests are necessary 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.



This leaflet has been adapted, with permission from Christie Hospital's leaflet, 'Bladder reconstruction (neo-bladder) – information about your operation'.

## Further information

**Macmillan Cancer Support** provides information and support to anyone affected by cancer.

Tel: **0808 808 0000** or visit **[www.macmillan.org.uk](http://www.macmillan.org.uk)**

**Cancer Research UK** has a patient information website, with information on all types of cancer and treatment options. Visit **[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)**

## Contact us

If you want any further information or any help, do not hesitate to contact the urology department. Ring **020 7188 7636** to speak to the bladder cancer clinical nurse specialist, Monday to Friday, 9am to 5pm. Alternatively, ring switchboard on **020 7188 3026** and ask the operator to bleep **2840 or 1227**.

Out of hours call **Aston Key Ward** on **020 7188 8860** or **Florence Ward** on **020 7188 8818**.



**Dimbleby  
Cancer  
Care**

**Dimbleby Cancer Care** provides cancer support services for Guy's and St Thomas'. We have a drop-in information area staffed by specialist nurses and offer complementary therapies, psychological support and benefits advice for patients and carers.

Dimbleby Cancer Care is located in the Welcome Village of the Cancer Centre at Guy's. **t:** 020 7188 5918 **e:** [DimblebyCancerCare@gstt.nhs.uk](mailto:DimblebyCancerCare@gstt.nhs.uk)

## Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS) **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints) **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

**t:** 020 7188 8815 **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

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