

Department of surgery

# Cystectomy for patients who are born male

Your doctor has recommended a cystectomy as treatment for your condition. This information describes:

- what a cystectomy involves
- what happens during the operation
- possible side effects
- aftercare.

## What is a cystectomy?

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

A cystectomy and a radical cystectomy involve the removal of the entire bladder and the prostate gland (see diagram on page 2). A cystourethrectomy involves the removal of the bladder, prostate and urethra (water pipe).

## Agreeing to treatment

This information has been written to explain more about the operation to remove the bladder as a treatment for bladder cancer.

### Consent

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had The Christie's written description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you. Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

## What are the benefits of the operation?

The operation to remove your bladder is intended to get rid of all the cancer cells that are there and so to reduce the chance of cancer coming back.



## What are the risks of the operation?

There are risks that are common to all types of major surgery. We take precautions but there is a possibility of:

- infection in the wound
- bleeding from the wound
- blood clots in the legs (DVT or deep vein thrombosis) or lungs (PE or pulmonary embolus)
- heart irregularities because of the anaesthetic or operation
- chest infection
- bleeding and the need for a blood transfusion
- poor wound healing or weakness in the wound site
- injury to nearby nerves or tissues

## Long term risks

There is about a 1 in 20 risk of narrowing at the junction of the ureters (tubes from the kidneys). This may be due to long term healing processes and scarring. If it is interfering with the function of your kidneys you may need an operation to correct this.

## Are there any alternatives to this operation?

There may be other ways of treating the cancer in your bladder such as chemotherapy (medicines) and radiotherapy (X-ray treatment). The specialist team at the hospital will have discussed this with you.

Chemotherapy is usually offered in addition to surgery or radiotherapy. It is not usually considered to be a cure for bladder cancer on its own.

## What will happen if I do not have this operation?

If you do not have treatment for the bladder cancer, the cancer will continue to grow inside the bladder and some cancer cells may spread to other parts of the body making any further treatment unlikely to cure the cancer.

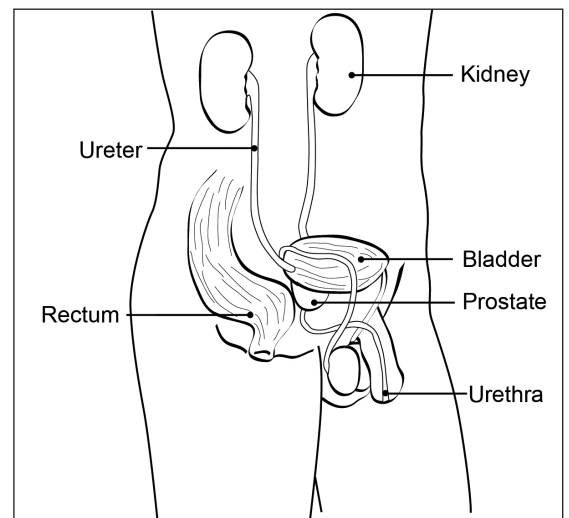
## What exactly is done at the operation?

There are some variations in what has to be removed during a cystectomy operation. Usually the surgeon takes out the bladder, the prostate (the gland that produces a fluid which forms part of the semen) and the seminal vesicles (where the semen is stored).

In some cases, the surgeon will also remove the urethra (the tube that urine passes down from the bladder through the penis).

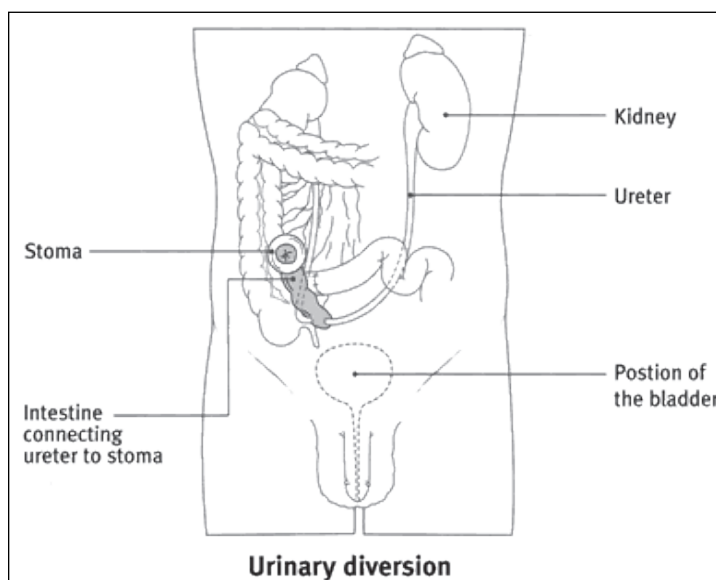
Internal lymph glands that lie inside the pelvis are usually removed at the time of operation. Lymph glands are part of the body's immune system which can collect infected cells or cancer cells that have broken away from the main tumour.

It is important that your surgeon discusses the exact nature of the operation with you and that you feel that you understand what is going to happen during the operation before it is carried out.



## How will I pass urine after the operation?

During the operation the surgeon carries out a procedure called a 'urinary diversion'. The tubes that connect the kidneys to the bladder (the ureters) are disconnected from the bladder. The ureters are then joined to one end of a segment of bowel that is isolated from the rest of the intestine. This is then brought to the skin surface, usually on the right hand side of the abdomen. The end of the bowel that opens on to the abdomen is known as a stoma, or a urostomy. Your urine then empties through this stoma into a small bag. See diagram.



## How else will my body be affected?

The organs, nerves and blood supply are close together in the pelvis. When major surgery is carried out, such as a cystectomy operation, the nerves that supply the penis are affected. This means that the ability to obtain an erection is lost. This effect is usually permanent in most patients.

Treatment to restore erections using tablets and/or injections is helpful for some patients, but not all. If you would like further information, it would be advisable to discuss this specifically with the medical and nursing team looking after you before you are admitted for your surgery.

Having a cystectomy involves surgery to the bowel as well as the bladder. A small portion of the bowel is used to make the urostomy, so the bowel that is left for digestion and absorption of food products is shorter. This means that for some people their motions become looser after this type of surgery.

There are obviously major changes for you that happen after a cystectomy and 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 surgery done who are willing to answer questions that you might have. Ask your doctor or nurse for more details.

## Admission to hospital for your operation

### Day of admission

You will come into hospital the day before your operation for a stay of approximately 10 to 14 days. For some patients, this stay can be longer.

On your admission day, we will allocate you to a ward where you will meet the nursing and medical staff who will be looking after you. There will also be an opportunity to meet the anaesthetist and physiotherapist who will take part in your care.

After admission, the ward staff will ask you not to have anything more to eat until after the operation. However, we will encourage you to drink plenty of fluids. This is part of the bowel preparation. Nursing staff will give you some medicine that will clear your bowels in preparation for your surgery.

A stoma nurse will teach you how to look after your urostomy. They will visit you and put a mark on your abdomen where your urostomy will be sited. It is important to do this with you while you are awake to ensure that it goes in the most suitable place. This will be away from any skin creases when you sit up, away from any previous operation scars and somewhere that you can see easily.

### The day of the operation

You will be given fasting instructions before your admission explaining when you must stop eating and drinking. You may still need to take some of your regular medications on the morning of your surgery. You will be advised by the pre-operative nurse or the anaesthetist exactly what to take. We may also give you some tablets as part of the preparation for your anaesthetic; the 'pre med'.

## After your operation

After you come out of theatre, staff will transfer you to the recovery area in theatre for an hour or 2 until you are moved to the oncology critical care unit (OCCU). The purpose of your stay in the OCCU is to monitor your blood pressure, heart rate and fluid levels. You will stay in the OCCU for approximately 1 to 2 days until you are ready to return to the main ward.

To reduce the pain in your abdomen after the operation ward staff will give you painkillers. The anaesthetist will discuss the options with you. These are either:

- an epidural by which painkillers 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, or
- a painkiller device that you control, that releases painkillers into your blood stream via a drip (patient controlled analgesia).

After about 2 days, the need for these types of painkillers is greatly reduced and you will be able to have the painkilling devices removed. The ward staff will then give you painkilling tablets or injections instead. Please tell the staff looking after you if you are still in pain or discomfort so we can alter the medications to make you more comfortable.

- 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 surgery).
- 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 2 after your operation.
- As well as a dressing over your wound on your abdomen you will have a stoma bag, collecting urine from the new urostomy. You will notice thin tubes coming out of the urostomy. These are called stents. They will be removed 7 to 10 days after your operation. There will also be a small plastic drain tube from your abdomen that will stay in place for about 5 to 7 days.

## 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 surgery.

## Preparation for home

When you are eating and drinking and the various drain tubes have been removed you will be taking part in caring for your urostomy. We will arrange a date for your discharge home when you feel that you are able to look after the urostomy yourself.

The stoma nurse will ensure that you have everything that you need for your urostomy when you get home and will explain how to obtain further supplies. The ward nurses will arrange for a district nurse to visit you at home while you are recovering.

We will give you a letter for your GP and you will have a week's supply of any medication that you have been prescribed. An outpatient's appointment will normally be made for you 6 weeks after your discharge home.

## Getting back to normal

Recovery time after abdominal surgery varies but generally you should feel improvements from between 6 to 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 that you are in hospital. Your GP can then supply you with any further sick notes.

## Stopping smoking

If you continue to smoke, this will reduce the chance of the treatment being successful. It also increases the risk of serious late side effects as well as the risk of further cancers. We strongly advise you not to smoke. There is a free smoking cessation service at The Christie available to patients and carers. Please call **0161 956 1215** or **07392 278408**. You can also contact the Smokefree National Helpline free on **0300 123 1044**.

## Follow up after a cystectomy

We will see you 6 weeks after surgery in the outpatient clinic.

About 3 months after the surgery, 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.

## Benefits and financial information

You may have had to stop work and had a reduction in your income. You may be able to get benefits or other financial help.

Personal Independence Payment (PIP) is a social security benefit and has replaced Disability Living Allowance (DLA) for new claimants. It's for people who need help either because of their disability or their illness. You can apply if you are aged 16 or over and have not reached State Pension age. You can apply for DLA if you are under 16.

Find out more today:

- to get a claim pack for Attendance Allowance, call **0800 731 0122** and for PIP call **0800 917 2222**.
- Carer's Allowance: call **0345 608 4321**.
- for benefits advice, contact Maggie's centre on **0161 641 4848** or email [manchester@maggies.org](mailto:manchester@maggies.org)
- The Christie at Oldham has a benefits advice session on Thursday afternoons, call **0161 918 7745**.
- contact your local social services department for help with equipment and adaptations, or for an assessment of care needs. Visit [www.gov.uk](http://www.gov.uk) for further information.
- Macmillan Cancer Support can give advice on helping with the cost of cancer, call **0808 808 00 00** or visit [www.macmillan.org.uk](http://www.macmillan.org.uk)

## Prescriptions

NHS patients being treated for cancer are entitled to free prescriptions. Prescriptions from The Christie pharmacy are free for NHS patients. You will need an exemption certificate to get free prescriptions from a community pharmacy. Exemption certificates are available from your GP or pharmacy.

## Contacting The Christie

For health queries about your operation:

Your nurse specialist is .....

Phone .....

For urgent support and specialist advice out of hours, contact The Christie Hotline on **0161 446 3658** (24 hours a day, 7 days a week).

## Further information

### Christie information

The Christie produces a range of patient information booklets and leaflets. You can find a large selection of these, along with other information, at The Christie cancer information centre and on The Christie website. The service is open Monday to Friday, 9am to 4pm (excluding bank holidays).

Telephone: **0161 446 8439**

Email: **[the-christie.informationcentre@nhs.net](mailto:the-christie.informationcentre@nhs.net)**

### Macmillan Cancer Support

Cancer information nurse specialists can answer questions about cancer, treatments and what to expect. Information about living with cancer, practical support as well as benefits advice is also available. Interpreters are available for non-English speakers. Tel: **0808 808 0000** (7 days a week, 8am to 8pm) or visit **[www.macmillan.org.uk](http://www.macmillan.org.uk)**

### Cancer Research UK

For information about cancer treatment and support in other languages. Freephone: **0808 800 4040**. You can speak to an information nurse via an interpreter.

### Maggie's centres

The centres provide a full programme of practical and emotional support including psychological support, benefits advice, nutrition and headcare workshops, relaxation and stress management.

#### Maggie's Manchester

Tel: **0161 641 4848** or email **[manchester@maggies.org](mailto:manchester@maggies.org)**

#### Maggie's Oldham

Tel: **0161 989 0550** or email **[oldham@maggies.org](mailto:oldham@maggies.org)**

### Fight Bladder Cancer

A bladder cancer charity founded and run by bladder cancer survivors and their families.

Tel: **01844 351621** Website: **[www.fightbladdercancer.co.uk](http://www.fightbladdercancer.co.uk)**

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard. If you would like to have details about the sources used please contact **[the-christie.patient.information@nhs.net](mailto:the-christie.patient.information@nhs.net)**

For information and advice visit the cancer information centres at Withington, Oldham, Salford or Macclesfield. Opening times can vary, please check before making a special journey.



Contact The Christie Hotline for  
urgent support and specialist advice  
**The Christie Hotline: 0161 446 3658**  
Open 24 hours a day, 7 days a week