

***TOTAL CYSTECTOMY
AND FORMATION OF
ILEAL CONDUIT
PATIENT
INFORMATION***

The information contained in this booklet is intended to assist you in understanding your proposed surgery; some of the content may or may not apply to you. Feel free to discuss any issues and questions you may have about your surgery with the medical and nursing staff looking after you. If required, your nurse will arrange for an interpreter to assist with explaining the contents of the booklet. The interpreter can also be present for doctors' consultations. Please bring this book with you to hospital as it is a useful guide.

What does the Bladder do?

The bladder is a hollow, muscular organ in your pelvis situated behind the pubic bone. The function of the bladder is to collect, store and expel urine produced by the kidneys. The urine passes down the ureters into the bladder.

When the bladder is full, the nerves that supply it send a message to the brain that you need to pass urine. Under your control, the urethral sphincter relaxes and the bladder contracts until it is empty of urine (voiding). The exit tube from the bladder is called the urethra.

What is a Total Cystectomy?

A Total Cystectomy is the removal of the bladder and surrounding organs.

- In men, the bladder, prostate gland and seminal vesicles (small glands near the prostate) are removed.
- In women, the bladder, urethra, uterus and ovaries are removed and the vagina is shortened.

If you having a Total Cystectomy, another way must be found to collect urine and remove it from the body. There are different ways this can be achieved surgically. This book discusses the formation of an Ileal Conduit.

What is an Ileal Conduit?

An Ileal Conduit is a passage formed using a small portion of bowel. One end of the conduit is closed with sutures and the ureters are implanted into it while the other end is brought through to the surface of the skin. The open end is called a stoma and is similar in colour to the inside of the cheek. An external bag (urostomy bag) covers the stoma and collects the urine.

Why do I need a Total Cystectomy?

A Total Cystectomy may be required for one of the following reasons:

- cancer of the bladder
- cancer of the uterus, vagina or bowel that involves the bladder
- severe radiotherapy damage with ongoing bleeding from the bladder

Why do I need an Ileal Conduit?

- *With a Total Cystectomy*
In this scenario, the ileal conduit acts as a passage for the ureters to be attached to. This passage enables urine to be channelled through the stoma, out of your body and into a urostomy bag.
- *Without a Total Cystectomy*

In some cases a decision is made to leave the bladder in place but to divert urine away from it. This option may be chosen if there is a urine leak caused by a connection (fistula) that has developed between the bladder and uterus, vagina and/or rectum as a result of cancer, infection or radiotherapy. Another reason for an Ileal Conduit formation without Total Cystectomy is to treat uncontrolled incontinence resulting from conditions such as multiple sclerosis.

Potential Complications

All urological surgical procedures carry a small risk of post-operative bleeding and wound, chest and urinary tract infection. You will be monitored for these risks and treated promptly if they occur.

- **Excessive bleeding**

Your wound, drain(s) and vital signs (blood pressure and pulse) will be monitored for signs of excessive bleeding.

- **Infection**

Your chest, wound and urine will be monitored for early signs of infection and intervention will be put in place if it occurs. To reduce the risk of infection antibiotics are given directly into your bloodstream during your operation and continued post-operatively if necessary. You can also assist with the prevention of infection by maintaining good hygiene and doing your deep breathing exercises. Early mobilisation also helps.

- **Alteration in sexual function**

If your surgery includes the removal of the bladder (total cystectomy), damage to the muscles and nerves of the pelvic floor is often unavoidable.

◆ **Women**

For women the surgery may result in a shortened vagina and loss of pelvic floor sensation. The ability to experience the sensation of orgasm may also be affected. This surgery usually involves the removal of the ovaries and uterus. If this is necessary, your surgeon will discuss the ongoing effects of this with you.

◆ **Men**

For men the surgery will result in the loss of ejaculatory fluid and infertility because of the removal of the prostate gland and seminal vesicles. Impotence occurs in the majority of men. The degree to which an individual is affected is often linked to their sexual function before surgery.

If you experience impotence that is ongoing, there are some possible solutions to this problem (currently none of these are government-funded):

- medication
- vacuum devices
- prostaglandin injections
- penile implants

● **Sexuality**

Sexuality is also affected by an individual's emotional health. This type of surgery often requires an ongoing period of both mental and physical adjustment. Examples of concerns that impact on people's sexuality after surgery include discomfort, change in body image, fatigue, fear and anxiety. If these occur for you, you can be reassured that they generally resolve with time and with the support of those near to you. However, if you have ongoing concerns in this area, it is often helpful to discuss them with your doctor or nurse.

- **Prolonged bowel inactivity (paralytic ileus)**

There is a small risk of paralytic ileus following any major surgical procedure that involves handling of the bowel, prolonged anaesthetic time or large amounts of strong pain killing medication. This means the intestinal tract is very slow to return to its normal function. If a paralytic ileus occurs, you are likely to experience nausea, vomiting, a bloated abdomen and/or intestinal cramps. These symptoms can be relieved by the use of a nasogastric tube to drain the stomach's normal secretions while the bowel rests and recovers.

- **Potential bowel leak**

There is a very small risk of a bowel leak as the bowel has been divided to take a segment out and the two ends then joined back together.

- **Incisional hernia**

As a wound heals, scar tissue forms creating a bond between the two sides of the incision. The scar tissue is strong but can still occasionally tear or give way. This leads to a bulge developing along the scar (incisional hernia) usually within one to five years after surgery. A hernia may not cause any discomfort but if it is troublesome it may require repair.

Length of Stay

The usual length of stay is seven to fourteen days. However, if you need to stay longer for a medical reason, your doctor will discuss this with you.

Before Surgery

Informed consent

After consultation with the doctor you will be asked to sign a form to give written consent for the surgeon to perform the operation and for an anaesthetic to be administered. Relevant sections of the form must also be completed if you agree to a blood transfusion and/or if your particular surgery involves the removal of a body part and you wish to have this returned. Our expectation is that you feel fully informed about all aspects of your surgery before giving written consent. The following health professionals are available to help you with this process.

Nurses

A nurse will explain what to expect before and after surgery. Please ask questions and express your concerns; your family or people close to you are welcome to be involved.

When you are discharged from hospital your nurse will arrange for you to receive ongoing support, advice and practical help if required.

Stoma Nurse

This is a nurse who specialises in the care of people who have a stoma. The Stoma Nurse will visit you prior to your surgery to talk with you about having a stoma and will mark on your skin the ideal site for the new stoma to be situated. This nurse will visit you again after surgery to check on your progress and then to begin the process of teaching you how to care for your stoma yourself. A referral to a Community Stoma Nurse will be made to ensure continuity of care once you are at home again.

Ostomy Society

The Ostomy Society is a society run by people who have undergone similar surgery and that have had a stoma formed. The Ostomy Society has people who are available to visit you before and/or after your surgery so that you have an understanding of the changes in your lifestyle that this surgery may bring about. The Ostomy Society also provides access to information about stoma care and arranges meetings and support groups that may interest you.

Cancer Society

You may wish to contact the Cancer Society if you are being operated on for a cancer. This organisation can provide information, counselling and arrange help such as nursing care and involvement in support groups.

District Nurses

When you are discharged from hospital District Nurses may visit to help you look after your new stoma in conjunction with the Community Stoma Nurse.

General Practitioner (Family doctor)

When you are discharged from hospital you will be under the care of your family doctor who will look after your general health and monitor the treatment of your cancer. Your GP will receive a letter from your hospital doctors, which describes your surgery and progress.

Tests

Blood samples

Samples of your blood will go to the laboratory to check your general health before surgery.

Blood transfusions

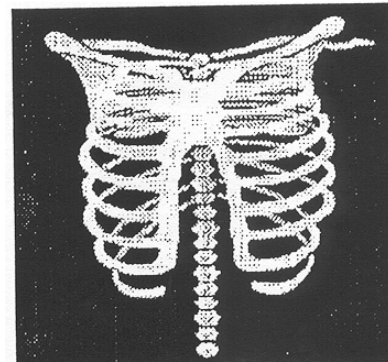
A sample of your blood will go to the blood bank to identify your blood type so this can be matched with donated blood. This donated blood is then ready for transfusion during or after surgery if required. **We will need your written consent before a transfusion is able to take place.**

Midstream urine

A sample of your urine is sent to the laboratory to check that there is no infection.

Chest x-ray

If requested by the doctor or anaesthetist, a chest x-ray will be performed to check on the health of your lungs.



ECG

An electrocardiogram (ECG) of your heart may be required depending on your age and any diagnosed heart conditions.

CT or MRI scan

If you have not had a recent CT (computerised tomography) or MRI (magnetic resonance imaging) scan as an outpatient, your surgeon may request one.

Other measures

Nil by mouth and bowel preparation

In order that a clean segment of bowel can be obtained to create the ileal conduit (passage), you will be asked to do one of the following the day before your surgery:

- drink a special bowel cleansing solution
- consume clear fluids only



Your nurse or physiotherapist will teach breathing exercises to you pre-operatively. They are important as they help to keep your lungs clear of fluid and prevent chest infection. They should be carried out regularly after surgery by supporting your abdomen with a soft pillow, taking four to five deep, slow breaths, then one deep cough.

Leg exercises

Leg exercises help keep muscle tone and promote the return of blood in your leg veins to your heart. These include pedalling the feet, bending the knees and pressing the knees down into the mattress.

Do not cross your legs - this squashes your veins causing obstruction to the blood circulation

Anti-embolus stockings

These are special stockings that help prevent clotting of the blood in your veins while you are less mobile. The stockings are used in combination with leg exercises and are fitted by your nurse before your surgery. If you currently have leg ulcers, please let your nurse know as the stockings may not be suitable for you. Along with anti-embolus stockings, you may be prescribed a blood thinning medication.

Wound site

Your wound will be abdominal and the suture line (stitches or staples) will extend from just below the sternum to the pubic bone. Sutures are usually removed seven to ten days after the surgery. There will be a stoma on the right hand side of your abdomen just below your belt line.

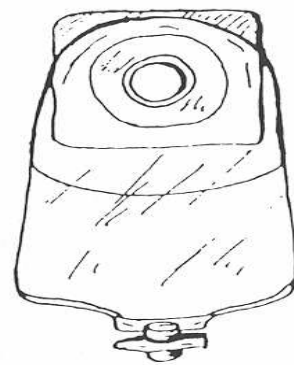
Types of ostomy bags

Initially a two-piece urostomy bag will be fitted around the stoma. This allows the nurses to see and check your urine and stoma immediately after surgery.

There are many types of urostomy bags available and you will be helped to find the one most suited to you.

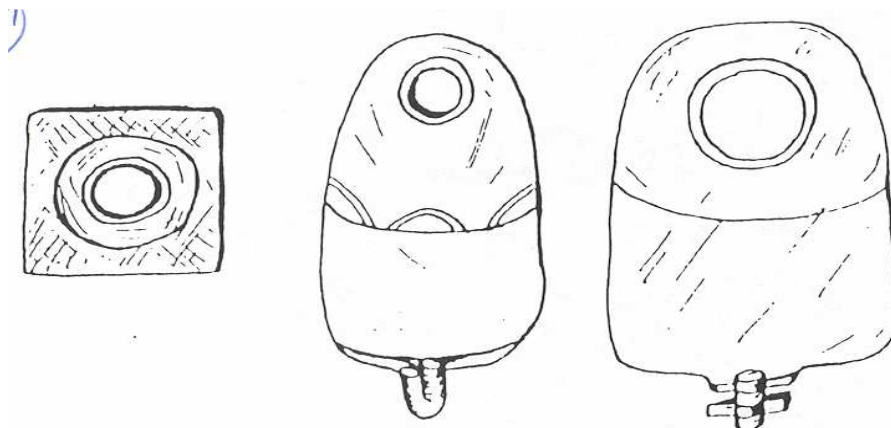
One-piece bag

This consists of a base plate (flange) which fits around the stoma and a urostomy bag (pouch) which collects the urine. The flange and pouch are already combined and are removed and reapplied as one piece.



Two-piece bag

The two-piece bag consists of a separate flange and pouch. The flange sits around the stoma providing an adhesive barrier that seals and protects the skin around the stoma from damage by urine. The pouch clips onto a ridge on the flange. The flange and pouch may be applied separately or joined together and then applied.



Many one and two-piece urostomy pouches are made with a valve to prevent back-flow of urine. A tap or outlet device is found at the bottom of the pouch to empty the urine.

After Surgery

You are transferred to the Recovery Room next to the theatre. Your condition is monitored and when you are awake and comfortable a nurse and an orderly will escort you back to the ward on your bed.

On the ward

Your nurse will check the following regularly:

- Vital signs - your blood pressure, pulse, respiration rate and temperature
- The severity and location of any pain or discomfort
- The effectiveness of pain relief
- The level of numbness that an epidural is producing
- The amount of oxygen in your blood
- The amount of urine you are producing
- The colour and shape of your new stoma
- The wound site and wound drains

You may have

Intravenous (IV) fluids

To give you fluids and medications a tube may be placed in a large vein in the neck (central venous line) and a smaller tube will be placed into a vein in the forearm.

Oxygen

Oxygen is often given for the first 24 hours after surgery via nasal prongs or a facemask to help with breathing and healing.

Urostomy bag and ureteric stents

The urostomy bag is the urine collection bag that attaches onto the skin around the newly formed stoma. For seven to ten days ureteric stents (fine plastic tubes) will be visible coming out of the stoma into the urostomy bag. These stents pass through the conduit up into each ureter and support the new structure while healing occurs.

Nasogastric tube

This is a tube down your nose into your stomach. It helps drain the stomach of secretions (fluids) while your digestive tract is recovering from the surgery.

Wound drains

You will have several wound drains. These will drain blood and fluids from your operation site.

Pain relief after your surgery

Your nurse will work alongside your doctors and the anaesthetist to keep your pain at a minimum.

The **PAIN SCORE** is a way of your nurse establishing how much pain you are experiencing by asking you to grade your pain from 0 to 10 where 0 = no pain and 10 = the worst pain you can imagine.

The following methods of pain relief may be used singly or in combination with each other.

Patient controlled analgesia (PCA)

This infusion machine has a button you press each time you need pain relief. It will help your pain by immediately delivering a

specific amount of pain relief into your blood stream. The pump is programmed according to your anaesthetist's instructions.

Epidural

An epidural is a very small tube inserted by your anaesthetist into the epidural space in your back. A local anaesthetic is infused through this tube via a pump for the first few days after surgery relieving pain at your operation site by numbing it.

Intravenous (IV) pain relief

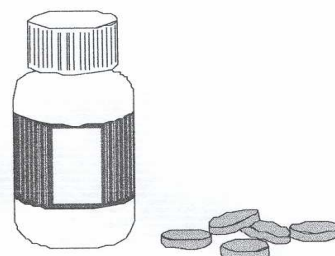
Intravenous pain relief can be administered to supplement a PCA or epidural or on its own to manage pain that is not controlled by tablets or suppositories alone.

Rectal pain relief

Pain may also be controlled by the insertion of suppositories if you are not able to take tablets orally.

Oral pain relief

When you are able to drink, you may have tablets by mouth (orally).



Comfort cares after your surgery

To help keep you comfortable your nurse will give you bed washes, linen changes and move you around in the bed regularly.

Medications are available for the relief of nausea and vomiting, if they occur. You will be given mouthwashes and ice to suck while you are not eating and drinking.

You will be reminded about and assisted with deep breathing exercises. These should be performed every hour while you are awake.

Food and fluids

After your surgery, progress to a full diet will be cautious starting with sips of water and graduating to larger amounts of fluid as tolerated. If you are not troubled by nausea, your nasogastric tube will be removed and you may progress to full meals as your appetite dictates. If your digestive system is slow to return to normal or you have special dietary needs, a dietician will be involved to assist your recovery.

Mobility

You will usually be up in a chair for a short time and assisted to walk a short distance within a day or two of your surgery. Your level of activity will increase as you recover.



Removal of drips and drains

Nasogastric tube

As above, the nasogastric tube will be removed when your digestive system begins to return to normal and you are drinking small amounts of fluid without difficulty.

Intravenous fluid

This is removed when you are drinking normally. The central venous line in your neck and the line in your arm will be removed when you no longer require intravenous medications.

Wound drains

These are removed when the amount of drainage is minimal and the operation area is healing. Sometimes a special x-ray of your new conduit (a conduitogram) is required before any drains are removed to ensure that all the joins in the Ileal Conduit are healed and watertight.

Ureteric stents

These are removed seven to ten days after surgery once the conduit is functioning as expected.

Sutures (stitches or staples)

Sutures are usually removed seven to ten days after surgery. If you are not going to be in hospital at this time, you will be given a date for you to arrange for your GP or practice nurse to remove them.

Managing your Ileal Conduit

While you are in hospital, the Stoma Nurse and the ward nursing staff will help you to learn to care for your ileal conduit. Correct application of your urostomy bag is important as it provides a protective seal for the skin around your stoma preventing damage by urine. It is anticipated that you will feel confident in managing the bags before your discharge.

The following information is intended as a reference.

Procedure for changing your urostomy bag

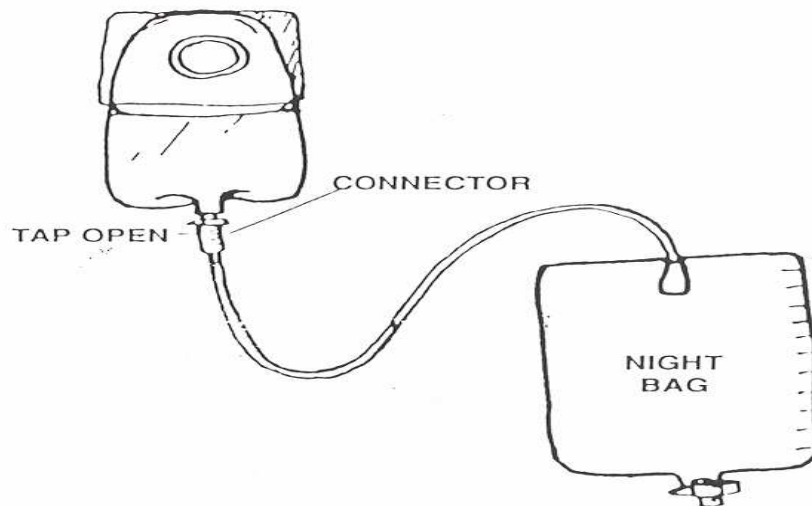
- On a clean, easily accessible surface prepare the following equipment:
 - urostomy bag

- tissue to clean and dry skin around stoma (not cotton wool as this will leave threads around the stoma and the new bag may not adhere properly to the skin)
- warm water in a bowl (don't use soaps, antiseptics or creams unless advised by your District Nurse)
- paper barrier/towel to protect your clothing while changing the bag (this can be held in place with pegs or safety pins)
- measuring jug (if your urine output is being recorded)
- plastic bag for disposal of used ostomy bag
- Wash your hands.
- Remove the ostomy bag gently and slowly.
- Moisten the tissue with warm water and gently clean around the stoma – remove all previous adhesive gum. Slight bleeding from areas of the stoma is normal – go gently. Apply a cold compress if bleeding persists and contact your District Nurse or Community Ostomy Nurse.
- Dry the skin around the stoma with tissue.
- Apply the new ostomy bag promptly and check that there are no wrinkles or creases in the flange and that it is secure. If you are using a two piece bag, check the pouch is clipped properly onto the flange.
- Dispose of the used ostomy bag in the plastic bag. Do not flush the used ostomy bag down the toilet.
- Wash your hands.
- Watch for sore skin, rashes, bleeding, or offensive urine. Report any of these to your District Nurse or Community Ostomy Nurse who can give you the correct advice.

Overnight drainage

As the amount of urine produced overnight by your kidneys may be more than your urostomy bag can hold, you will need to connect an overnight drainage bag to your urostomy bag. You will be shown how to do this while you are in hospital. The

overnight drainage bag tubing connects to the tap of the urostomy bag. Make sure that this connection is secure and that your urostomy bag tap is open.



Cleaning the overnight drainage bag

In the morning, the overnight drainage bag should be emptied, cleaned and stored in a dry place.

Procedure

- Wash the overnight drainage bag inside and out with warm, soapy water, then rinse it with warm water.
- Add one tablespoon of bleach, eg. Janola or White Magic, to a jug of water.



- Rinse the inside of the drainage bag with the solution (a funnel may make this easier).
- Store the overnight drainage bag empty in a cool and dry place.

Tips for managing your ileal conduit

- The urostomy bag will usually last three to five days. Do not change it earlier unless necessary as frequent removing of the adhesive flange will irritate and damage the skin around the stoma causing soreness.
- If the bag leaks, change it as soon as you can. The longer the skin is exposed to urine, the more damage to the skin will occur.
- The flange will not adhere so well to moist or damaged skin. This may result in odour and leaking bags.
- It is normal to find mucus in the urine. The portion of the bowel used to form the ileal conduit produces the mucus.
- Make sure you are using a flange of the correct size – the stoma may become smaller as times goes by.
- Where possible, equipment should be stored in a cool, dark place.
- Keep adequate supplies so you don't run out. You may wish to keep a spare bag in the car or at work in case it needs to be changed. Keep a plastic bag handy for disposal of your old ostomy bag.
- When you go on holiday, remember to take enough supplies with you. Let your District Nurse or Community Stoma Nurse know if you are going away.
- Empty the pouch before it is too full as the weight of the urine may 'pull' on the flange causing it to come away from the skin.

- When you leave hospital you will be given enough supplies to last approximately one month. After this your supplies will come from the District Nursing Service.

Discharge Advice

- The majority of wound strength is reached within the first six weeks after surgery so it is important to avoid strenuous activity, heavy lifting and straining during this period. This includes such things as contact sports, mowing lawns, gardening, vacuuming and lifting heavy washing baskets.
- Sexual activity may be resumed when you feel comfortable to do so.
- See your GP promptly if you experience chills, fever or pain in your bladder or back, or your urine is cloudy and offensive smelling. These symptoms may be indicative of a urinary tract infection and require treatment.
- Drink one to two litres of water daily to maintain flushing of your conduit.
- Your hospital doctor will provide your first sickness benefit certificate/medical certificate and will advise you when you are able to return to work.
- Your bag is designed to allow you to shower, go swimming and take a bath. If you plan a long soak, it is wise to do this just before your bag is changed.

Follow-up

Discharge letter

You and your GP will receive a copy of a letter outlining the treatment you received during your hospital stay. This will be posted to you if it is not completed by the time you leave hospital.

District Nurse

When you are discharged from hospital, arrangements are made for you to be visited by the District Nurse to help you adjust to managing your new ileal conduit at home. The District Nurse will also arrange your ongoing supplies of ostomy equipment. Contact your Community Stoma Nurse or District Nurse if you have any problems with your stoma.

GP

When you are discharged from hospital you will also be under the care of your GP who will look after your general health and monitor your progress.

Outpatients appointments

You will receive an appointment to attend Urology Outpatients approximately six weeks after discharge. This will be posted to you.



3 References: Mosby's Genitourinary Disorders, Clinical Nursing, Mikel Gray 1992
Urological Nursing 3rd Edition, Urological Nursing' 2004
Campbell's Urology 7th Edition, Urology, 1998