

Bladder reconstruction (neo-bladder) following a cystectomy (removal of the bladder)

This information is for people who have been advised by their urologist that they are suitable to have a bladder reconstruction following a cystectomy (removal of the bladder).

What is a neo-bladder?

A neo-bladder is a new bladder made from bowel tissue that is connected to the urinary system so that in the long term you will not need to wear a bag on your abdomen to collect urine. Instead the neo-bladder is connected to 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.

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

Agreeing to treatment

Consent

This has been written to provide information to patients who have been informed that they need to have an operation to remove their bladder and who may be suitable for an operation to reconstruct a new 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 Your consent may be withdrawn at any time before or during this treatment.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 this operation?

The operation has been discussed with you as a treatment to remove your bladder cancer.

By having a bladder reconstruction you would not need to wear an external bag to collect the urine that your kidneys make.

What are the risks of this operation?

There are risks that are common to all types of major surgery, and although precautions are taken to avoid them there is a possibility of:

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

Are there any alternatives to the operation?

There may be other ways of treating your bladder cancer such as with chemotherapy (drugs) and radiotherapy (x-ray treatment); this will have been discussed with you by the specialist team at The Christie.

You will also have been informed of another operation in which your bladder is removed and a stoma (urostomy) is formed for the passage of urine out of your body. This requires a bag to be worn on the abdomen to collect the urine.

What will happen if I do not have treatment?

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

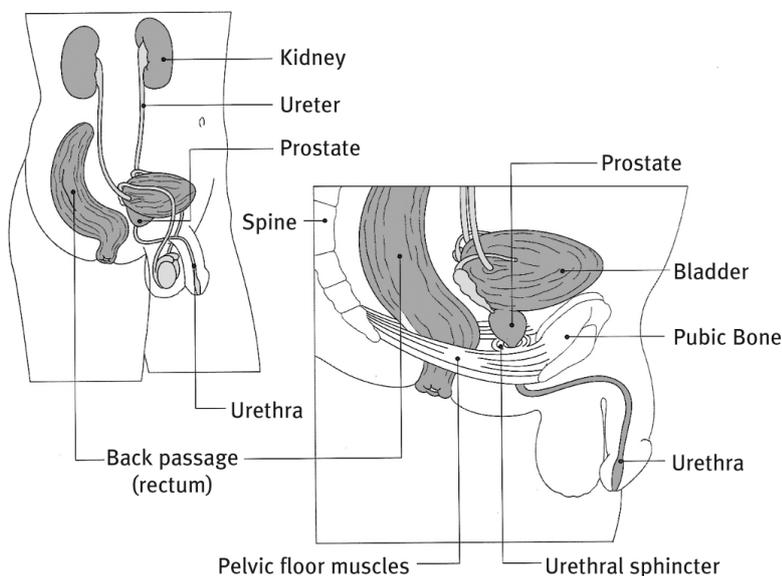
Stopping smoking

If you are a smoker and 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. The Christie has a free smoking cessation service. Please ring **0161 446 8236**. You can also contact the Smokefree national helpline on **0300 123 1044**.

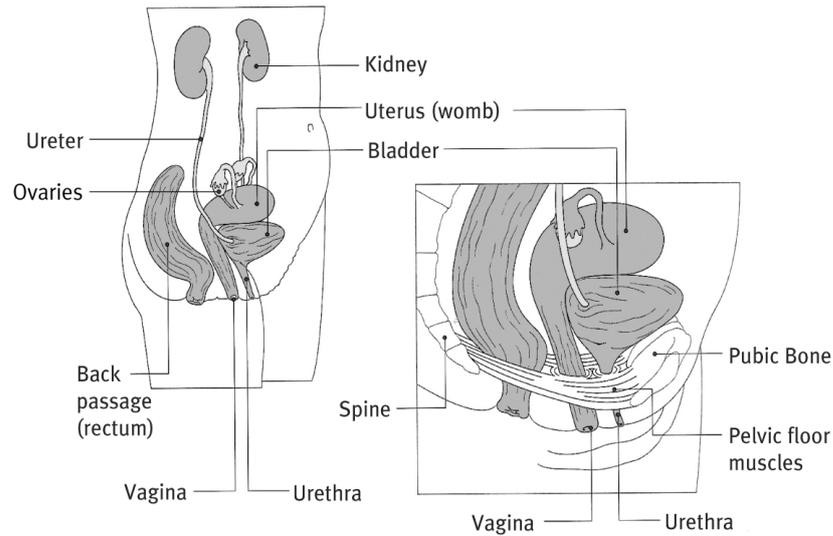
The operation

The operation to remove the bladder includes removing the prostate gland in men, and the uterus and a cuff of vagina in women. If a woman having this operation has not been through the menopause, it may be possible to leave the ovaries to provide normal hormonal balance.

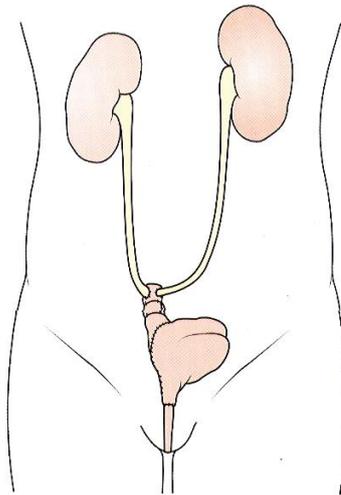
Male pelvis



Female pelvis



Orthotopic or neobladder



Orthotopic bladder reconstruction can be carried out in several ways.

The operation involves using a section of the small bowel between 45 to 60cms long. This piece of bowel is used to make the new reservoir 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 for removal of the catheter. The healing process usually takes about 3 to 4 weeks.

How will the operation affect me?

As we have described in the section about the operation, there are permanent changes made to the body by this surgery. These changes affect urinary, 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 the 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.

To pass urine, many people who have had this operation will need to relax their pelvis and use some abdominal pressure or straining to empty the new bladder. The capacity of the new bladder will increase over time. 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 until you are able to build up the time in between as the bladder reaches its full capacity.

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 control may be difficult when you are asleep if the bladder is full. About 1 in 10 people who have undergone this surgery 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 Christie for surgery. When you are able to identify these muscles, it will also make it easier to empty the new bladder completely.

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 or infection and difficulty controlling leakage of urine from the 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 3 in 10 people having this type of operation will need to insert a catheter once or twice a day in the long term.

Fertility and sexual function

As we have mentioned earlier, the aim of the operation to remove the bladder is to eradicate all the bladder cancer cells. So other 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. Because of the surgery, even if orgasmic function returns, there is no ejaculation and therefore semen cannot be delivered to the female for an unassisted conception.

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). The result is that there may be some shortening of the vagina, and full intercourse may not be possible for some women. You should wait for several weeks after surgery before attempting intercourse and we advise you to use a lubricant such as KY jelly.

As the uterus is removed, it will be impossible for a woman to conceive, carry and deliver a baby after this surgery.

Bowel function

Following this operation some people notice a change in bowel habit. You may go to the toilet more frequently 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.

Possible late consequences of surgery

Your urologist will have discussed the potential complications of this surgery with you.

- There is about a 1 in 20 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

There are obviously major changes for you that happen after a bladder reconstruction, 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 Christie or nearer to home, 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.

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. The catheters are obtainable on prescription and can either be collected from the local chemist or delivered to your home. You can read more about this in the section '**Preparation for home**' on page 7.

Admission to The Christie

Day of admission

- You will come into hospital the day before your operation for a stay of about 2 weeks.
- 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 the 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 which clears the bowel in preparation for your surgery.
- The urology nurse specialist will teach you how to pass a catheter into your bladder before you have surgery. She will also teach you pelvic floor exercises before your operation.

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 will 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:
 - a painkiller device that *you* control, that releases painkillers into your blood stream via a drip (patient controlled analgesia), or
 - 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.
- After about two days the need for these types of painkiller is greatly reduced, and you will be able to have the systems 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.
- 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 the stomach to stop you from being sick. This tube is usually removed a day or two after your operation.
- Immediately after your surgery, you will have a catheter inserted 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. There will also be thin tubes placed in the ureters that will come out of a small hole on your abdomen. A bag will be attached to collect urine that drains from them. These tubes and the bag will be removed about a week to ten days after the 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.

The nurses on the ward will use the catheter to wash out your new bladder 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 will 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 will begin to take care of yourself including managing the bladder washouts. A discharge date will be arranged 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 / GP have been able to supply you with some more.
- The ward nurses 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 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 discharge home is about two weeks after surgery. We will then give you a date to be readmitted to have the catheter removed. You will come to the Diagnostic Radiology department for a test called a 'cystogram'. This test involves putting dye into the catheter to ensure 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 frequently, 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 taught to you before the operation.

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 you are in hospital. Your GP can then supply you with any further sick notes.

Improving your continence with pelvic floor exercises

Pelvic floor exercises can help you regain control of your bladder. The exercises work by strengthening the muscles that control passing urine. 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 can be done to 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 passing urine or passing wind. You should feel a lifting sensation inside and a tightening of the muscles around your anus. 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 passing urine. Don't do this regularly though, just do it to find the muscles.

The exercises

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

1. 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.
2. Wait 10 to 20 seconds then repeat the 'lift'. You should aim to lift then relax 12 times.
3. Do 5 to 10 short fast lifts.
4. You should try to spend 5 to 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 to 6 months will improve the control you have over passing urine. If you suffer from stress incontinence, remember to contract the muscles before you sneeze, cough or try to lift anything.

Follow up after bladder reconstruction

We will see you six weeks after surgery in the outpatient clinic for your first post operative surgery check-up.

About three months afterwards, we will ask you to come to The Christie 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.

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. Once a year, you will also need to have a flexible cystoscopy to check your bladder.

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.

- 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**.
- 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 56191**

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.

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The Christie Patient Information Service
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