Cystectomy (partial/entire bladder removal): information and advice for patients on the enhanced recovery programme

This leaflet contains information on:

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

Introduction

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.

The usual length of stay in hospital for this sort of surgery is between 5 and 10 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. There are two types of cystectomy:
– **Partial cystectomy** is the removal of part of the bladder. It is used to treat cancer that has invaded the bladder wall in just one area. Partial cystectomy is only a good choice if the cancer is not near the openings where urine enters or leaves the bladder.

– **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. Both types of operation are 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 a chronic bladder degeneration.

**How well does cystectomy work?**

About 75% of people who have a cystectomy for bladder cancer in the muscle of the bladder are disease-free after 5 years. People with more deeply invasive bladder cancer have a 5-year survival rate of 30% to 50% after cystectomy.

**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. There are however, always alternative options which can be discussed with your consultant and clinical nurse specialist.

**What are the risks?**

Complications are common after a radical or partial cystectomy and may include:

– **Urine infections** – This is the most common complication and requires drinking approximately 3 litres fluid daily plus taking vitamin C, which you will be advised about.

– **Acidosis** - This in an imbalance in electrolytes in the body such as calcium and potassium. It can be caused by using a part of the intestine to divert urine after a cystectomy. People with acidosis often need to take medicine to control it.

– **Urine leak** – This is where the internal tissue may not have sealed together, if left alone it will often seal together independently, if it persists, minor surgery may have to be considered.
- **Fistula formation** – A fistula is an abnormal communication between two organs which, as you recover and build nutrition, often recovers. However, in severe cases it may require further surgery.
- **Bowel obstruction** – This is a temporary blockage of your bowel and will require you to rest your bowel by not eating. If it doesn't resolve, it may require surgery to move the blockage.
- **Rectal injury** – This is very rare but can be caused by instruments used during surgery and will require review by our general surgical colleagues to determine a long term plan.
- Cystectomy can also lead to **erection problems for men** if nerves are damaged during surgery. At the Royal Berkshire Hospital we have an Andrology clinic that specialises in helping patients with erectile dysfunction problems (impotence).
- For women if a hysterectomy has been necessary this may cause **sensory changes during sex** and our staff will be happy to discuss with you.
- **Stone formation** – Caused by a build-up of mucus, which has not been flushed out by drinking sufficiently.

**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.

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.

**What do I need to prepare at home before I leave for the hospital?**

Please tell your neighbours or friends that you will be going into hospital. It is a good idea to make a list of telephone numbers of family and friends to bring to the hospital with you. If you are living alone, remember to cancel your papers and milk and remember not to leave food that will spoil in your fridge. Make sure that any pets will be cared for whilst you are away. If you have a freezer it may be a good idea to freeze some bread and milk so that it is there for when you get home. Make sure that you have some simple over-the-counter medicines, such as Paracetamol and anti-acids like Gaviscon liquid, at home for when you return.
What do I need to bring with me into hospital?

Please bring with you all of your usual medication in its original packaging. Please bring a change of clothes, a night-gown or pyjamas, slippers and all of the toiletries that you may need, including any creams or ointments. A dressing-gown would be useful as well as a box of tissues or hand wipes. You may wish to bring some reading material and some extra supplies such as orange squash or small cartons of juice drinks.

What will happen before the operation?

After you have been seen by a doctor in the outpatients clinic, you will need to attend the Pre-Operative Assessment Unit. 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 need a follow-up assessment to complete all the documentation, an appointment which is convenient for you will be arranged at this assessment.

You will also have seen the stoma nurse for stoma care, who would have provided additional information regarding a urinary diversion and you will be seen again on the day of surgery, when your abdomen will be marked.

You will also be invited to attend our Enhanced Recovery School. This school is held by a nurse working within the Surgical Division and gives you factual and complete information about what to expect during your stay in hospital.

When do I come into hospital?

You will be admitted to the ward either the evening before your surgery or the morning of the operation itself. This 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, give you an injection called Tinzaparin - a drug to prevent clots forming, and take blood and urine samples.

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. You may eat a normal evening meal the night before your operation; this will usually be on the ward at the hospital. As well as this evening meal you will be given four cartons of a lemon flavoured drink specially designed to give your body nourishment and help you recover. On the morning of your surgery you will be given a further two cartons of this drink and...
also be encouraged to drink clear fluids up until two hours before your surgery. The nursing staff on the ward will be able to tell you when this will be.

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, if needed, then one enema will be given on the morning of the operation. Not all patients will need an enema.

Passing water:

Ileal conduit

- An **ileal conduit** (also called a noncontinent diversion) uses a segment of your intestine to create a channel that connects your ureters (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. 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.

Neo bladder (new bladder)

- A **continent reservoir** (continent diversion) uses a segment of your intestine to create a storage pouch that is attached inside your abdomen. The pouch is effectively treated as a new bladder. If your urethra (tube that goes from your bladder to the genitals) was not removed as part of the cystectomy, you may be able to have this type of procedure. In an orthotopic diversion (neo bladder) the pouch 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.

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. This involves coming back into hospital about two weeks after discharge for 2-3 days. We will remove the urethral catheter you have been using to pass urine though and ask you to pass urine naturally every hour. By attempting to hold on to your urine for one hour and then void you are training your bladder to contract and empty. At night time we will fit a sheath (for men) and a pad (for women) and wake you at regular intervals for you to pass urine. This keeps your bladder alert to emptying and stops the muscles getting lazy. Women will have a pad.
What will happen on the morning of the operation?
You will be seen on the ward 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. However, in some cases this will have been done already in the outpatients department. You will be seen by the stoma nurse and marked on your abdomen. The nurse will give you a hospital gown and stockings to help with your circulation 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?
Although the operation itself is usually not more than a couple of hours you will be off the ward for a much longer period of time. There will 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.

What happens in the anaesthetic room?
Most of our patients have an epidural for pain relief. This is a pain relief pump that connects to you through your back. It is an excellent way to keep you comfortable after the operation. An alternative to this is a pain relief pump connected to the arm, which is controlled by the patient with a press button. This is called Patient Controlled Analgesia or PCA. The anaesthetic consultant will see you on the ward beforehand and explain which type of pain relief he or she feels would be best for you. The epidural is inserted in the anaesthetic room as well as drip lines into the veins in your arm. The epidural will remain in place for the first 48 to 72 hours after your operation. Fluid drips are in place for the first day only. When the anaesthetist is happy that all of the monitoring equipment is fitted, then you will be sent off to sleep.

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 a pelvic drain in place to collect fluid and usually an epidural in your back for pain relief. If you have had a neobladder (new bladder made from the bowel or an internal pouch) you will have a urethral catheter as well as a suprapubic catheter (a tube placed into the bladder with the opening coming through the skin) and two tubes which are connected to the ureters then come out of the abdomen and fitted into an appliance stuck on the
abdomen. 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.

What will happen the night after my operation?
You will be encouraged to practice deep breathing and to move your legs around. 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 drink whatever you like after your surgery. It is important to eat and drink early after your operation and you will be encouraged to do so. 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.

What can I eat after my operation?
You will be able to eat a soft fluid based diet from the day after your operation. The fluid drip will be removed from your arm after 24/48 hours and it is important to drink plenty of liquid and to start eating, as your body will need the nutrition to help with the repair process.

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.

Prevention of blood clots and pain relief
You will be given tiny injections of a drug called Tinzaparin under the skin and a pair of stockings to wear to help prevent blood clots. The amount of time out of bed increases every day. The epidural or PCA will usually be removed after 48 to 72 hours and you will be given tablets for pain relief instead. If you have had a neobladder, on Day 4 of your recovery you will be shown how to flush your neobladder through the urethral catheter independently, and between Days 8 and 10 you will have the other tubes and your suprapubic catheter removed.

When will I be discharged?
We expect you to be in hospital between 5 and 10 days. Before you go home, your pain will be well controlled on tablets. You will be given a supply of any 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. If you have a neobladder you must be able to flush your catheter before you can be discharged as we need to make sure that you are able to manage before arranging your
discharge from hospital. The nurse who has been looking after you will contact your district nurses and order catheter and flush supplies for you to use at home if this is required. If you have an ileal conduit you must be competent to change the appliance before going home and the stoma nurse will follow you up in their own clinics and arrange delivery of supplies.

What will happen after I am discharged?
You will then 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 a neobladder we will ask you to come back to the ward for bladder training in two weeks time. A detailed explanation of what the bladder training entails will be given to you when you are discharged.
If you have a stoma, the stoma nurse will contact you within the first five days to check that you are managing with it.
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.
Follow-up for a partial cystectomy includes cystoscopy and urinary exams every 3 to 6 months for at least 2 years, with regular ultrasound, intravenous pyelogram (IVP), or CT scans of the pelvis and abdomen.
Ureteric stents are removed after 10 days by the specialist nurses unless they are to be permanent. If they are permanent they will be changed every 3 months in hospital.

At home
After you have had a cystectomy, contact your GP immediately if:
- Any increase in your pain.
- 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 numbers
Hopkins Ward 0118 322 7771
Uro-oncology nurse specialists 0118 322 7905
Stoma care clinical nurse specialists 0118 322 7640
Mr Jones’ secretary: 0118 322 8551
Mr Charlesworth’s secretary: 0118 322 8869
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.

British Association of Urological Surgeons
www.baus.org.uk
There is a list of publications and consent documents for download.

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

For more information about the Trust, visit our website www.royalberkshire.nhs.uk

References

This document can be made available in other languages and formats upon request.

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