

Department of surgery

Cystectomy for patients who are born female

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 or may be a component of a larger operation called an anterior pelvic clearance where additional structures are removed.

Agreeing to treatment

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Your consent may be withdrawn at any time before or during this treatment.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

Why have I been offered a cystectomy?

Your surgeon will talk to you in more detail about why you have been offered a cystectomy. Surgery may be recommended because:

- you have cancer in your bladder which would be best managed by complete removal of the bladder
- your bladder may be damaged from radiation treatment
- your bladder may be bleeding after chemotherapy or radiotherapy
- your bladder may be damaged or bleeding uncontrollably from other causes or treatments



Are there any alternatives?

Your doctor or nurse will explain the choices and alternatives to this treatment. These will depend on why you have been recommended a cystectomy but may include:

- having radiotherapy or chemotherapy if you have bladder cancer
- choosing not to have any treatment while recognising the risks of this

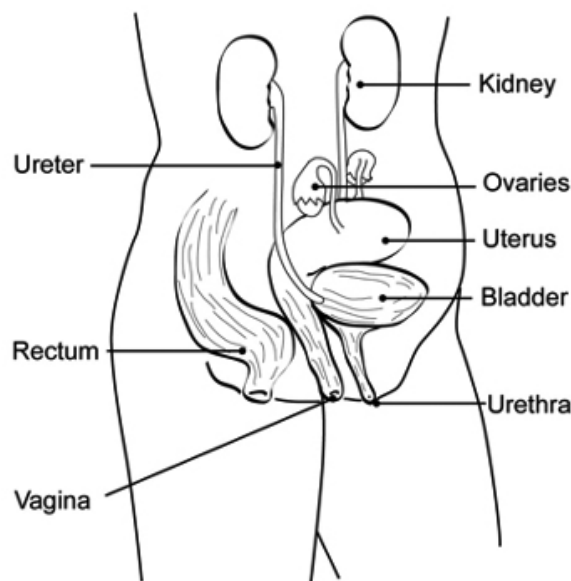
What exactly is done at the operation?

The type of cystectomy you will have will depend on your individual circumstances. Usually the surgeon will remove your bladder, urethra (tube that urine passes down from the bladder before leaving the body), ovaries, uterus (womb) and the upper part of your vagina.

Your surgeon will discuss the operation with you in more detail and explain exactly what will be removed during your surgery.

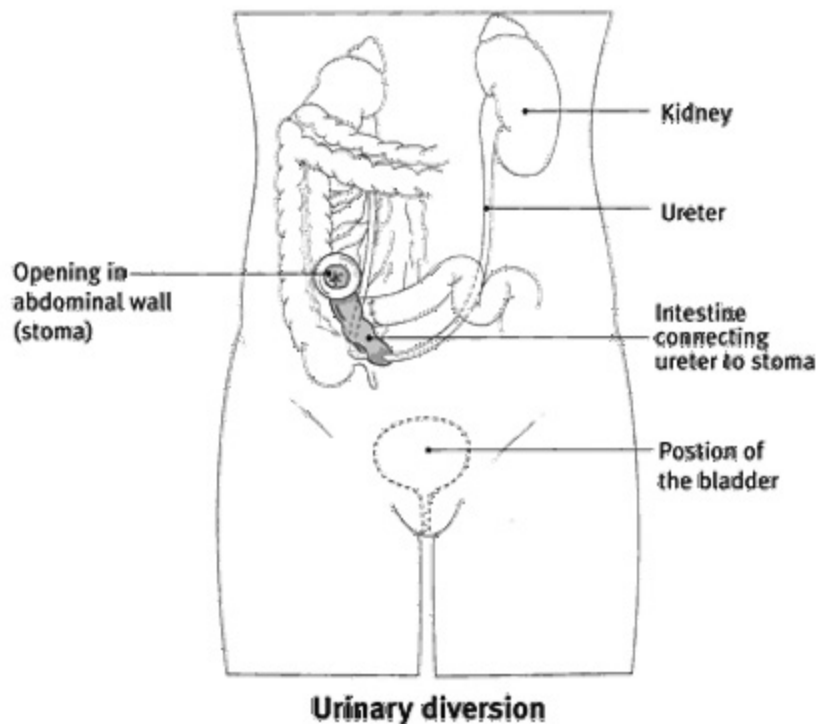
Internal lymph glands that lie inside the pelvis are usually removed at the time of operation. Lymph glands are part of the body's immune system which can collect cancer cells that have broken away from the main tumour.

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 removed 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 on the next page).



How else will my body be affected?

Having sex and having children

If your ovaries, womb and/or part of your vagina are removed, the operation will affect your ability to have sex and children. If the surgeon removes the front wall of your vagina in the operation, this leads to shortening of the vagina. For patients who are keen to remain sexually active, we would aim to spare as much of the vagina as possible.

In most cases, the remaining length of the vagina is very small, which means that penetrative sexual intercourse will be more uncomfortable and will require lubrication. In some cases, the entire vagina has to be closed or removed. Your ovaries are usually removed with your womb, although they may be left in place if you have not gone through the menopause.

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.

What are the risks of the operation?

Your surgeon will talk to you in more detail about the risks of the operation before you are asked to sign the consent form.

Possible complications of any types of major surgery

- Infection in the wound.
- Bleeding requiring blood transfusion or return to the operating theatre.
- Blood clots in the legs (DVT or deep vein thrombosis) or lungs (PE or pulmonary embolism).
- Heart irregularities because of the anaesthetic or operation.
- Chest infection.
- Poor wound healing or weakness in the wound site.
- Injury to nearby nerves or tissues.

Possible complications of cystectomy specifically

- Damage to your rectum requiring surgical repair and/or colostomy formation (additional temporary stoma for faeces).
- Leakage from, or narrowing of, your intestine or ureters where the section of the bowel was removed and connected requiring further treatment.
- Nerve compression due to the pressure from the positioning of your body during surgery.
- Hernia (lump) of the incision (abdominal cut) requiring further surgery.
- Worsening of kidney function over time.
- The operation may not remove all of your cancer or it may become apparent once surgery has begun, that the cancer is not operable (if cancer was the reason for your surgery).
- Your sexual function, and ability to have children, will be affected by the surgery.
- There is a small risk of dying from this surgery (1 to 2 in 100 patients).

Admission to hospital for your operation

You will have a pre-operative assessment prior to your admission. It is compulsory that you attend for this appointment as they will determine if you are physically fit enough to have surgery and an anaesthetic. They will also make sure you have had the relevant tests and examinations.

The Christie runs an enhanced recovery after surgery programme (ERAS) for patients undergoing a cystectomy. Having surgery can be both physically and emotionally stressful. Taking part in this programme can help reduce the risk of complications and get you back to full health as quickly as possible. You will meet a member of the enhanced recovery team before your surgery and they will discuss the programme with you in more detail. They will tell you how you can prepare yourself for your surgery and talk you through what to expect during your recovery.

You will also get the chance to meet the specialist stoma nurse. They will talk to you in more detail about how to look after your stoma and will mark your abdomen where your stoma will be sited 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.

Day of admission

You will come into hospital on the morning of your surgery, though some patients will be admitted the day before. Your stay will be approximately 10 to 14 days.

On your admission day, you will meet the nursing and medical staff who will be looking after you.

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.

You should have a shower or bath either at home if you are admitted on the day of surgery, or on the ward if you are admitted the day before surgery. You will be given a clean gown and anti-thrombosis stockings (also known as TEDS) to put on. These help to prevent blood clots forming in your legs during surgery. You may take them off to shower during your hospital stay, but you must keep them on at all other times to help reduce the risk of blood clots. You should continue to wear them for 4 weeks after you leave hospital.

After your operation

After you come out of theatre, you will be transferred to the recovery area 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 when you will be ready to return to the main ward.

To reduce pain in your abdomen after the surgery, you will be given 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
- a painkiller device that you control, that releases painkillers into your blood stream via a drip (patient controlled analgesia or PCA)

After a few 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 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 enough normally.
- While you are asleep during your operation, 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 2 after your operation. Soon after this you will be able to start eating.
- 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 10 days after your operation. There will also be a small plastic drain tube in your abdomen that will stay in place for a few days.

The recovery period and discharge home

Research shows that the earlier a person gets out of bed and starts walking, eating and drinking after having an operation, the shorter their recovery time will be. The nursing staff and physiotherapists will help you get out of bed on the first day after your operation and help you to start walking soon after this. For the first few days while you are recovering from your surgery, the ward staff and stoma nurses will provide stoma care for you. As you feel better you will be able to start caring for your own stoma and the ward staff and stoma nurses will teach you how to do this. The stoma nurse will make sure that you have everything you need for your stoma before you leave hospital and will explain how to get further supplies. They will also make sure that you have a follow-up arranged with the stoma team when you are discharged.

When you are eating and drinking, the various drain tubes have been removed, you are independently mobile and you are independently caring for your stoma you will be discharged home

We will arrange for you to go home with 28 days of heparin injections to help prevent blood clots. You will be taught how to self-administer these or we can arrange the district nurse to do it for you.

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 appointment will normally be made for you 6 weeks after your discharge home.

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**.

Getting back to normal

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

- In the first few weeks after your surgery, you might experience blood-stained urine, bruising around your incision, and/or red or sore areas around your stoma site.
- Recovery time after abdominal surgery varies, but you should generally start to feel back to normal about 6 to 12 weeks after your surgery.
- Do not try to drive a car during the first 6 weeks after your surgery. Before you start driving again, make sure you feel able to do an emergency stop, and check with your insurance provider that you are covered.
- Do not try to lift or move heavy objects, do strenuous activity or do housework for the first 6 weeks after your surgery.
- To help aid your recovery you should slowly increase your activity levels back to normal. Within the first 6 weeks this will be through slowly increasing the amount of walking you do or your activities around the house.
- When you can return to work will depend on the type of job you do. Please ask your surgeon if you are unsure how much time off you will need.

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 the 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.

If you are state pension age or older, and need help with personal care or supervision, you 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 **0800 731 0122** and for PIP call **0800 917 2222**
- Carer's Allowance: call **0345 608 4321**
- for DLA: If you are under 16 call **0800 121 4600**
- for benefits advice, contact Maggie's centre on **0161 641 4848** or email **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** 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 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

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** (7 days a week 8am to 8pm). 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:

- Talking about cancer
- Talking with someone who has cancer
- Talking to children and teenagers when an adult has cancer
- Cancer and complementary therapies

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

Fight Bladder Cancer

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

Telephone: **01844 351652**

Website: www.fightbladdercancer.co.uk

Action Bladder Cancer

For patient support, raising awareness and supporting research into bladder cancer.

Website: www.actionbladdercanceruk.org

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**

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