Waitemata
District Health Board

Best Care for Everyone

Total cystectomy and formation of neobladder

What you need to know

The information contained in this booklet is intended to assist you in understanding your proposed surgery. Not all of the content may apply to you. Feel free to discuss any issues and questions you 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.

Maori Health – He Kāmaka Waiora

The He Kāmaka Waiora team works with Maori patients and their whānau when they need access to hospital services.
Please talk to your Health Professional if you would like support via this service.

Contacts - Urology:

Urology Nurse Specialist
Ph: 021 815424 within working hours Monday to Friday

Urology Cancer Nurse coordinator
Assistance with further information in regard to your cancer diagnosis management plan. This includes contacts and referral to supporting services as appropriate, such as Maori/Pacific/Asian Health; Psychology and Social Work.
Contact via Urology Nurse phone number or email:
urologycancercoordinator@waitematadhb.govt.nz

Other contacts:

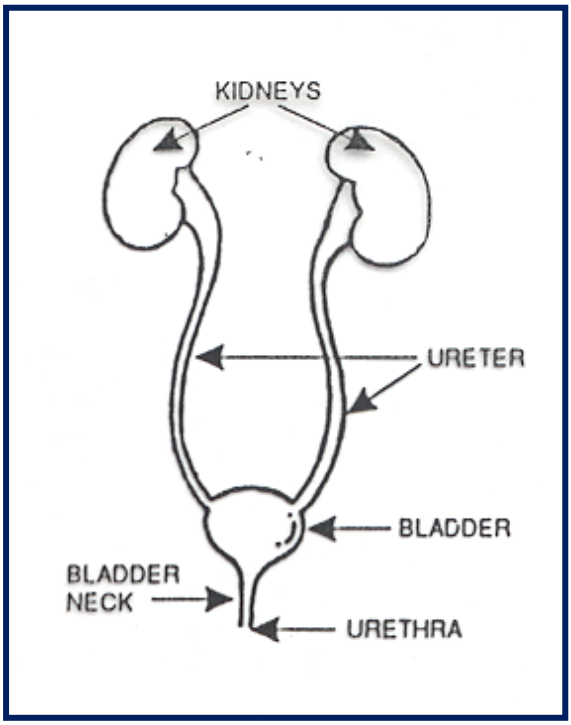
Auckland Cancer Society – Supportive Care
Phone - 09 308 0168; Website - www.cancernz.org.nz/welcome/

Bladder cancer information and support -Internet sites:
Patient information- independent charity, government funded sites:
www.cancer.gov/bladder (USA); www.cancer.org (USA)

What does the Bladder do?

The bladder is a hollow, muscular organ that collects and stores urine. Urine is produced by the kidneys and travels to the bladder via two tubes called ureters.

When the bladder is full, nerves send a message to the brain that you need to pass urine. Under your control, the bladder empties by contracting and urine travels down the outlet pipe (urethra) to the outside. This is called voiding.



What is a Total Cystectomy?

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

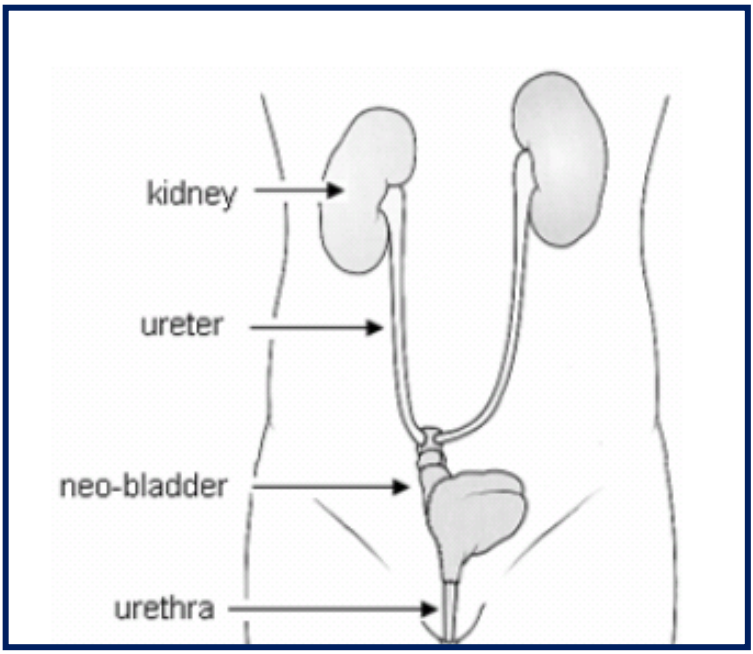
- In men, the bladder, prostate gland and seminal vesicles (small glands near the prostate) are removed.
- In women, the bladder and uterus are removed and the vagina is shortened. Sometimes the ovaries also need to be removed.

Once the bladder is removed a new method for storing and passing urine must be used. There are different ways this can be achieved surgically.

This booklet discusses the formation of a Neobladder.

What is a Neobladder (or orthotopic bladder reconstruction)?

This is a procedure that involves making a new bladder to store the urine. A section of bowel is used and made into a pouch that will hold the urine. Bowel ends are sewn up to allow the bowel to continue as before. The tubes from the kidneys (ureters) are implanted into the new pouch. This is then sewn onto the urethra (outlet pipe) through which you will eventually pass urine.



There is always the possibility, for a number of reasons that the surgeon may not be able to form a neobladder and may have to form an ileal conduit instead. This is an alternative to a neobladder and will have been discussed with you prior to surgery.

Why do I need a Total Cystectomy?

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

- cancer of the bladder and / or urethra
- cancer of the uterus, ovary, vagina or bowel that involves the bladder.

Potential short term complications

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

1. Excessive bleeding

This may occur during surgery and require a blood transfusion. Excessive bleeding can potentially be a serious event causing death. This is very rare.
Your wound, drain(s) and vital signs (blood pressure and pulse) will be monitored for signs of excessive bleeding.

2. Infection

Your chest, wound and urine will be monitored for early signs of infection and interventions 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 after surgery. You can also assist with the prevention of infection by maintaining good hygiene, getting up and around early after your operation and doing your deep breathing exercises.

3. Blood clot

There is an increased risk of blood clots in your veins while you are less mobile. Regular leg exercises and the use of antiembolism stockings for the prevention of clots are discussed further in this booklet. You will also be prescribed a blood thinning medication (anti coagulant).

4. Alteration in bowel function

Your bowel function may be slow to start following your operation but the medical staff will be monitoring this closely and give you laxatives as necessary. When your bowel starts moving again you may experience a period of loose motions (diarrhoea).

You should not be discharged until you have had a bowel motion.

5. 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 bowel 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. This condition is temporary but occasionally needs a nasogastric tube to drain the stomach's normal secretions while the bowel rests and recovers.

6. Bowel leak

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

Long term outcomes and potential complications

1. Changes in urinary storage and the ability to pass urine

a) Inability to store large amounts of urine in your new bladder

Your new bladder needs training to allow it to expand over time and store larger volumes of urine.

To start with, you will need to go to the toilet every 2 hours during the day to empty your bladder. At night time you will need to set the alarm to wake 3 hourly to empty your bladder.

b) Inability to empty your new bladder satisfactorily

You may not be able to empty your bladder satisfactorily, leaving a lot of urine behind.

You will need to relax your pelvic floor muscles to help empty your bladder. It may be easier to sit on the toilet to pass urine, leaning forward, arms folded across your lower tummy.

If you are not able to pass urine or small amounts only, you may need to pass a tube (nelaton catheter) up through your urethra (outlet pipe) and into your bladder to drain the bladder. This is called intermittent self catheterisation (ISC). You will be taught and supported to

do this procedure which may be temporary or may need to continue long term.

c) Mucus in the urine

Mucus is often seen in the urine as the lining of your new bladder is made of bowel and will continue to produce mucus. Mucus can sometimes block the passage of urine down your urethra (outlet pipe).

You will need to irrigate (wash around inside) your bladder by inserting saline into the bladder via a syringe connected to a nelaton catheter. Fluid is pushed into the bladder and then withdrawn to remove urine plus mucus. You will be taught and supported to do this procedure which may need to continue for a period of time.

d) Urinary Leakage

It is not unusual to have leakage (incontinence) following this procedure. This will improve over time.

You may need to wear pads to manage the leakage. You should continue to perform pelvic floor exercises (3-4 sets a day) to help strengthen the pelvic floor muscles and regain urinary control.

2. Metabolic Imbalance

Abnormal chemical reactions can occur as a result of absorption of chemicals, found in the urine, through the inside lining of the neobladder. If uncorrected, it can lead to deterioration in overall general health and wellbeing.

To prevent this, you may be asked to present to the lab for weekly blood tests initially. This is so that we can

prescribe appropriate medication to support your recovery.

3. Bladder stones

Very occasionally stones may occur in your new bladder and you may need treatment to remove them.

4. Sexuality and alteration in sexual function

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.

a) Women

For women, surgery results in a shortened vagina and loss of pelvic floor sensation. This may make sex difficult or uncomfortable and the ability to experience the sensation of orgasm may be affected. You should wait several weeks after surgery before attempting intercourse. It is advisable that you use a water based lubricant.

Total cystectomy often involves the removal of the uterus and sometimes the ovaries. If this is necessary for you, your surgeon will discuss the ongoing effects of this.

b) Men

For men, surgery involves the removal of the prostate gland and seminal vesicles. This results in the loss of ejaculatory fluid and

infertility because of the removal of the prostate gland and seminal vesicles.

Erectile dysfunction (impotence) occurs in the majority of men. This is because the nerves that supply the penis to achieve an erection lie very close to the bladder and prostate gland and it is sometimes impossible to avoid damage to these nerves during surgery. The degree to which an individual is affected is often linked to their sexual function before surgery.

For men experiencing erectile dysfunction that is ongoing, there are some possible solutions to this problem (currently none of these are government-funded):

- medication
- vacuum devices
- penile injections
- penile implants

5. 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 can be repaired if troublesome.

Length of Hospital Stay

You will come into hospital the day before your surgery. You will be given medication or enemas that help prepare the bowel for surgery. The usual length of stay is ten to fourteen days after surgery.

Before Surgery

Nil by mouth

The nurses in the ward will let you know when you need to stop eating and drinking before your 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 for you to agree to a blood transfusion and / or if you wish to have any of your body parts returned to you after surgery.

Our expectation is that you feel fully informed about all aspects of your surgery before giving written consent.

The following health professionals and support services are available to help you with this process:

- **Medical staff**

The Medical staff will explain the reason for the Cystectomy and the risks associated with the surgery. Your doctors will visit you every day while you are in hospital to provide medical care and answer questions about your surgery and progress.

Please ask questions and express your concerns; your family or people close to you are welcome to be involved.

- **Nurses**

The Urology Nurse Specialist is available during working hours on 021 815424 to help you with particular queries or concerns. Nurses will provide your preparation for surgery and care until you are discharged from hospital. When you are discharged from hospital your ward nurse will arrange for you to receive ongoing support, advice and practical help, if needed.

- **Cancer Services: Psychology and Social Work**

The Cancer Support Psychologists and Social Workers within our District Health Board are able to provide support to patients with a cancer diagnosis and complex psychological and social needs. If you feel you would benefit from referral to this Service, please talk to your Medical and Nursing team.

- **Cancer Society**

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

Tests

Blood samples

Samples of your blood will go 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.

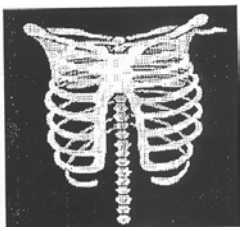
We will need your written consent before a transfusion is able to take place.

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

Pelvic floor exercises

The pelvic floor muscles form the floor of the pelvis, supporting the organs within. A toned pelvic floor assists with bladder and bowel control. Pelvic floor muscles help prevent leakage by closing off bladder and bowel outlets. Relaxation of pelvic floor muscles allow for effective bladder and bowel emptying.

Pelvic floor exercises are necessary to assist you in regaining urinary control. These should be taught to you prior to your surgery. Following surgery, stop the exercises while the catheter is in place. Once the catheter is removed, you should continue to perform these exercises.

View the following internet web site for more information on pelvic floor muscle and exercises:

Male pelvic floor muscle – 3D animation

https://www.youtube.com/watch?v=rQQSqLCF12g&feature=youtu.be&list=PLdpC0SZfU2Oj72fBJBpvBRHw_92PBYiQb

Female pelvic floor muscle – 3D animation

https://www.youtube.com/watch?v=q0_JAoaM6pU&list=PLdpC0SZfU2Oj72fBJBpvBRHw_92PBYiQb

Breathing exercises

Breathing exercises will be taught to you by your nurse or physiotherapist.

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 the muscle tone and promote the return of blood in your leg veins to your heart. These include pedaling 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-embolism stockings and blood thinning medication

Special stockings are worn to 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.

You will also be prescribed a blood thinning medication (anti-coagulant) called clexane. This will be injected into your tummy daily via a fine, short needle. The injections will commence after your surgery while you are on the ward and continue for about a month following your discharge.

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. You may need to spend a night or two in the High Dependency Unit (HDU) for more intensive nursing care.

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 wound site and wound drains

Wound site

Your wound will be abdominal and the suture line (stitches or staples) will extend from just below the breastbone to the pubic bone.

Stitches (if not dissolvable) and staples 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.

Wound drains

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

These are removed when the amount of drainage is minimal and the operation area is healing.

Urinary catheter

You will have a tube in the urethra (outlet pipe) that drains urine from your bladder. This tube must be secured to your leg for comfort and to prevent any tugging that may damage the newly rejoined urethra to the neobladder. Please inform your nurse if your catheter is not secure.

Another catheter may be inserted into the bladder through the abdominal wall (suprapubic catheter). The nurses will flush the catheter with saline to keep it free from mucus.

The timing of the removal of the urinary catheters varies according to your doctor, usually about ten - twelve days after surgery. If you are discharged prior to this, you will be taught how to manage the catheter and drainage bags. The District Nurse will contact you at home to ensure you are managing your catheter and have adequate supplies.

Ureteric stents

Ureteric stents (fine plastic tubes inserted at the time of surgery) will be visible coming out of the abdomen and into a temporary bag on your abdomen. These stents pass up into each ureter and support the new structure while healing occurs.

These are usually removed ten days after surgery. This is a simple procedure that does not require anaesthetic.

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.

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.

Oxygen

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

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 separately 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. It is important that you use this if necessary to allow you to move more freely without pain.

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 Patient Controlled Analgesia (PSA) or epidural or on its own to manage pain that is not controlled by tablets alone.

Oral pain relief

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

Medications are available for the relief of nausea and vomiting, if they occur. The nurse will give you your usual medications while you are in hospital.

Comfort cares after your surgery

To help keep you comfortable, your nurse and / or health care assistant will assist with bed washes, and showering. They will help you to get out of bed, sitting in a chair initially and moving about as soon as possible. Mouthwashes, ice to suck and sips of fluid will be encouraged until it is appropriate for you to progress your diet.

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, you may slowly progress to full meals as your appetite dictates. Your doctors will keep you informed about what you can eat and drink. 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 be encouraged and assisted to mobilise as soon as possible. This includes: sitting in a chair for a short time the day following your surgery; walking short distances within a day or two of your surgery. Your level of activity will increase as you recover.

Importants points:

What to expect after your catheter has been removed and when discharged

See pages 7-8 for more details

- The sensation of bladder fullness in your new bladder is different
- You will need to empty your bladder frequently (2 hourly during the day and 3 hourly overnight to start)
- You may need to perform intermittent self catheterisation to help empty the bladder once the catheter is removed
- You will need to check the urine for mucus and washout the bladder as necessary to prevent blockage
- Urinary leakage is common. Be prepared with pads and restart pelvic floor exercises
- You will be discharged home with medication to help your recovery, including daily clexane injections
- You may be asked to attend the lab for weekly blood tests.

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 (no more than 5kg) and straining during this period. This includes such things as contact sports, mowing lawns, gardening, vacuuming and lifting heavy washing baskets.
- You can drive about 6 weeks after the operation. You need to feel comfortable to do an emergency stop without difficulty.
- Sexual activity may be resumed when you feel comfortable to do so. This may take several weeks.
- 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 indicate a urinary tract infection and require treatment.
- Drink two to three litres of fluid daily as you are particularly prone to dehydration.
- Your hospital doctor will provide your first sickness benefit certificate/medical certificate and will advise you when you are able to return to work.
- Expect your normal energy levels to take up to 3 months to return following surgery.

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 Nurses

- When you are discharged from hospital District Nurses may visit if you require nursing care following discharge. Contact details will be left on the first visit.

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 if applicable.

Outpatient's appointments

- You will receive a follow up appointment through the Urology Service two to six weeks after discharge (as requested by the surgeon). This will either be a telephone appointment or an appointment to attend the Outpatient clinic at the hospital. The details will be on a letter which will be posted to you.

Issued by: **Urology Department**
Date reviewed: **August 2020**
Classification: **01004-20-001**