

Having a cystectomy (bladder removal)

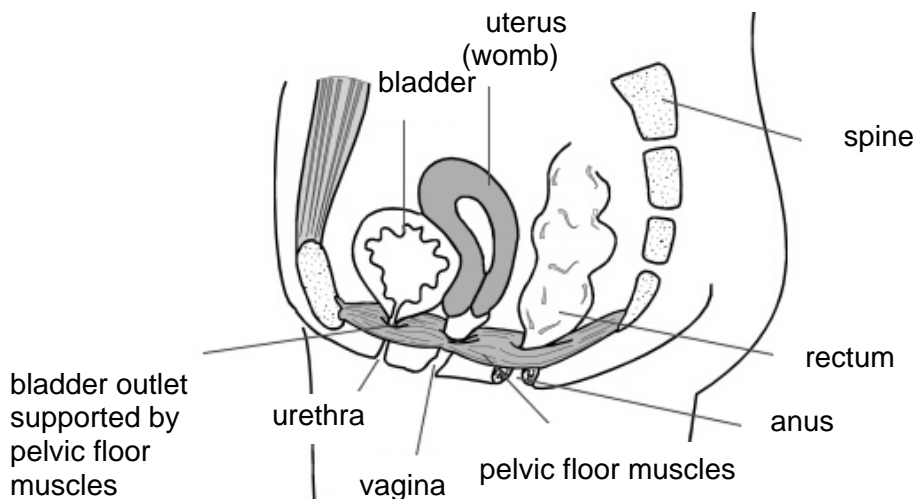
Information for women

This leaflet explains more about cystectomy, including the benefits, risks and any alternatives and what you can expect when you come to hospital.

If you have any further questions, please speak to a doctor or nurse caring for you.

What is cystectomy?

Cystectomy is the medical term for removing the entire bladder. It is sometimes called a radical cystectomy or anterior pelvic clearance.



The female pelvic organs. Diagram copy EMIS and PIP 2006, as distributed on www.patient.co.uk

What does the operation involve?

The operation is performed under a general anaesthetic. This means that you will be asleep for the whole operation, so you will not feel any pain. The anaesthetic is given through a small injection into the back of your hand. For more information about having an anaesthetic, ask your nurse for a leaflet.

The type of cystectomy you will have will depend on your individual circumstances. The operation is usually referred to as an anterior pelvic clearance. 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**. Internal **lymph glands** that lie within your pelvis are usually removed during the operation as well.

Your surgeon will discuss the operation with you in more detail and explain exactly what will be removed for your surgery. **It is important that you understand what is going to happen, so please ask questions if you are uncertain.**

Why should I have a cystectomy?

The benefits of this operation will be discussed with you in more detail, but your doctor may be recommending surgery for you 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 may be bleeding uncontrollably from other causes or treatments.

Are there any alternatives?

Possible alternative treatments will depend on the reason you are being recommended a cystectomy. However, examples include:

- having radiation therapy with or without chemotherapy, or other forms of cancer treatment if you have cancer
- choosing not to have treatment while recognising the risks of your condition.

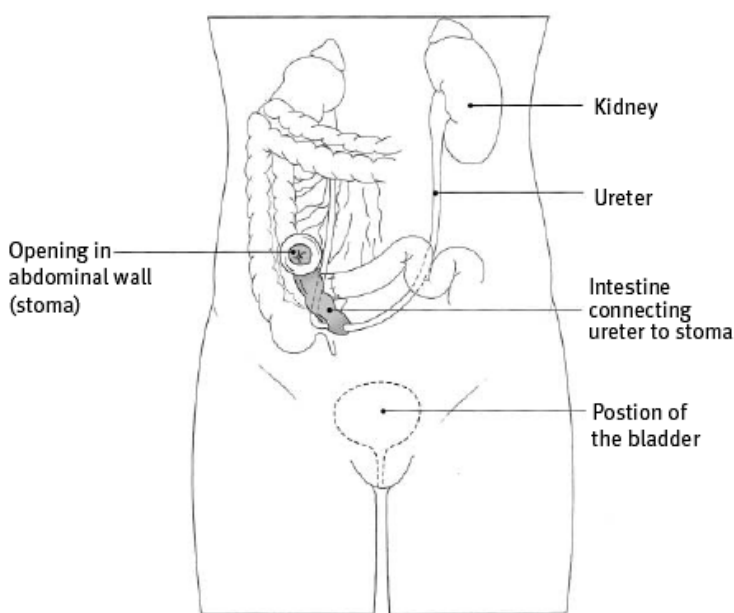
Your doctor or nurse will explain your choices and any alternative treatments to you in more detail.

How will the surgery affect me?

This is a major operation, which permanently changes your body in several ways. It affects how you pass urine, your ability to have sex and children, and to some extent, your bowel function.

Passing urine

During the operation, your surgeon will carry out a procedure called a **urinary diversion**. The tubes that connect your kidneys to your bladder (the ureters) are disconnected from the bladder. They are joined to a short segment of your bowel that is isolated from the rest of your intestines. This is then brought to the skin surface, usually on the right hand side of your abdomen. This is known as an **ileal conduit**. The part of your bowel that opens on to your abdomen is known as a **stoma** or a **urostomy**. Your urine then empties through this stoma into a small bag, which you need to empty and change regularly.



Urinary diversion

Urinary diversion. Source: Christie Hospital

In some cases, an artificial bladder can be created from a section of your bowel removing the need for a stoma. This is only suitable for a small proportion of patients – your consultant will discuss this with you if it is suitable for you. A leaflet on this type of surgery called **Bladder removal (cystectomy) and bladder reconstruction (neo bladder)** is available.

Having children and sexual intercourse

If your ovaries, womb and/or part of your vagina are removed, the operation will affect your ability to have children and sex. If the surgeon removes the front wall of your vagina in the operation, this leads to shortening of the vagina. In patients who are keen to remain sexually active we would aim to spare as much of the vagina as possible to assist in reconstruction. This would be dependent on the original size of the cancer. 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 uterus, although they may be left in place if you have not gone through the menopause (either naturally or due to previous treatment to the pelvis).

Bowel function

As a small portion of the bowel is used to make the urostomy, your bowel may also be affected by the operation. The remaining part of your bowel left for digestion and absorption of your food will be slightly shorter. This means that you may find that you go to the toilet more frequently or notice that your bowel movements are more 'loose' than before. Alternatively, you may experience some constipation for which you may require laxatives to help your bowels. This may last for up to a year. Your doctor can discuss this in more detail with you if this 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.

What are the risks of a cystectomy?

Your surgeon will discuss the possible risks of this operation with you in more detail before asking you to sign a consent form. Please ask questions if you are uncertain about anything.

Possible early complications of any major operation

Problems that can occur while you are in hospital recovering are similar to those for any major operation. These include:

- bleeding requiring the need for a blood transfusion or re-operation
- injury to nearby nerves or tissues
- a chest infection
- blood clots in your lower leg (deep vein thrombosis or DVT) which could pass to your lung
- wound infection
- bruising around your wound, poor wound healing or weakness at the wound site.

Specific risks for a cystectomy include:

- damage to your rectum requiring surgical repair and/or colostomy formation (additional temporary stoma for faeces)
- leakage from or narrowing of your intestine where the section of the bowel was removed, which may need surgery
- urine could leak out where the ureters are joined to the section of your intestine
- your ureters could become blocked and prevent urine from passing to your urostomy (stoma). This may require treatment in the future.
- Nerve compression where the pressure from the positioning of your body during the operation can reduce the blood flow supplying your nerves and cause damage. This may require further treatment.
- 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 (one to two in a hundred women people).

Preparing for your surgery

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.

The urology department currently runs an Enhanced Recovery Programme (ERP) for patients undergoing cystectomy. 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 dietician, the physiotherapist and the stoma nurse specialist.

- The CNS will prepare you for your surgery and your hospital stay, answering any questions you may have and talking 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.
- 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/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 and will teach you how to manage your stoma and change your urostomy bags. He/she will also make a mark on your tummy to help guide the surgeon as to the most suitable place for your stoma 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. He/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 0 169**.

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 or POPS. They will give you special instructions. If you take any 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.**

Coming into 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 in hospital for seven to 10 days after your surgery.

Giving my consent (permission)

We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

The day of your operation

You will not be able to eat or drink anything for six hours before you go to theatre. 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 are able to take.

On the morning of your surgery you should have a shower, either at home if admitted on the day of surgery, or on the ward if admitted the day before surgery. You will be given a clean gown and anti-thrombus stockings 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 two weeks after you leave hospital.**

From SAL or the ward you will be taken to the anaesthetic room, where you will be seen by the anaesthetic nurse and doctors. Once anaesthetised, you will be taken through to the operating theatre.

After your operation

After the surgery is finished, we will transfer you to the Guy's Critical Care Unit (GCCU) on the 1st Floor of Tower Wing. In GCCU we are able to monitor your blood pressure, heart rate and fluid levels using very accurate equipment. You will usually stay there for 24 hours, until you are ready to return to your ward. In exceptional circumstances you may need to stay in intensive care a little longer (24–48 hours).

On the day of your surgery, friends and family members can visit you afterwards but you should try to limit your visitors on the first night, as you will still feel tired from the anaesthetic. Your urologist will come to see you following your surgery.

To reduce the pain after your operation, the anaesthetist will have discussed two options with you before your surgery. You will usually have:

- an epidural, which allows painkillers and local anaesthetic to be given directly into your spinal nerve system. This involves inserting a very fine plastic tube into your back. When you are asleep in theatre. This will remain in place for approximately three days.
- if there is a need for additional pain control post surgery you will have a device that you control, that releases painkillers into your blood stream via a drip in your arm (patient-controlled analgesia or PCA).

After two to four days, you should not usually need this level of pain relief and the ward staff will give you tablets or injections instead. Please tell the staff looking after you if you are still in pain or discomfort.

After your operation you will also have:

- a drip running into a vein in your arm or neck to give you fluids until you are able to drink normally. This will be removed about three to five days after your operation. Soon after you are able to drink normally, you will be allowed to start eating again.
- a fine plastic tube from your nose through to your stomach to stop you from being sick. This is rarely needed and will be inserted while you are in theatre and is usually removed before you wake up.
- a dressing over your wound on your abdomen and a stoma bag, collecting urine from your new urostomy.
- One small plastic tube (drain) from your abdomen to drain away excess fluid. We will remove this five to seven days after your operation, but sometimes it will stay in a little longer if it continues to drain fluid.
- a tube (catheter) from your urethra, also draining excess fluid. We will remove this one or two days after your surgery.

You will also have two thin tubes (stents) coming through the urostomy. The stoma nurse specialist will remove these about 10- 14 days after you leave hospital. Sometimes they may be removed before you leave hospital. These tubes are inserted to make sure the join between the ureters and the piece of bowel forming the ileal conduit has healed and will not leak if urine passes over this join.

The doctors will check your stomach with a stethoscope every day, listening for any bowel sounds or 'gurgling'. They may also ask you whether you have passed any wind. Please do not be embarrassed – these are both signs that your bowel is recovering from the surgery and that you will be able to start drinking again. If you start to eat or drink before this, you will feel nauseous and may be sick.

You may notice some swelling around your eyelids and face. This is because of the position you were in during surgery (head down). This usually disappears within 48 hours.

Your recovery

The ward staff will help you to get out of bed on the first or second day after your operation and to start walking soon after this. Usually, people are independently up and about around four to five days after surgery. A physiotherapist will help you with this.

For the first few days whilst you are recovering from your surgery, the ward staff and stoma nurses will provide stoma care for you. As you improve you will be able to start caring for your own urostomy, 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 urostomy before you leave hospital and will explain how to get further supplies. He/she will also ensure that you have follow-up arranged with the stoma team on discharge.

We will arrange a date for you to leave hospital (your discharge date) when you, and the team looking after you, feel that you are fit for discharge and able to look after your urostomy yourself. This is usually about seven to 10 days after your surgery.

Before you leave hospital, we will:

- arrange for a district nurse to visit you while you are recovering
- send a letter to your GP and give you at least two weeks' supply of any new medicines that we have supplied you and a replacement of your own medicines, (if these have been used in hospital and you have less than 14 days of treatment with you or at home).
- give you a date for your follow-up appointment, which is usually made for about two to three weeks after you leave hospital.

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.

Getting back to normal

- 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 six to 12 weeks after your surgery.
- Do not attempt to drive a car during the first six 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 attempt to lift or move heavy objects, start digging the garden or do housework for the first six weeks after your surgery.
- To help aid your recovery you should slowly increase your activity levels back to normal. Within the first six weeks this will be through slowly increasing the amount of walking you do or your activities around the house.
- During your stay on the ward you will see a physiotherapist who may discuss coming to an exercise class following your first six weeks of recovery. This is an eight week course aimed at increasing your strength and ability to do more. If you would like to attend this class please discuss with your physiotherapist or CNS.
- 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.

Your follow-up appointment

You will have a follow-up appointment in the outpatient clinic two to three weeks after leaving hospital. Three and six months after your surgery you may have further follow-up appointments. These may involve blood tests and/or scans. Follow-up after that will be every six to 12 months depending on your final results. Your follow-up may be different to this if you need more treatment.

Cancer information

Dimbleby Cancer Care is the cancer support service for Guy's and St Thomas'. They have drop-in information centres, and also offer complementary therapies, psychological support and benefits advice.

Drop-in information centres are located at Guy's in Oncology Outpatients (Ground floor, Tabard Annexe) and at St Thomas' on the Lower Ground Floor, Lambeth Wing.

t: 020 7188 5918 **e:** RichardDimblebyCentre@gstt.nhs.uk

Macmillan Cancer Support (all numbers freephone)

t: 0808 808 2020 (information on living with cancer)

t: 0808 800 1234 (information on types of cancer and treatments)

t: 0808 801 0304 (benefits enquiry line)

w: www.macmillan.org.uk

Cancer Research UK has a patient information website, with information on all types of cancer and treatment options.

w: www.cancerhelp.org.uk

This leaflet has been adapted, with permission from Christie Hospital's leaflet, Cystectomy for women – information about your operation (removal of the bladder).

Contact us

If you want any further information or any help, do not hesitate to contact the urology department on the numbers below for advice.

Ring **020 7188 7636** to speak to the bladder cancer clinical nurse specialists Monday to Friday, 9am to 5pm. Alternatively, ring the bleep desk on **020 7188 3026**, ask the operator to bleep **2840 or 1227** and wait for a response.

Outside of these hours, please call **Aston Key Ward** on **020 7188 8860** or **Florence Ward** on **020 7188 8818**.

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

t: 020 7188 3514 (complaints) **e:** 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

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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