

Information about

# **Cystectomy (Removal of Bladder)**

**and**

# **Orthoptic or Neo Bladder (Bladder Reconstruction)**





This booklet is for people who have been advised by their doctor that they need to have a cystectomy.

## What is a Cystectomy?

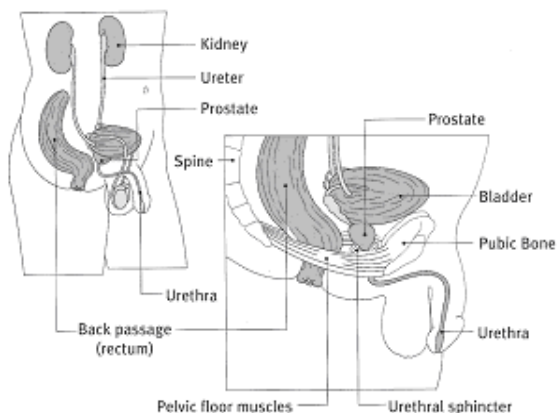
Cystectomy is sometimes referred to as a radical cystectomy, a cystoprostatectomy or a cystourethrectomy. Cystectomy is the medical term for the removal of the bladder.

### Males

In males, a cystectomy and a radical cystectomy involve the removal of the entire bladder and the prostate gland (see diagram below).

A cystourethrectomy involves the removal of the bladder, prostate and urethra (water pipe).

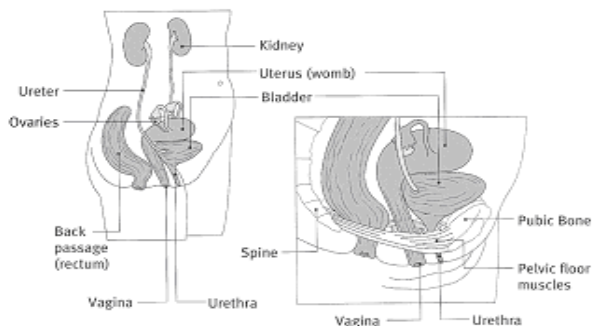
### Male Pelvis



### Females

In females, a cystectomy involves removal of the entire bladder and urethra (water pipe), the ovaries, uterus (womb) and the upper part of the vagina.

### Female Pelvis



## What is a Neo (new) Bladder?

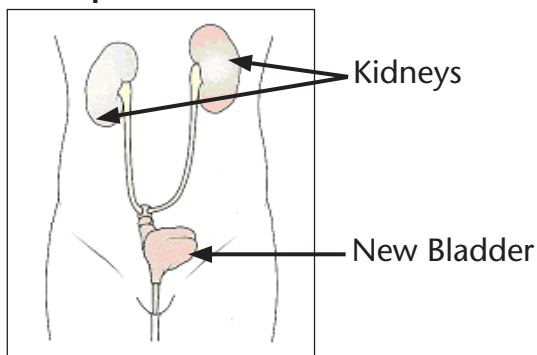
This booklet is for people who have been advised by their urologist that they need to have a cystectomy (removal of the bladder) and who may be suitable to have a new bladder reconstructed out of bowel tissue. The advantage of this operation is that, in the long term, you will not need to wear a bag on your abdomen to collect urine. Instead the neo (new) bladder is connected onto the urethra (the water pipe) and urine is passed naturally. Some people may need to use a small disposable catheter once or twice a day to empty the neo bladder.

The operation has several names.

This type of bladder reconstruction is sometimes called an Orthoptic Reconstruction or Neo bladder.

This operation is not possible for everyone who has a cystectomy, especially if you have previously had radiotherapy to the pelvis or if you have a history of bowel abnormalities.

### Orthoptic or Neo Bladder



## Consent

This booklet will give you information about the operation to remove your bladder and if suitable to reconstruct a new bladder.

Your surgeon will explain the operation and why you need it. The information in this booklet is to remind you of what your surgeon has explained. We advise you to read the booklet before you sign a consent form which states that you are prepared to go ahead with the operation.

## **What happens during the operation?**

The operation involves using a section of the small bowel between 45 – 60cms long. This piece of bowel is used to make the new reservoir (tank) that replaces the existing bladder. The tubes from the kidneys (the ureters) are implanted into this new reservoir or pouch which is then sewn onto the urethra (water pipe). A catheter is placed into the new bladder through the urethra and left in place for 4 weeks.

You will then be admitted later for the removal of the catheter. (The healing process usually takes about 3 to 4 weeks.)

## **How will this affect me?**

As we have described in the section above, the operation includes permanent changes to the body. These changes affect;

- urinary function
- sexual and reproductive function, and to some extent,
- bowel function.

## **Passing urine**

After the operation the kidneys will produce urine in the normal way, and the ureters (tubes from the kidneys) will drain urine into your new bladder.

The new bladder will store urine until you decide to empty it. The sensation of the bladder being full is different from the usual feeling. Some people say that they get a full sensation in the abdomen, others say that it feels a bit like having “wind”. Another way of knowing when to empty the new bladder is by keeping an eye on the time and emptying the bladder at regular intervals (i.e. every 2-3 hours).

To pass urine, many people who have had this operation will need to relax their pelvis and use some abdominal pressure to prevent straining to empty the new bladder. Over time your new bladder will be able to increase what it can hold. After about 3 to 6 months, it should hold around a pint of urine (similar to a normal bladder capacity). At first you will need to empty your bladder every 1 to 3 hours.

At night we recommend that you get up at least once or twice to empty your new bladder before it is full. This is important, as bladder control may be difficult when you are asleep if the bladder is full. About 10% of people who have undergone this operation may have some leakage at night. As the new bladder stretches, and is able to hold more urine, you will not need to empty it as often.

Pelvic floor exercises are helpful to restore tone to the muscles in the pelvis. These muscles help you to control leakage. We will teach you these exercises when you are admitted to the hospital for your operation.

Occasionally you may need to pass a catheter into the new bladder after you have emptied it to ensure that there is no urine left behind. If a significant amount of urine is left behind in the bladder this could cause problems with the kidneys; infection and or difficulty in controlling leakage of urine from your neo bladder. To prevent this, we recommend that you use a special catheter twice a day to make sure the bladder is completely emptied. About 30% of patients having this type of operation will need to insert a catheter once or twice a day in the long term.

## **Sexual and Reproductive Function**

The aim of the operation is to remove the bladder and to remove all the bladder cancer cells. This means that tissues that touch or lie close to the bladder are removed at the time of the operation. These other organs and tissues affect sexual function.

### **In men**

The prostate, which sits directly below the bladder, is removed. The nerves that are responsible for obtaining an erection touch the prostate gland and are removed at the time of operation. It may be possible in some cases to preserve the nerves on one side of the prostate which would increase the chances of restoring potency (the ability to get an erection) by using tablets and or injections. This is usually discussed at follow up clinics.

## **In women**

There is a body of tissue between a small area of the bladder and vagina which has shared blood supply. This means that when this tissue is removed, a strip of the front wall of the vagina is removed along with the uterus (womb). This result is that there may be some shortening of the vagina, and full intercourse may not be possible in some patients. You should wait for several weeks after your operation before attempting intercourse and we advise you to use a lubricant such as KY jelly.

## **Bowel function**

Following this operation some people notice a change in bowel habit. You may go to the toilet more often or notice that you are more “loose” than you were before. This is due to the effect of shortening the bowel when a section is removed to make the new bladder.

## **Admission to Hospital**

### **Pre-assessment**

- You will attend a pre-assessment appointment approximately 1-2 weeks before you are admitted to hospital.
- A nurse will see you and will ask you questions about your general health and past medical history including your current medications.
- You will have a blood test and it is likely that you will be sent for an E.C.G. (tracing of your heart).
- A doctor will examine you.
- You may also see the anaesthetist (the doctor who will put you to sleep for your operation.)
- The Urology Nurse Specialist may teach you how to pass a catheter into your bladder.
- You will also meet the Stoma nurse who would look after you

while in hospital in the event that it has not been possible to reconstruct a new bladder during your operation.

## **Day of Admission**

- You will come into hospital 2 days before your operation. (You can expect to be in hospital for a stay of 2 to 4 weeks). This is so we can start some preparation to clean out your bowel for your operation.
- On your admission day, we will admit you to a ward where you will meet the nursing and medical staff who will be looking after you. There will also be the opportunity to see your Consultant and to ask any further questions before the operation. If you did not see the anaesthetist at your pre-assessment appointment then you will see them too.
- On day one-you will be allowed a low residue diet (the nursing staff will advise you what you can and cannot eat).
- Day two – you will only be allowed fluids. This is part of the bowel preparation. The nursing staff will give you some medicine that causes diarrhoea; this clears the bowel in preparation for your operation.

## **The Day of the Operation**

- You will not have anything to eat or drink for 4-6 hours before your operation, as directed by your anaesthetist.
- We will advise you which prescription medications you can take. The nursing staff will also give you some tablets as part of the preparation for your anaesthetic: known as “the pre med”.

## **After your Operation**

- After you come out of theatre, we will transfer you to the recovery area for an hour or two until we move you to the High Dependency Unit (HDU). Your stay in the HDU will probably last for 24 to 48 hours until you are ready to return



to the main ward. The purpose of your stay in the HDU is to monitor your blood pressure, heart rate and fluid levels using accurate equipment.

- To reduce the pain in your abdomen (stomach) after the operation, we will give you pain killers. The anaesthetist will discuss the options with you.

Either:

- a Patient Controlled Analgesia (PCA) device that you control, that releases pain killers into your blood stream via a pump or
- an epidural from which pain killers and local anaesthetic are given directly into the spinal nerve system. This involves inserting a very fine plastic tube into your back through which these drugs are given.
- You will have a fine plastic tube inserted through your nose into the stomach to stop you from being sick. This tube is usually removed a day or two after your operation.
- Immediately after your operation, you will have a catheter into your new bladder. The catheter is put there to drain urine, so that the new bladder does not fill until it has had time to heal.
- After about two days the need for these types of pain killers is greatly reduced, and you will be able to have the epidural or drip line removed. We will then give you pain killing tablets or injections instead. Please tell the staff looking after you if you are still in pain or discomfort.
- You will have a drip running into a vein in your neck to give you fluids until you are able to drink normally (about 3 to 4 days after the operation). When you are able to drink you will then be allowed to start to eat again (about 4 to 6 days after your operation).

## **The Recovery Period**

The nursing staff will help you get out of bed on the first or second day after your operation and help you to start walking soon after this. Usually, people are up and about independently about 4 to 5 days after your operation. You will have regular visits from the Physiotherapist who will encourage you and give you some simple exercises.

The nurses on the ward will use the catheter to wash out your new bladder once or twice a day following your operation. The washout is done to help clear the bladder of mucus that is produced by the bowel tissue that the bladder is made from. When you are feeling well enough they will begin to teach you how to do this. This is essential, as you may go home with the catheter in and it is important that the catheter does not become blocked.

## **Preparation for Home**

- When you are eating and drinking and the various drain tubes have been removed, you can take care of yourself including managing your bladder washouts. We will arrange a discharge date when you feel confident to cope at home.
- The ward staff will give you a supply of syringes for the bladder washouts to take home. These should last you until the district nurses or GP give you some more.
- We will arrange for a district nurse to visit you at home whilst you are recovering.
- We will give you a letter for your GP and you should have a week's supply of any medication that you have been prescribed.
- We will give you a date for readmission for a cystogram to check your bladder function and for removal of the catheter.

## **The Cystogram**

The new bladder takes around 4 weeks to heal, during which time you will have a catheter in the bladder to drain the urine.

Usually you will come back into hospital about 2 - 4 weeks after your operation to have your catheter removed. You will come to the Diagnostic Radiology department for a test called a "cystogram". This test involves putting dye into the catheter and taking an x-ray, to make sure that there are no leaks from the neo bladder. Once the test confirms this you will have your catheter removed on the ward.

You will normally be in hospital for about 24 hours after removal of the catheter until you get used to emptying your new bladder.

Immediately after the catheter is removed you will find the need to empty your bladder very often, but in the following days and weeks, as the bladder stretches and its capacity increases, you should be able to manage 2 to 3 hours in between emptying your bladder.

At this time it is important to be doing the pelvic floor exercises as directed later in this booklet.

## **Stopping Smoking**

If you are a smoker and continue to smoke, this will increase the chance of the operation being unsuccessful. It also increases the risk of serious side effects as well as the risk of further cancers. We strongly advise you to give up smoking. Please ask to speak to the Smoking Cessation Nurse.

## **Possible Risks**

Your consultant will have discussed the potential complications of having a major operation with you, but specific complications from this type of operation are:

- there is about a 5% risk of narrowing at the junction of the ureters (tubes from the kidneys) and the new bladder. This may be due to long term healing processes. An operation may be needed to correct this if it is interfering with the function of your kidney.
- urine leakage from the new bladder usually settles down as

the bladder stretches, but in rare circumstances, further treatment may be needed.

- very occasionally, stones may occur in the new bladder which may need treatment to remove them.

## **Managing in the Long Term**

After bladder reconstruction there are major changes for you. It is important to us too that you should be 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 for you to talk to at the hospital and there is a network of patients who have had this type of operation who are willing to answer questions that you might have. Ask your doctor or nurse for more details.

If you need to use a catheter to 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 when done under clean conditions and can be carried out at home, work or wherever with a minimum of fuss. You can get catheters on prescription that can either be collected from the local chemist or delivered to your home.

## **Getting Back to Normal**

- Recovery time after bladder reconstruction varies, but generally you should feel improvements from between 6-12 weeks.
- During the first 6 weeks you should not attempt to drive a car.
- During this time you should not attempt to lift or move heavy objects, start digging the garden or do housework.
- Getting back to work will depend 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 you are in hospital. Your GP can then supply you with any further sick notes.

## **What are the benefits of this operation?**

The operation is part of your treatment to remove your bladder

cancer. By having a bladder reconstruction you will not need to wear an external appliance (bag) to collect the urine that your kidneys make.

## **Improving your continence with pelvic floor exercises**

Pelvic floor exercises can help you regain control of your bladder. These exercises work by strengthening the muscles that control peeing. This can mean re-strengthening weakened muscles or training surviving muscles to deal with what was once dealt with by two muscles. Pelvic floor exercises are also called Kegal exercises, after their inventor.

**Pelvic floor exercises can help prevent future incontinence.**

**Pelvic floor exercises should not be practised if you have a catheter in place.**

## **Finding the correct muscles**

Sit or lie down. Relax your thighs, buttocks and stomach. Tense your muscles as if you are trying to stop peeing or passing wind. You should feel a lifting sensation inside and a tightening of the muscles around your back passage. You should not be tensing your thighs, buttocks or stomach. You can also learn what tensing the correct muscles feels like by stopping and starting your stream whilst peeing. Don't do this regularly though, only to find the muscles.

## **The exercises**

Once you have found the correct muscles, and know what it feels like when you tense them, try the following exercises.

- Tense the muscles so you feel a lifting sensation. Hold this lift for as long as you can up to 10 seconds. Don't hold your breath whilst doing this. Relax. You should have a definite feeling of letting go.
- Wait 10-20 seconds then repeat the 'lift'. You should aim to lift then relax 12 times.

- Do 5-10 short fast lifts.
- You should try to spend 5-10 minutes each day on this exercise routine.

As you get better at the exercises, you should try to increase the time you hold the contractions. Try to see how many you can do before your muscles start to feel tired. Also, increase the number of short, fast lifts you do.

Regular training of these muscles for 4-6 months will improve the control you have over peeing. If you suffer from stress incontinence, remember to contract the muscles before you sneeze, cough or try to lift anything.

## **Follow up after Cystectomy and bladder reconstruction**

We will see you approximately six weeks after your operation in the outpatient clinic for your first post operative 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 every 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.

## **Contacting the hospital**

If you have any worries or would like advice you can contact:

Sister Fiona Muirhead	Glasgow Royal Infirmary and Gartnavel Hospital 0141 211 5714
Sister Gail Brown	Southern General 0141 232 7950
Sister Jacqueline Campbell	Stobhill 0141 355 1257

## **Benefits and Financial Information**

You may be entitled to benefits while you are recovering and unable to work. You can find out benefit advice from;

Maggie's Centre (benefit office) - 0141 330 3311

Beatson Macmillan benefit office - 0141 301 7374

Glasgow Macmillan benefits team - 0141 420 8045

Dumbarton team - 01389 737 050

## **Support Organisations**

### **Maggies CentreThe Gatehouse**

Western Infirmary

10 Dumbarton Road

Glasgow

G11 6PA

Tel: 0141 330 3311

Fax: 0141 330 3363

Email: [glasgow@maggiescentres.org](mailto:glasgow@maggiescentres.org)

A Maggie's Centre is a place to turn to for help with any of the problems, small or large, associated with cancer.

Under one roof you can access help with information, benefits advice, psychological support both individually and in groups, courses and stress reducing strategies. You don't have to make an appointment, or be referred and everything we offer is free of charge.

### **Tak Tent Cancer Support Scotland**

Flat 5, 30 Shelley Court,

Gartnavel Complex

Glasgow G12 0YN

Phone: 0141 211 0122

Fax: 0141 211 0010

Email: [tak.tent@care4free.net](mailto:tak.tent@care4free.net)

Tak Tent promotes the care of people on the cancer journey, their families and friends by providing emotional support to all.

## **Macmillan Cancerbackup Scotland**

Suite 2

Third Floor

Cranston House

104/114 Argyle Street

Glasgow, G2 8BH

Tel (helpline): 0808 800 1234

Tel (admin): 0141 223 7676

Fax: 0141 248 8422

Web: <http://www.cancerbackup.org.uk/Resourcessupport/Cancerbackupsservices/CancerbackupScotland>

Best time to telephone: 9am - 8pm, Monday - Friday

## **The Urostomy Association**

Central Office

18 Foxglove Avenue

Uttoxeter

Staffs

ST14 8UN

Tel: 08452 412 159 or 01889 563191

Web: [www.uagbi.org](http://www.uagbi.org)

**This leaflet was adapted from The Christies Hospital NHS Manchester.**



## Notes





