

Cystectomy and formation of ileal conduit: 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. An ileal conduit (also called a non-continent diversion) uses a segment of your intestine to create a channel that connects your ureters (the tube that goes from the kidney to the bladder) to a surgically created opening (stoma) on your abdomen. This procedure is called a urostomy. After a urostomy, the urine passes from the ureters through the conduit and out the opening into an appliance that is stuck to your skin on your abdomen.

You will need to empty the bag several times a day, and a larger bag that allows for longer storage can be worn overnight. Initially after the operation you will have two stents (tubes) coming from the conduit – these may or may not be visible depending on the type. They will be removed at a later date, which will be explained to you on discharge.

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

Regional lymph nodes will be removed (lymphadenectomy) during cystectomy. 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.

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 recommended treatment. There are however, always alternative options, which 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)

- Discomfort or difficulty with sexual intercourse due to narrowing or shortening of vagina.
- Menopause may occur if your ovaries are removed.
- High risk of impotence (lack of erections).
- Inability to ejaculate or father children because the structures which produce seminal fluid have been removed (this occurs in all patients).
- 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.
- Need to remove the penile urethra (water pipe) as part of the procedure.
- Blood loss requiring repeat surgery.
- Decreased kidney function in time.
- Ileus (obstruction of the gut).
- Constipation.
- Diarrhoea leading to vitamin deficiency due to shortened bowel, requiring treatment.

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Rare (less than 1 in 50)

- Bowel and urine leakage from the anastomosis (surgical joins) requiring further surgery.
- Scarring to the bowel or ureters (water pipes) requiring further surgery.
- Scarring, narrowing or hernia formation around stomal opening, requiring surgery.
- Intra-operative rectal (back passage) injury requiring colostomy (stool bag).

Pre-operative testing

During your outpatient appointment where 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. You will also have seen the uro-oncology clinical nurse specialist, who will have advised you on all aspects of your treatment.

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 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.

Stoma care

Prior to your operation you will be seen in outpatients by a stoma nurse specialist who will give you information on your planned stoma. They will show you how to change and empty a stoma bag and will give you a practice kit of equipment for you to use and familiarise yourself with prior to admission. You will see the stoma nurse again on the morning of your operation when they will mark your abdomen indicating the best place for the stoma.

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 eat and drink up to the times given to you by the hospital. Please eat only low fibre foods for the two days prior to surgery including the evening before your operation (i.e. no vegetables or fibre). You will also be given four cartons of a lemon flavoured drink, specially designed to give your body nourishment and to 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 will also 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 where the best place for the ileal conduit.

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 (ICU) overnight for additional monitoring.

What happens in the anaesthetic room?

In the anaesthetic room a cannula is placed in your arm. Sometimes, a local anaesthetic injection is given in your back. 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 be sent off to sleep. Further lines are then placed in your arm, and maybe one in your neck.

What will I feel like when I wake up?

After the operation, 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 a pelvic drain in place to collect fluid and usually an epidural in your back for pain relief. 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.

The nursing staff will help you with your stoma bag initially and you will have two stents which may or may not be visible. If they are visible they will be seen coming out of your stoma into the bag, these will be removed at a later date by either the stoma nurse or consultant depending on the type, this will be explained on discharge. Occasionally, you may feel sick or have some pain. It is important to tell the staff so that they 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.

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 two hours. You may have sips of water and some chewing gum the evening of your surgery. 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 partner) and given a supply 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 (wind). Once you have passed flatus you can build up to clear fluids and then a light diet. You will be encouraged to chew gum three times a day; this will help with passing wind and having your bowels open. 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 needs to continue for 30 days. You will be given a supply to go home with.

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 six 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?

You will have a bag stuck to your abdomen for urine to drain into. You will need to empty the bag several times a day, and a larger bag that allows for longer storage can be worn overnight. Throughout your hospital stay, the stoma nurses will visit you regularly to demonstrate how to care for stoma and monitor your progress and discuss the best products for you. You will also be encouraged to practice stoma care with the ward nurses on a daily basis once you are alert and mobile.

There will be two tubes (stents) going into the stoma which will be removed by the stoma nurse specialist or doctor 6-10 days after the operation, with antibiotics given 1 hour prior to their removal. Their removal is a simple and painless procedure.

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 performing an emergency stop.

How will I be followed up?

The stoma nurse will contact you within the first five days to check that you are managing with the stoma.

You will most likely have a telephone consultation appointment with the consultant, or a face to face appointment if deemed necessary, in the Outpatients Department. This is 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 scans after this operation. The results of these are then reviewed by the consultant who will then contact you shortly afterwards. You will also be able to contact the specialist nurses if you have any concerns between appointments, as well as the stoma nurses.

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

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When will I be discharged?

We expect you to be in hospital between 4 and 7 days. Before you go home, your pain will be well controlled on tablets. You will be given a supply of any new tablets that you need before you leave. You must be eating and drinking and you need to be able to walk about on your own. You will need to continue having the enoxaparin 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.

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. You could also contact the Urology CNS nurses or the stoma nurses.

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

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Please ask if you need this information in another language or format.

RBFT Urology, February 2023

Next review due: February 2025