

Cystectomy and formation of neobladder: information and advice for patients on the enhanced recovery programme

This leaflet will explain what will happen when you come to the hospital for your operation. It is important that you understand what to expect and feel able to take an active role in your treatment. Your surgeon will have already discussed your treatment options with you, including the risks, benefits and any alternatives.

This leaflet includes:

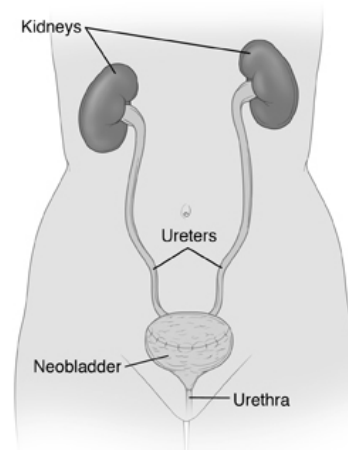
- Types of and reasons for surgery.
- Alternatives, risks and side effects.
- How best to prepare for surgery.
- Admission.
- Fasting and bowel preparation.
- Immediately before and straight after surgery.
- The days in hospital following surgery.
- Your discharge and aftercare.
- Useful numbers and further information.

The usual length of stay in hospital for this sort of surgery is between 4 and 7 days. There will be many different health professionals involved in your care during your stay and there will be a clear plan for any after care when you are discharged from hospital. This leaflet will answer some of the questions that you may have but if there is anything that you and your family are not sure about, then please ask.

What is a cystectomy?

Cystectomy is an operation to remove all or part of the bladder. It is used to treat bladder cancer that has spread into the bladder wall (stages II and III) or to treat cancer that has come back following initial treatment. Radical cystectomy is the removal of the entire bladder, nearby lymph nodes (lymphadenectomy), part of the urethra, and nearby organs that may contain cancer cells. Removing lymph nodes helps your doctor determine whether cancer is present in the lymph nodes and provides more accurate information about the stage of the cancer.

The operation is carried out under general anaesthetic (you are asleep).



A neobladder is a replacement bladder which enables you to pass urine normally through the normal passage (urethra). The new bladder is formed using a length of your intestine to create a storage pouch that is attached inside your abdomen.

In men the prostate, the seminal vesicles, and part of the vas deferens are also removed. In women the cervix, the uterus, the ovaries, the fallopian tubes, and part of the vagina are also removed.

Why is a cystectomy done?

Cystectomy is used to remove and attempt to cure cancer that has invaded the wall of the bladder, or has come back (recurred) following initial treatment, or has a high chance of spreading. It can also be a treatment for chronic bladder degeneration.

Is there an alternative treatment?

Your consultant will have investigated the options to treat your cancer and is offering a cystectomy as the first line recommended treatment. However, there may be alternative options that can be discussed with your consultant and uro-oncology clinical nurse specialist.

What are the risks or side effects?

All procedures will carry a risk and the potential for side effects these may include:

Common (greater than 1 in 10):

- High risk of impotence (lack of erections).
- Inability to ejaculate or father children because the structures which produce seminal fluid have been removed (occurs in 100% of patients).
- Incontinence of urine.
- Need to self-catheterise if neobladder fails to fully empty.
- Cancer may not be cured with removal of bladder alone.

Occasional (between 1 in 10 and 1 in 50):

- Anaesthetic or cardiovascular problems possibly requiring intensive care admission (including chest infection, pulmonary embolus, stroke, deep vein thrombosis, heart attack and death).
- Infection or hernia of the incision requiring further treatment.
- Scarring to the bowel or ureters (water pipes) requiring further surgery.
- Blood loss requiring repeat surgery.
- Decreased kidney function in time.

Rare (less than 1 in 50):

- Bowel and urine leakage from the anastomosis (surgical joins) requiring surgery.
- Recurrence of the urethral cancer.
- Need to remove the penile urinary pipe (urethra) as part of the procedure.
- Intra-operative rectal (back passage) injury requiring colostomy (stool bag).

- Diarrhoea resulting in vitamin deficiency, requiring treatment.
- Technical failure to create a neobladder, requiring formation of a urinary stoma (bag).

Pre-operative testing

During your outpatient appointment when the operation has been discussed with you, your consultant may also ask you to have a CT scan of your pelvis, abdomen and chest before your surgery. This scan gives the surgical team a complete insight into the full extent of the cancer.

What will happen before the operation?

You will need to attend the Pre-Operative Assessment Unit before the operation. An assessment will take place to make sure that you are fit to have an anaesthetic. At this assessment you will be asked to answer some general health questions. A nurse will record your blood pressure, pulse, weight, height and lung function (peak flow). A urine and a blood sample will also be taken. You may also require an ECG (heart tracing) or x-ray. If you have an existing heart condition you may be asked to return to the hospital for a full anaesthetic review before your surgery. This is to ensure that you are given an appropriate amount of anaesthesia without putting your heart at risk. At this appointment the anaesthetist may ask you to use the exercise bike to test the strength of your heart in preparation for an anaesthetic.

You will also have seen the uro-oncology clinical nurse specialist and stoma nurse, who will have provided additional information regarding an alternative procedure called an ileal conduit (the use of part of your intestine to create a channel connecting your ureters to an opening (stoma) on your abdomen to drain urine into a bag). This is discussed in case the planned operation is not technically possible. The stoma nurse will see you again on the day of surgery, when your abdomen will be marked to indicate the best place for the stoma should it be necessary.

You will be reviewed by your consultant in a designated cystectomy clinic where you will receive factual and complete information about what to expect during your stay in hospital.

Prior to going home you will need to be able to flush your catheter. To help you get used to this, you will be given a catheter and syringe to take home with you before your operation in order to practice the technique.

When do I come into hospital?

You will be admitted to the ward on the morning of the operation itself. If it is difficult to get to the hospital for 6.30 – 7.30am then please let us know, so alternatives can be arranged. The date will be confirmed in a letter from the waiting list office, even if you have already been given a date by the surgeon.

What happens when I am admitted?

A nurse will check all your information with you, including contact details for next of kin. You will be requested to wear an identity bracelet at all times whilst you are an inpatient. A nurse will check your blood pressure, take blood and urine samples and will prepare you for theatre.

What can I eat and drink before the operation?

It is important that you follow the hospital's instructions about eating and drinking prior to your operation. Please eat only low fibre foods for the 2 days prior to surgery, including the evening before your operation (i.e. no vegetables or fibre). This is because it stays within the part of the bowel used for the neobladder reconstruction and can increase the risks of infection. You will be also given 4 cartons of a lemon flavoured drink specially designed to give your body nourishment and help you recover, to be taken the night before the surgery. On the morning of surgery you will be given a further two cartons of this drink and you will be encouraged to drink clear fluids up until two hours before your surgery. Please note if you have diabetes you will not be given these drinks as they can raise your blood sugar.

Will I need to have any bowel preparation, laxatives or enemas?

You will not need any laxatives or oral bowel preparation. Sometimes, you may need an enema (not all patients will need one). If needed, then one enema will be administered by the nursing staff on the ward on the morning of the operation.

What will happen on the morning of the operation?

You will be seen in the admission suite by the consultant anaesthetist and the consultant surgeon. They will explain to you the method of pain relief that will be used and also will be able to answer any questions that you may have about the operation. The consultant surgeon will ask you to sign a consent form which gives consent for the surgeon to operate on you, if this has not already been done in the outpatient clinic. You will be seen by the stoma nurse and marked on your abdomen to indicate the best place for an ileal conduit (should it be needed). The nurse will give you a hospital gown and will ask you to remove any make-up, dentures, contact lenses, jewellery (except wedding rings) and other prostheses.

We strongly advise you not to bring in any valuables. Please ask a friend or relative to take them home. If this can't be helped, please hand in such items to the ward staff. Your valuables will be locked in a safe and you will be given a receipt for them.

How long will I be away from the ward?

The operation takes most of the day. There will also be time in the anaesthetic room when you will be connected up to the monitoring equipment and there will be time in the recovery room afterwards when you are waking up after your operation. In some cases you will remain in the recovery unit or Intensive Care Unit overnight for additional monitoring.

What happens in the anaesthetic room?

In the anaesthetic room, a cannula (fine plastic tube) is placed in a vein in your arm. You are then attached to a number of monitoring devices. When the anaesthetist is happy that all of the monitoring equipment is fitted, you will then be sent off to sleep. Further lines are then placed in your arm, and maybe one in your neck. You will be asleep when these are inserted.

What will I feel like when I wake up?

You will wake up gradually in the recovery room and may still feel a little sleepy. There will be some extra oxygen to help you breathe and a fluid drip in the arm. You will have 6 small incisions in your abdomen, with a pelvic drain in one of them to collect fluid, and a urethral catheter. The nursing staff will measure your urine output hourly and monitor you closely as you wake up. This is all routine after a general anaesthetic. Occasionally, you may feel sick or have some pain. It is important to tell the staff, who can provide medication to relieve these symptoms. When you are fully awake and ready to return to the ward, the nursing staff will accompany you back there. In some cases you will remain in the recovery area or be transferred to Intensive Care overnight.

What will happen the night after my operation?

You will be encouraged to practice deep breathing and to move your legs around. If you return to the ward on the day of your surgery, depending on what time you return to the ward, you will be assisted by the staff to get out of bed for 2 hours. You may have sips of water and some chewing gum the evening after your surgery; this will help with passing wind and having your bowels open. You will be monitored quite closely during this period and you may need to be woken up during the night to have your blood pressure and urine output checked hourly.

Prevention of blood clots and pain relief

You will be given tiny injections of a drug called enoxaparin under the skin and some inflating cuffs will be placed on your legs to stimulate circulation to help prevent blood clots. The amount of time out of bed increases every day. The enoxaparin injection needs to continue for 30 days, so you will be taught how to administer them yourself or by a family member and given a supply of the injections to go home with.

What can I eat after my operation?

You will be able to have sips of water until you are passing flatus (gas). Once you have passed flatus you can build up to clear fluids and a light diet. You will be encouraged to chew gum three times a day. The fluid drip will be removed from your arm once you are drinking properly. You will be started on an antacid tablet to prevent stomach ulcers. This will be reviewed prior to your discharge home.

How quickly will I be up and about?

The day after your operation you will be assisted by the physiotherapist or one of the nurses to walk and to remain out of bed for 6 hours, either sitting or walking. It is important to get moving very soon after surgery as this reduces the risk of clots in the legs, and speeds the recovery of your bowels.

How will I pass urine?

The pouch is effectively treated as a new bladder and is attached to your ureters at one end and your urethra at the other. This allows you to pass urine through the same opening as you did before surgery.

How do I manage my catheter?

A catheter (fine plastic tube) is placed through the urethra into the neobladder during the operation. The urine drains from the new bladder into the catheter and out of your body. This is left in place for 3 weeks to allow your neobladder to heal, and become water-tight. As it is made from bowel tissue, the neobladder produces mucus. This mucus can block the end of your catheter. If the catheter becomes blocked at any stage, this can lead to very serious life-threatening complications. The catheter is therefore flushed at regular intervals. This is done initially by the doctors and nurses on the ward, but they will teach you how to do this yourself. You will have been given a practice catheter and syringe before your operation to familiarise yourself with the equipment. The wash is done by flushing in approximately 50mls of sterile water / saline and then sucking this fluid out again with the same syringe. This is repeated at least four times (with 50mls of saline each time), or until there is no more mucus in the syringe after the flush. This process is repeated every 8 hours (i.e. 3 times a day) until the catheter is removed (3 weeks after your operation).

If there are any concerns about the catheter, i.e. if it is blocked, or you cannot withdraw the fluid, or if you get fluid by-passing around the catheter, then you MUST call Hopkins Ward on 0118 322 7771 any time of the day or night. The nurses on the ward can advise you, but will most likely suggest that you come to the ward for assistance.

DO NOT let anyone remove your catheter without clear permission from the operating surgeons.

When do I learn to pass urine again?

Because your 'new' bladder does not know how to fill, contract and release urine as your original bladder did, you will have to undergo bladder training.

After 3 weeks at home, you will be readmitted to the ward for removal of the catheter and bladder training. You are usually only in for one to two nights during this time. The key to the success of this operation is careful attention to detail when learning to pass urine. When the catheter tube is removed you will be asked to pass water at regular timed intervals. There is usually very little or no sensation from the new bladder. For this reason you have to rely on the clock.

On the first day, you will be asked to empty your bladder every hour. We will then increase the time so that you pass urine every 2 hours. During this time you will need to wear a pad because you are likely to leak urine. One way to improve your control is by performing pelvic floor exercises which may help to restore tone to the muscles in the pelvis. These muscles help you to control leakage. We will give you written information on how to do these exercises when you come into hospital to have your catheter removed.

While you are in hospital, we will be measuring the amount of urine you pass and you will be encouraged to drink as this helps to gradually increase the size of your new bladder.

Over the next several weeks you will be asked to increase the time between passing urine to 3 hours and then finally to 4 hours. We encourage you to measure the amount that you pass in a jug a couple of times a day for the first few months. After about three to six months your bladder should be able to hold around a pint of urine.

It is important to understand that you must never go longer than 4 hours between passing urine. It is important that you do not over-stretch your new bladder so the volumes should not exceed 400mls (1 pint).

How do I pass water?

It is different to what you are used to! You start by relaxing the muscles in your lower abdomen and letting the urine begin to run out. You can then begin to gently strain and this will increase the speed at which the urine drains. It will drip at the end but it is important to be patient to make sure that the bladder is emptied fully. It sounds complicated but you will quickly learn the knack. We may scan your bladder on the ward to ensure you are emptying it completely. Occasionally, some patients may need to be taught to pass a small catheter into their water passage and up into their bladder (intermittent self-catheterisation), if they are not emptying completely. This may be needed on a temporary basis each time you need to pass urine or on a long term basis. This is done to prevent urine infections and to protect your kidneys. Learning to pass a catheter into your bladder is not as difficult as it sounds and it doesn't take long to become skilled. It is a safe procedure as long as it is done under clean conditions and can be carried out almost anywhere. The catheters are available on prescription via your GP and you can collect them from your local chemist or get them delivered to your home.

How do I manage incontinence?

During the day you will quickly develop control and dryness; however, you may feel more confident wearing a pad for a while, and especially when you go out. Urinary continence pads can be obtained free of charge via the Continence Advisory Service, following an assessment. Please ask your clinical nurse specialist for advice and support.

Patients find night-time incontinence management takes a bit more work and needs more patience. You may leak during the night for anything between six and nine months, although some patients become dry at night much earlier. To keep dry, women will need to wear a pad at night where as men will need to fit an appliance each night before go to bed. This is like a contraceptive condom that you attach to yourself and to a catheter bag into which the urine drains while you sleep. The nurse will show you how to put it on and you will quickly become an expert at fitting it yourself. As you become drier you will start wearing a pad at night until you are completely dry.

Will surgery affect my sex life?

Apart from the psychological adjustments, the operation may have made physical changes that can cause problems with sex. There may be damage to the nerves in the pelvis during the operation which results in men losing the ability to have an erection naturally. However, this does not stop the sensation of an orgasm, although you will not be able to ejaculate. You may

be able to regain an erection with the use of drugs or devices; however, there are no guarantees that they will work.

Your clinical nurse specialist will talk to you about this and can refer you to a specialist clinic within the department if you would like.

Women may be able to continue to have intercourse although there may be some loss of vaginal sensation and vaginal depth that may make having an orgasm more difficult. For some people the vagina can be fully preserved, but for others the vagina may need to be shortened. If the operation is due to cancer then it is usual for a hysterectomy to be done at the same time as the bladder operation.

You may find it difficult or embarrassing to talk about any sexual problems you may have. However, talking to your doctor and/or specialist nurse about the problem will help to bring fears and worries out into the open so that support and advice can be given to you.

Do I have to change my diet?

You do not have to change what you eat or drink after this operation. You can drink alcohol; however, large volumes of beer should be avoided as they can result in over-stretching the bladder.

It is a good idea to drink a glass of cranberry juice a day as this will help to reduce the mucus that naturally occurs in the new bladder. You will also need to take a tablet called sodium bicarbonate once a day. This helps to neutralise the extra acid that may over time be reabsorbed through the new bladder lining.

Are there any restrictions with my new bladder?

Remember:

- **You must not go more than 4 hours without passing urine.**
- You will have to set your alarm to get you up at 4 hours every night to pass urine.
- You should never have more than one pint of beer/lager before falling asleep!

How quickly will I be back to normal life?

Because this is a major operation it will take time for you to recover physically and emotionally. It can take up to three months before you feel you have the strength and energy that you had before the operation and at times this can be very frustrating. It is important to be patient and give yourself time to recover.

We recommend that you do not drive for the first 10-12 weeks after the operation. Before this time you would have difficulty and hesitation performing an emergency stop.

How will I be followed up?

You will have an appointment to be seen at the hospital in the Outpatients Department to discuss any results from tests on the bladder that we may have taken away, and also to check that you are recovering well. If you have had the bladder removed due to cancer you will have regular follow-up appointments after this operation. These will involve scans and examinations.

You will also be able to contact the specialist nurses if you have any concerns between appointments.

More treatment may be needed following a radical cystectomy and may include radiation therapy or chemotherapy. If this is felt necessary, your health details will be passed onto a cancer specialist doctor who will devise a treatment plan that is appropriate to you and your cancer.

The uro-oncology clinical nurse specialists are there for you as a point of contact for support and advice. Please contact them if you have any questions or worries on 0118 322 7905 (Monday – Friday, 9am to 5pm).

After the operation it is a good idea to wear a medi-alert bracelet. It should say that you have a neo-bladder and that you would need to be catheterised in the event of a major accident and/or in the event of becoming unconscious. These can easily be obtained from a chemist or contact Medic-Alert Foundation, tel: 020 7833 3034, web: www.medicalert.org.uk.

When will I be discharged?

We expect you to be in hospital between 4 and 7 days following the main procedure. Before you go home, your symptoms will be well controlled. You will be given a supply of any new tablets that you need before you leave. You must be eating and drinking, you need to be back to your mobility baseline and you must be able to flush your catheter before you can be discharged from hospital.

You will need to continue having the injections to help prevent clots forming in your legs or lungs for one month. The nurses on the ward will show you or a family member how to do this or arrange for a district nurse if you are unable to do them.

You will be asked to come back to the ward for bladder training in 3 weeks' time.

If you feel there will be issues related to coping at home after this operation, please let the ward staff know at the outset.

At home

If you have any problems or questions between leaving hospital and your first follow-up appointment, please contact Hopkins Ward and speak to one of the nurses who will be able to offer advice and contact your consultant, if necessary.

Contact Hopkins Ward or your GP immediately if:

- You have any increase in your pain.
- You have any bleeding or increase in your bleeding.
- You develop symptoms of wound or urine infection, such as increased pain, inflammation, discharge from wound, pain or burning when passing urine.
- You are unable to pass water.

Useful organisations

Macmillan Cancer Support Tel: 0808 808 00 00 www.macmillan.org.uk

Charity providing accurate and up-to-date information on every type of cancer. Also provides information in other languages.

Bladder Cancer Support Group

Meet monthly every fourth Tuesday 2pm-3.30pm in St Andrew's United Reformed Church, London Road, Reading RG1 5BD.

British Association of Urological Surgeons www.baus.org.uk

Publications and consent documents for download.

Who can I contact for more help or information?

Hopkins Ward 0118 322 7771

Uro-oncology nurse specialists 0118 322 7905

Stoma care clinical nurse specialists 0118 322 7640

Urology Clinical Admin Team (CAT 3a) 0118 322 8629 or email rbb-tr.CAT3A@nhs.net

References

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4. Rosenberg JE, et al. (2008). Bladder. In AH Ko et al., eds., Everyone's Guide to Cancer Therapy: How Cancer is Diagnosed, Treated, and Managed Day to Day, 5th ed., pp. 447-458. Kansas City, MO: Andrews McMeel.

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