Introduction

It is essential that you read this booklet carefully. If there are any areas that are not clear, or there are questions you need answering, then please use telephone numbers at the back of this booklet to contact the urology nurse specialists. It is very important that you understand the operation and how it will affect you.

The specialist nurses are available to you even after you are discharged. If you have any questions or concerns, please feel free to contact them. They are there to help you through the whole process.

Why do I need this operation?

Your doctor will have discussed with you the need for a cystectomy (this is the surgical removal of the bladder and surrounding lymph nodes). This operation is nearly always performed for patients who have been treated for bladder cancer. You may or may not have had other forms of treatment for bladder cancer before the decision for a cystectomy was discussed with you.

Why do I need this operation?

The reason for undergoing this surgery is to attempt to cure you of having bladder cancer by removing the bladder. The reason for offering bladder reconstruction is to prevent you from living with a urostomy (urinary diversion). There is no other surgical alternative to a cystectomy. If you do not want to undergo this treatment option, then you and your doctor can discuss whether chemotherapy and radiotherapy may be possible.

If this treatment option proceeds, then your bladder will need regular inspections with cystoscopy and CT scans to make sure
that the cancer has not returned. However, there is a risk for some patients who have undergone chemo-radiation, that they will then require a cystectomy if the cancer returns.

If you choose **not** to undergo curative treatment, you will continue to be seen in clinic. We can see you on a regular basis and deal with any issues and new symptoms you may have. Continued support will be given to and arranged by your specialist nurse, with referrals to community (district) nurses, home care (hospice) nurses and GP as necessary.

Having a neo (new) bladder reconstruction means that you do not have to have a urinary stoma on the abdomen. The neo-bladder is made using a length of your bowel, and it is made into a bladder-shaped structure. This is then attached onto your urethra.

For male patients, the prostate gland is also removed.

For female patients the removal of the womb, fallopian tubes and ovaries are included.

**Buddy system**

No matter how many leaflets and booklets you read discussing this operation, sometimes it is helpful to talk to a patient who has undergone this operation.

If you feel that you would like to talk to one of our patients, please ask your specialist nurse who can put you in contact with someone. All *buddies* have volunteered their services to help other patients through this process.

If, following your surgery, you would like to be a *buddy*, please mention this to your specialist nurse or consultant.
Admittance to hospital

What care will you need before the operation?

You will receive an appointment to attend a pre-clerking clinic before your operation, to see the specialist nurse, so all of the necessary investigations can be done in preparation for your surgery. The specialist nurse will see you again on your admission day. The nurse will go through all of your questions you may still have.

A member of the medical team will visit you in the evening to put up an intravenous infusion (IVI) into your arm. This is to keep you hydrated whilst you are waiting for the operation and are nil-by-mouth (NBM).

The medical and nursing staff will also give you some medication to enable you to open your bowels. Once you have taken this medicine, you will only be able to drink clear fluids (drinks that contain no milk).

After your operation

What care will you need after the operation?

Sometimes, your consultant may decide that you need to be nursed in the Intensive Therapy Unit (ITU) for a short time immediately after the operation. Once you have recovered, you will then be transferred to the ‘post op room’ on the urology ward where you will continue to be closely monitored. As you improve, you will then be moved back onto the ward. The need to be nursed on ITU depends on the surgery and other health issues you may have.

If there is no need for you to be cared for in ITU, then you will be nursed in the ‘post op room’. There will be certain tubes attached to you, but each tube serves a purpose and helps you to recover. These are detailed overleaf:

To help you wake up from the anaesthetic, you may have
some oxygen therapy in the form of a small tube near your nose. As you breathe normally, you will breathe in the oxygen. This usually lasts for 1–2 days.

Your pulse and blood pressure will be monitored very frequently for the first 24–36 hours. This will be done by a machine connected to your arm with a Velcro cuff. You will remain NBM for a while, whilst your bowel recovers and heals from the operation. All of the fluid that your body requires will be given to you through the IVI either in your arm or neck. As your bowel begins to work normally again, you will be allowed to drink. Once you are drinking normally, your IVI will be removed. You will then be able to eat.

You may have a fine tube into your nose and down into your stomach (naso-gastric tube). This helps to stop you feeling sick, and is usually removed 24–36 hours after the operation. It will be attached on free drainage to a small bag.

Your pain will be controlled with an epidural infusion. This is a special painkilling pump that works continuously and is set up whilst you are having your anesthetic, decreasing the need for further pain killing injections. The anesthetist will discuss this with you before you go to theatre. The infusion will stay until you are drinking. Then you may be given pain relief in the form of a tablet or suppository. Please ask the nursing staff if you need anything more for pain relief.

For the first few days after your operation, the nursing staff will assist you with your hygiene needs. Soon, you will be able to do this for yourself.

You will be helped to get out of your bed 24–36 hours after the operation and sit in a chair. This helps to reduce the risk of developing deep vein thrombosis (DVT) and to prevent developing a chest infection. Getting you moving as soon as possible stops you from becoming stiff and sore from the operation. Soon you will be walking without help around the ward. Whilst you are sitting in a chair or resting in bed, it is
important to do your ‘leg exercises’. These will have been discussed with you in the prevention of a DVT.

Your wound will have dissolvable sutures (stitches). These can take up to 2–3 months to completely dissolve. To begin with you will have a dressing over the wound, but once it is clean and dry, you no longer need a dressing.

Your bowels will need time to recover from this operation, and until you are eating and drinking normally, then you may need some gentle laxative to keep your motions soft and easy to pass. You need to avoid becoming constipated as straining to open your bowels may cause unnecessary pain and discomfort.

You will have two smaller tubes called ureteric stents, coming out of your abdomen. These tubes will be removed approximately on day 10. They help to keep the ureters open or clear (patent) until the new bladder heals inside. They are easy to remove and will come out before you go home.

You will also have a wound drain – this is a small tube that drains any excess fluid from where the operation was. The tube will be attached to a small bag. The wound drain will be removed before you go home.

You will have a urethral catheter down your water pipe, which will be attached to a drainage bag. This tube will need to be flushed at regular intervals. In the beginning, the nurses will do this for you. As you recover, the staff will teach you how to do this. The catheter flushes need to continue for 2–3 weeks. At some point during this time, you will be able to spend some time at home. You will be given a date to return to the urology ward.

On your return, an x-ray called a cystogram will be performed. This involves putting some contrast (x-ray dye) down the catheter. This is to check that your new bladder has healed and is watertight. Once this has been established, it is safe to remove the catheter. It is then time to begin using the new
bladder and to commence bladder training to regain continence (to remain dry). It is at this important time that you have support from the medical, nursing staff and your family during this time. By continuing to perform your pelvic floor exercises, you should see a gradual return of continence. Whilst this is improving, you will need to wear continence pads. Your specialist nurse will be able to discuss this with you whilst you are an inpatient.

**Going home**

**What aftercare will I require?**

You will need to expect to be in hospital for 1–3 days whilst your catheter is removed. A referral to the district nurses will be made on your behalf for a supply of continence pads whilst you are in the process of regaining bladder control.

You will need to recuperate for a while, and it may take you 6–12 weeks to fully recover before you consider returning to work. You should avoid heavy housework, shopping, gardening and active sports for the first 6 weeks. Gentle exercise such as walking at a steady pace will do no harm. Your activity can be slowly increased during this period.

Remember – during this time you will be concentrating on regaining bladder control. You may need to involve family and friends during this period if you live alone. You may be entitled to some help for the first few weeks at home. If you feel that this may apply to you, or you are worried about how you will cope, then please mention it to the specialist nurse during your pre-clerking appointment.

It is important to maintain a good fluid intake, particularly if the weather is hot or you are holidaying abroad.

You may notice ‘bits’ in your urine. Do not be alarmed, this is natural and is mucus. This is made naturally from the piece of bowel that has been used to create your new bladder. You
should be able to empty the mucus away from your bladder as you pass urine the normal way. The amount of mucus will differ from one person to the next. If you are concerned in any way, then discuss this with your consultant or specialist nurse.

You will be able to wash and dress and cope with the stairs on when you leave hospital but remember that you will tire quicker than is usual for you. You will need to gradually regain your strength. It is common to need to rest for a few hours each afternoon. As you recover from your surgery, you will gradually return to your normal activity.

You are not able to drive for 4–6 weeks following this operation or until you can comfortably wear a seatbelt and are capable of performing an emergency stop. It is advisable to check with your insurance broker as different insurance companies may have varying policies regarding the length of time following surgery they are happy to provide cover for.

You may find that you are unable to sleep well at night to begin with. This is because you are not as active during the day so soon after the surgery. This will settle as you begin to recuperate.

Remember – it is very important to set an alarm clock at least 1–2 times during the night and get up and empty your new bladder.

Your appetite will be poor to start with. Do not worry having 3–4 smaller meals will be easier to eat and digest. As your activity increases, you should be able to return to eating normally. If you feel this is not happening and you have concerns at home – please call your specialist nurse for advice.

You may find that your bowels are sluggish to begin with. This is due to many reasons; your appetite is smaller than normal, your analgesia may be a factor, your activity is slower than normal. Do not worry. Try to drink plenty of fluids and to eat some fibre daily. You should avoid straining to open your
bowels. If this is becoming a problem, contact your GP, who will prescribe a mild laxative. You can help yourself by drinking natural fruit juices, eating brown bread, vegetables etc. If you are worried about your diet, please ask the specialist nurse. They will be happy to discuss this with you before you go home.

You will be seen in the outpatient clinic at about 6 weeks following your discharge and regularly afterwards. Please contact your consultant’s secretary if you have not received this appointment.

Returning to work will depend upon what type of job you do. Please discuss this with your consultant/specialist nurse either before going home or at the outpatient appointment. You may need or choose to have more time off work to concentrate on performing your pelvic floor exercises, regaining bladder control and no longer being reliant on the continence pads.

You can get a sick note to cover the time spent in hospital from the ward clerk before you go home. Your GP will be able to organise a sick note for work to cover your recovery time spent at home.

**Regaining your continence – pelvic floor exercises**

These pelvic floor exercises should be practiced as soon as you have made the decision to opt for the neo bladder. By doing them before the operation you will become proficient at them so that after your catheter is removed you will know exactly how to do them correctly.

The floor of the pelvis is made up of layers of muscle and other tissues. These layers stretch like a hammock from the tail bone at the back to the pubic bone at the front. The pelvic floor supports the bladder and bowel. The urethra
(water pipe) and rectum (back passage) pass through the pelvic floor muscles. The pelvic floor muscles play an important role in bladder and bowel control.

**How to contract the pelvic floor**

The first thing is to correctly identify the muscles that need to be exercised.

1. Sit or lie comfortably with the muscles of your thigh, buttocks and abdomen relaxed.
2. Tighten the ring of muscle around the back passage as if you are trying to control diarrhoea or wind.
3. Relax the muscle again. Practice this movement several times until you are sure that you are exercising the correct muscle. Try not to squeeze your buttocks (pelvis thrust) or tighten your thigh or tummy muscles.
4. Imagine you are passing urine, trying to stop the flow midstream, and then restarting it. (You can do this for real if you wish, but do so only to learn which muscles are the correct ones to use and then do it no more than once a week to check your progress, otherwise it may interfere with normal bladder emptying).

For men – if your technique is correct then each time you tighten your pelvic floor muscles you may feel and see the base of your penis move slightly towards your abdomen.
Exercising pelvic floor muscle

Now you can feel the muscles working you can start to exercise them.

1. Tighten and draw in strongly the muscles around the anus and the urethra all at once. Lift them up inside. Try and hold this contraction strongly as you count to five, then release slowly and relax for a few seconds. You should have a feeling of letting go.

2. Repeat and relax. It is important to rest in between each contraction. If you find it easy to hold the contraction to the count of five, then try and hold for the count of ten.

3. Repeat this as many times as you are able to up to a maximum of 8–10 squeezes. Make each tightening a strong slow and controlled contraction.

4. Now do 5–10 short fast contractions, pulling up and immediately letting go.

5. Do the whole exercise routine at least 4–5 times each day. You can do it in a variety of positions; laying, standing, sitting and walking for example.

While doing The Exercises

Do not:

- hold your breath
- push down instead of squeezing and lifting up
- tighten your tummy, buttocks or thighs

Good results will take time. In order to build up your pelvic floor muscles to their maximum strength you will need to work hard at these exercises. Following the removal of catheter, you may not notice an improvement for several weeks, but it is important not to become disheartened; your control will improve.
It is important at this difficult time to remain positive, get support from family and friends and liaise with your specialist nurse.

**Sexual function**

**Males**
Your prostate will have been removed as part of your operation. The erectile nerves that run along side the prostate gland may have been temporally or permanently damaged. This is called being impotent. Therefore you may need assistance in achieving an erection. This will be discussed with you in preparation for your surgery and will form part of your informed consent.

There is an erectile dysfunction clinic managed by a specialist nurse. As you recover from the surgery and bladder control is regained, you can be referred to this clinic as apart of your ongoing recovery. The specialist nurse will discuss with you the different options that are available and provide expertise and support should you wish to pursue treatment and then monitor its effectiveness. This clinic is run separately from your appointments to see your consultant.

**Females**
As part of you surgery you may have had a hysterectomy. Your ovaries and fallopian tubes will also have been removed. During the operation, it may have been necessary for the top part of your vagina to be removed. This is unavoidable in this type of surgery. Intimacy will be possible but certain sexual positions may be more comfortable to begin with.

If you and/or your partner are concerned about this, please do not be afraid to raise these questions with your consultant/nurse. They will understand and be able to offer you help and advice.
Possible complications

Any type of surgery carries with it the risk of possible complications. These would have been discussed with you before. You can help prevent these from occurring with the following advice:

Your wound may become infected. It may feel hot and swollen. Do not use perfumed soaps/lotions. Bathe the wound with plain water and gently pat dry. If it is not responding, seek advice for your GP. He/she may take a swab to see if there is any infection that would need antibiotics. Sometimes the wound may leak serous fluid, do not worry, a district nurse will be asked to visit you at home. The district nurse will care for your wound until it has healed completely.

Deep vein thrombosis

You are at risk of developing a Deep vein thrombosis (DVT) if you are inactive following your surgery. Try not to sit down for long periods, potter around the house until you feel strong enough to go outside. Remember to practice the leg/ankle exercises taught to you on the ward. Continue to wear the surgical stockings worn during your hospital stay when at home for 2 weeks, depending upon your mobility.

Seek advice from your GP immediately if the muscles in the back of your lower leg(s) become hot, swollen and painful to touch.

Pulmonary embolism

Seek the advice of your GP if you experience sudden breathlessness. This may be caused by a Pulmonary Embolus (PE). This would require urgent admission to hospital to correct. This is caused by a blood clot which has formed in your legs, and has traveled to your lungs.
Acidosis

You may feel that you are recovering normally but then suddenly feel tired/lethargic. Please contact the specialist nurse who will be able to organise bloods tests. This may be due to a condition called ‘acidosis’. This is caused when your new bladder reabsorbs incorrect levels of chemicals thus causing an imbalance. It is diagnosed with blood tests and easily corrected with oral medication.

If you are concerned that you may be experiencing these symptoms, then please call your specialist nurse for clarification.

Other complications

You may be aware of not being unable to empty your new bladder as well as previously. Sometimes, sitting down to void may be an improvement. However if this is worrying you then contact your specialist nurse. There may be 2 things to consider. The new bladder does not empty properly. If this is true then you may need to pass a lubricated catheter down your urethra (water pipe) to drain the urine away. This may have to be done 2–5 times per day. There may be some scar tissue that has developed around where the new bladder has been sewn onto your urethra. A small operation will easily correct this.

Further advice

Once you have recovered from your surgery and getting on with things, you may wish to consider the following points:

1. You may wish to take a short break. This is acceptable within the UK. Please remember that driving long distances is tiring. You will need to plan to take extra breaks during your journey.
2. Holidays abroad are OK once you have fully recovered and are continent. Previous patients have commented that they were not ready for this type of travel until approximately 2–3 months. This is something to consider as this may pose problems in obtaining travel insurance.

3. Wherever you decide to go on holiday, you will need to consider taking your continence pads with you and possibly mattress protection.

4. If you are flying for a length of time, it is important to take precautions. Drink plenty and try to move around (mobilize) during the flight. If at all possible wear some support stockings (similar to those you wore after your operation) whilst flying.

Contact Numbers

For further advice please use the contact numbers as listed below:

**Urology specialist nurses**
Telephone: 0121 627 2277
Ward 409 – 0121 371 4090

**Macmillan cancer support**
Telephone – 0808 808 0000
www.macmillan.org.uk

**Cancer help UK**
www.cancerhelp.org.uk

‘The Patrick Room’
at the outpatient department, in the cancer centre at the Queen Elizabeth hospital
Tel: 0121 472 1311 Ext 8417
Glossary Of Terms

Cystectomy – an operation to remove the whole bladder

Urethra – the tube or water pipe that drains the urine from the bladder

Deep vein thrombosis (DVT) – Blood clots that have formed in the veins in the legs

Pulmonary embolism (PE) – a blood clot that has formed as a DVT and traveled to the lungs

IVI/Intravenous Infusion – commonly called a ‘drip’ is a method of giving fluid into a vein in the arm to provide hydration

Ureters – the two tubes that drain urine from each kidney into the bladder

Impotence – the inability to achieve or maintain an erection for sexual intercourse

Prostate – a small gland in males, usually the size of a walnut that lies at the neck of the bladder

Nil-by-mouth (NBM) – having nothing to eat or drink by mouth in preparation for surgery

Intensive Therapy Unit (ITU) – is where patients that have just had surgery and need to be closely monitored

Cystogram – an x-ray where contrast is placed down an urethral catheter to demonstrate whether there are ‘leaks’ or if the bladder is ‘watertight’

Neo-bladder reconstruction – is where new bladder is made using a length of bowel, usually performed where the original bladder has had to be removed, usually due to disease
The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk or call 0121 627 7803

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