

Department of surgery

Cystectomy for women

Introduction

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, anterior pelvic clearance or a cystourethrectomy.

Agreeing to treatment

Consent

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

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 Your consent may be withdrawn at any time before or during this treatment.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 or chest
- 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
- 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 with 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.

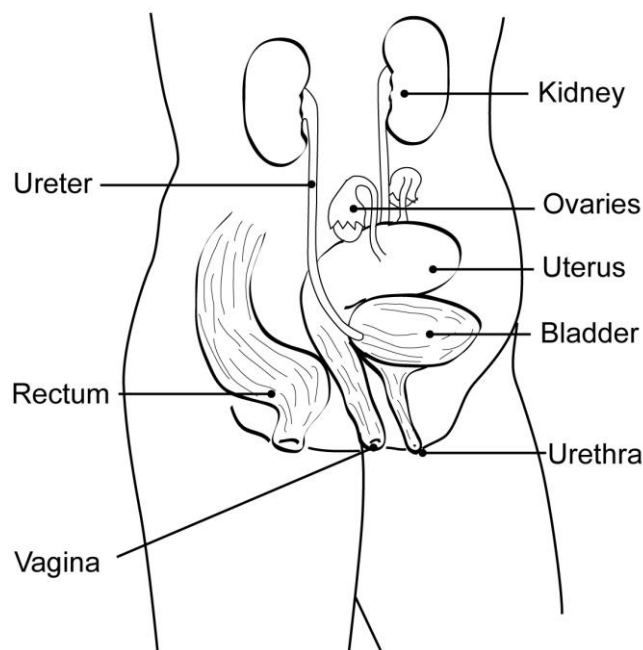
What will happen if I do not have this operation?

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?

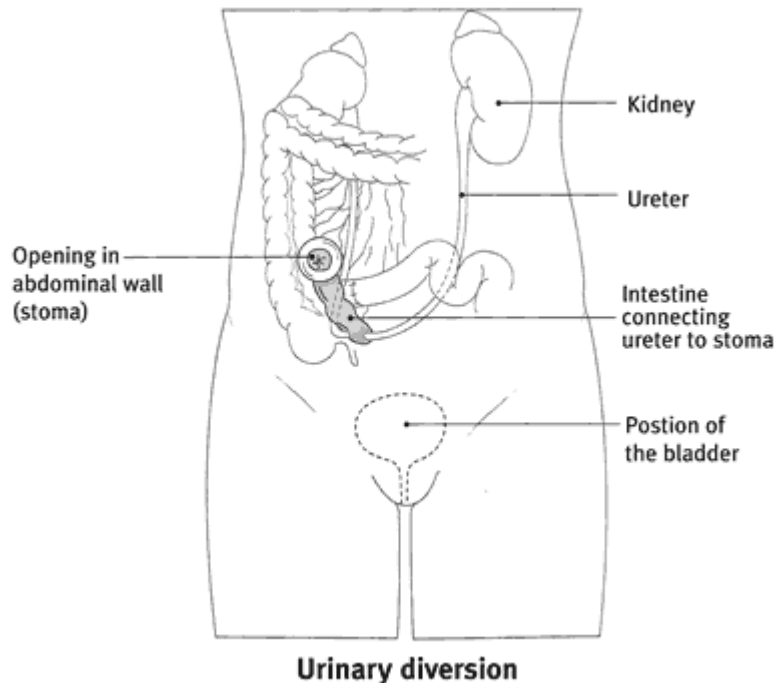
There are some variations in what has to be removed during a cystectomy operation. In women, the operation is usually referred to as an anterior pelvic clearance. This term means removal of the bladder and urethra (water passage), the ovaries, uterus (womb) and the upper part of the vagina (see diagram). 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 below).



How else will my body be affected?

This type of surgery will affect the female organs and sexual function.

The surgeon removes the front wall of the vagina in the operation and this leads to shortening of the vagina. In some cases, the remaining length of the vagina is very small which may mean that penetrative sexual intercourse is no longer possible. Rarely, the entire vagina is removed.

The ovaries are usually removed with the uterus (womb). The ovaries may be left in place in women who have not gone through the menopause - either naturally or following previous treatment to the pelvis such as radiotherapy. It is important to discuss with your surgeon exactly what is going to happen during your operation so that you can prepare for the recovery period.

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 about 14 days. For some women, 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 maintain a high fluid intake. 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 surgery.
- A stoma nurse will teach you how to look after your urostomy. She will visit you and put a mark on your abdomen where your urostomy will be sited. It is important to do this with you whilst 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

Before you go to theatre you will have nothing by mouth for 4 to 6 hours before the operation, apart from any prescription medicines you may be taking. The anaesthetist will discuss exactly which tablets you will be able 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 two until you are moved to the Oncology Critical Care Unit (OCCU). Your stay in the OCCU will probably last for 48 hours until you are ready to return to the main ward. The purpose of your stay in the OCCU is to monitor your blood pressure, heart rate and fluid levels.

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 two 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 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 your stomach to stop you from being sick. This tube is usually removed a day or two after your operation.
- As well as a dressing over the 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 in 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. Please ring **0161 446 8236**. You can also contact Smokefree national helpline on **0300 123 1044**.

Follow up after a cystectomy

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

About three 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 16-64.

People aged 65 or over who need help with personal care or supervision could be entitled to Attendance Allowance.

Your carer could get Carer's Allowance if you have substantial caring needs. Find out more today:

- To get a claim pack for Attendance Allowance, call **0345 605 6055** and for PIP call **0800 917 2222**.
- For DLA: If you were born on or before 8 April 1948 call **0345 605 6055**, if you were born after 8 April 1948 call **0345 712 3456**.
- Carer's Allowance: call **0345 608 4321**.
- For benefits advice, contact Maggie's centre on **0161 641 4848** or email **manchester@maggiescentres.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** for further information.
- Macmillan Cancer Support can give advice on helping with the cost of cancer on **0808 808 00 00** or **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 the pharmacy at The Christie and your GP.

Contacting The Christie

For health queries about your operation phone:

Nurse Specialists:	Jane Booker	0161 446 8018
	Stephen Booth	0161 918 2369
	Sharon Capper	0161 446 3856
	Helen Johnson	0161 918 7000
	Cath Pettersen	0161 918 7328

Out of hours - 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

Further information

Macmillan Cancer Support

Macmillan Cancer Support is a national charity which runs a cancer information service. The cancer support service freephone number is **0808 808 00 00**. Calls are answered by specially trained cancer nurses who can give you information on all aspects of cancer and its treatment. Macmillan Cancer Support also publishes booklets which are free to patients, their families and carers.

Booklets on specific cancers, for example, bladder cancer and booklets on living with cancer - some of these are listed:

- Who can ever understand? - talking about your cancer
- Lost for words: how to talk to someone with cancer
- Talking to children when an adult has cancer
- Cancer and complementary therapies

The Cancer information centre has a full range of Macmillan Cancer Support booklets available free to patients and their relatives or carers.

Christie information

The Christie produces a range of patient information booklets. Some of these are listed below:

- Where to get help: services for people with cancer. This booklet discusses sources of help when you have cancer, where to go for financial help, palliative care and cancer support groups.
- Booklets on diet and nutrition:
 - Eating help yourself - gives advice on eating problems when you don't feel well and you are having treatment
 - Advice about soft and liquid foods
 - Nutritional products - availability of nutritional drinks, powders and puddings
 - Eating well with diabetes when you have a poor appetite

Booklets are free to patients coming to The Christie. If you would like a copy, please ask the ward staff. If you are an outpatient, please ask your nurse or doctor.

Large print versions of this information are available. Please contact patient information on **0161 918 7033**.

The Urostomy Association

For people who are about to undergo or who have undergone surgery which results in a urinary diversion or bladder reconstruction.

Telephone: **01889 563191**

Email: secretary.ua@classmail.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.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

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For more information about The Christie and our services, please visit **www.christie.nhs.uk** or visit the cancer information centres at Withington, Oldham or Salford.

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

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