



Having a clam cystoplasty (bladder augmentation)

– Information for patients

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It is essential that you have read this booklet carefully and that you understand the operation and its effects on you.

If any questions arise from reading this booklet the urology clinical nurse specialists are available to talk to. You will find their telephone number at the end of the booklet. If your call is not answered please leave your name and telephone number on the answer phone and they will return your call as soon as possible.

The nurse specialists are also available to you after you have had your operation particularly in the first few weeks after discharge from hospital.

'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 you would benefit from speaking to another patient please ask your specialist nurse to put you in contact with someone. All 'buddies' have volunteered their services to help other patients through this process.

What is a clam cystoplasty?

A clam cystoplasty is a major operation to increase the size of the urinary bladder by placing a segment of your bowel (usually the small intestine) into the bladder wall. This operation increases the capacity and stretchiness of your urinary bladder. The nerve pathways are also disrupted which means the effect of bladder contractions are reduced.

Why do I need a clam cystoplasty?

Video urodynamic investigations have identified that your urinary bladder develops unusually high pressures which overwhelm your sphincter muscle allowing your bladder to leak.

A symptom of this maybe that you frequently leak urine and if you are aware of when you need to pass urine, you get very little warning ('urgency'). Occasionally high pressures in the urinary bladder can cause damage to your kidneys.

The aims of the operation are to;

- protect your kidneys from the effects of high pressures
- make you dry (less urinary leakages)
- reduce the frequency you have to empty your bladder
- to increase bladder capacity
- to control autonomic dysreflexia (please read below for more information)

What is autonomic dysreflexia?

Autonomic dysreflexia is a potentially life-threatening complication. It can affect people with paralysis as a result of a spinal cord injury at the middle of the chest or higher.

It is commonly seen in tetraplegia (where both the arms and legs are paralysed, also known as quadraplegia).

Autonomic dysreflexia is caused by a problem with the autonomic nervous system, the part of your nervous system that regulates many of the body's functions you do not have to think about, such as blood pressure, digestion and breathing.

It occurs when the normal function of your autonomic nervous system is interfered with. For example, irritation of the bladder wall such as urinary tract infection, a blocked urinary catheter or irritation of the bowel such as constipation could all affect the nervous system.

Your nervous system will send a signal to your brain to find out how to deal with the irritant. However, because of the injury to your spinal cord, the signal will be unable to reach your brain.

The blocked signal will then trigger a series of abnormal reflexes, which cause your autonomic nervous system to raise your blood pressure and slow your heartbeat.

If it is not treated, autonomic dysreflexia can cause seizures and bleeding inside the brain, which can be fatal.

Triggers of autonomic dysreflexia

The most common trigger of autonomic dysreflexia is a problem with the bladder, such as:

- a urinary tract infection - an infection of the kidneys, bladder, ureter or urethra
- too much urine in the bladder
- a blocked catheter (the tube used to drain the bladder)
- the bag used to drain the bladder being too full
- bladder stones

What are the alternatives to this operation?

- Observation
- Bladder training – learning how to resist visiting the toilet too often
- Pelvic floor muscle exercises
- Medication- such as anticholinergic or antimuscarinic agents which work by blocking certain nerve impulses to the bladder which stops it contracting so readily helping it to hold more urine
- Botox injections into the urinary bladder – please see Trust leaflet ‘Use of botulinum toxin (Botox) in bladder conditions’ for more information
- Urinary diversion - An operation to re-route urine flow from its normal pathway resulting in a stoma (opening on the abdomen)
- Neuromodulation – electro-stimulation of the nerves to the urinary bladder

What will happen before the operation?

You will receive an appointment for a ‘pre-assessment’ to assess your general fitness, and perform baseline investigations e.g. blood pressure and to screen you for MRSA.

You will be asked not to eat and drink for 6 hours before surgery.

You are usually admitted the same day as your operation via the admissions lounge. You will be asked to sign your operation consent form giving permission for your operation to take place, showing that you understand what is to be done and confirming that you wish to proceed.

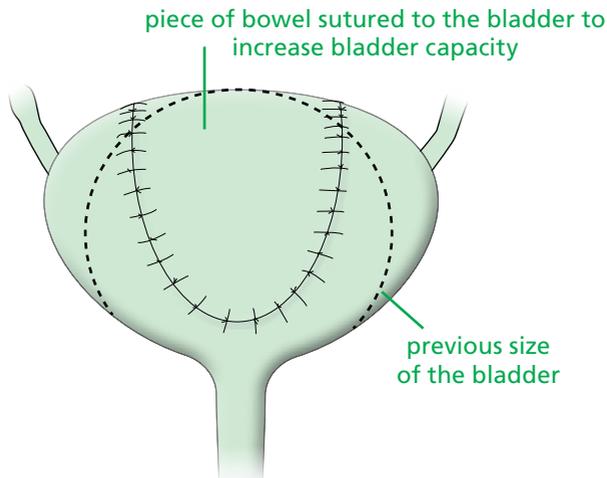
Ensure that you are given the opportunity to discuss any concerns and ask any questions you may still have before signing the consent form. An anaesthetist will also see you and will discuss pain relief for after the surgery.

You will be provided with elasticated stockings to help prevent venous thrombosis (blood clots in your legs) in addition to a drug called Clexzane; an injection given under your skin.

The operation

Your operation is performed under a general anaesthetic (being put to sleep) and takes approximately 3-5 hours. It is usually carried out through a vertical scar in the lower half of your tummy but occasionally it can be done through a curved horizontal scar in the 'bikini line'.

Through the incision (cut) the surgeon will open your bladder and divide it almost in two. A patch made from a separated segment of your bowel will be stitched in place to re-build the bladder wall. The surgeon will re-join the ends of the bowel where the segment has been removed.



What will happen after the operation?

After the operation you may spend a short period of time on a high dependency ward (Critical Care Unit) otherwise you will go to the Urology Ward (W624).

You may have a blood transfusion and a further drip in your arm for a few days until you can eat and drink.

You will have two catheters in your bladder; one in the urethra (water pipe) and one through your tummy (supra pubic catheter) to drain urine while your bladder is healing for about 4 – 6 weeks.

You will also have a drainage tube close to the wound to remove any excess fluid away from the internal area where the operation has taken place.

You may also have a small tube in your nose to drain your stomach. Gradually these will be removed 3 - 5 days after your operation.

If stents (small tubes) are used, which keep your ureters (the tubes that drain urine from your kidneys to your bladder) open, they will be removed approximately 7 -10 days after your operation.

It is likely that you will experience some pain following this major surgery, however please be re-assured that the ward staff are aware of this. It is our aim to keep you as comfortable as possible therefore please do not be embarrassed to tell a member of staff if you are in pain.

You will be encouraged to mobilise as soon as possible after your operation to encourage your bowel to start working again. You will start to consume food and drink as soon as possible.

A physiotherapist will show you some deep breathing and leg exercises.

It will take at least 6 weeks for you to recover fully from this surgery.

It will be necessary for you to avoid straining your abdominal muscles so you will be unable to do any heavy lifting for 3 months after your operation. Spinal patients will need to slide transfer or use a hoist for 6 weeks after the operation.

Clips or stitches are usually removed from your wound site after approximately 10 days, although some stitches dissolve and do not need to be removed.

Will I leak urine with the new bladder?

The bladder's natural continence (control) mechanism is not affected by the surgery. If it was working properly before surgery then you should not leak afterwards. Some people however may need some surgery to this area to prevent leakage and this can often be performed at the same time.

Some patients may need a completely new continence mechanism inserted called an artificial urinary sphincter.

The bladder can often be emptied in the normal (natural) way. Some patients however may have difficulty emptying their bladder adequately or not at all and will need to perform intermittent self-catheterisation.

Intermittent self-catheterisation involves inserting a narrow hollow plastic tube called a catheter into the bladder through the urethra (water pipe) or through a mitrofanoff continence stoma. Once urine is drained, the catheter is removed. This procedure is taught to all patients before surgery in case it is required.

How often should you empty your bladder?

At first you may find that you will only hold small amounts of urine and will have to empty your bladder every hour. As your bladder stretches to hold more urine you should be able to pass urine every 3 - 4 hours.

This depends on how much you can hold comfortably, how much you have had to drink and how much sensation of wanting to pass urine you get. Some patients do not need to pass urine for 4 - 6 hours.

You should never leave it longer than six hours to pass urine, if the bladder becomes too full it may 'burst'.

What happens at night?

Most people find that by cutting down on their drinking 2 hours before bedtime and completely emptying the bladder (either naturally or by catheterisation) before they sleep, they achieve a normal sleeping pattern.

If you produce a lot of urine at night or have had a lot to drink before bedtime you may have to get up to empty your bladder during the night. Allowing the bladder to get too full may cause it to 'burst'.

In time the full sensation of the bladder will probably wake you up naturally, but if you have no sensation of fullness you may need to set an alarm clock to wake you.

Mucus production in the urine

The interior wall of the intestine produces mucus (fluid) to protect and grease the wall and to allow for easier elimination of stools. It is a yellowish gelatinous (jelly-like) substance.

The segment of bowel used to increase the size of the urinary bladder will initially produce a lot of mucus. As the intestinal patch adapts to its new position over several months the amount of mucus will lessen.

It can however, be troublesome early on and tends to cause blockages in the catheters which need to be addressed promptly. Before you are discharged you will be shown home bladder washout management techniques and these will need to be performed at least twice daily at first. You may also see blood in your urine or in a vaginal discharge for up to 1 month after surgery.

Urinary tract infections

These may be more common after this surgery due in part to the difficulty in completely emptying the bladder. Drinking a good volume of fluid and regular self-catheterisation will help prevent these occurring.

If symptoms occur, a urine test is required by your GP Practice. Antibiotics are usually only needed if you have a temperature and feel unwell.

Fluid intake

You are advised to drink at least 8-10 cups of fluid each day to keep the mucus diluted (weak). Drinks which are high in vitamin C also help keep the urine free of mucus. Cranberry juice also helps make the mucus less thick and helps reduce the risk of infection. It is recommended that you drink 2 small glasses of this juice daily. If you find the taste too sharp you may dilute it with other fruit juices or water. You should drink more in hot weather.

Bowel

You may find that your bowel regime is affected by this surgery for several months. This is temporary; therefore you are advised to continue with your usual regime.

What should I expect when I return home?

Please allow yourself plenty of time for rest once you have been discharged. It is best to take gentle exercise at first, such as walking, slowly increasing as you feel able. You should aim to reach your pre-operation level of activity 3 months following surgery.

It is important that you make sure your catheters are always kept unblocked. If you cannot get them to flow again, please report by phone to the ward, nurse specialist or urology doctor on call as soon as possible.

Bathing and showering

Showering is preferred until your wound is healed. Avoid the use of highly perfumed soaps, creams and talc near the site and make sure you dry the area carefully. If the wound site becomes red, hot, swollen or leaking an unpleasant discharge please seek advice from your GP, district nurse or nurse specialist.

Equipment supplies

The nurse who discharges you home will give you the required equipment and ordering information for performing your bladder washouts. Further supplies can be obtained by prescription either directly from your chemist or from a delivery company such as Fittleworth.

You and your GP will be informed of the products you require by the nurse and the first order placed with the home delivery company should you choose to use it.

Diet

Try to eat a healthy well balanced diet with plenty of fresh fruit and vegetables and fluids. In hot weather you should increase your fluid intake.

Sex

You may resume your sex life after 6 weeks if you feel ready and comfortable. Speak to your urologist if you want to become pregnant. Although there should be no undue difficulties with pregnancy, you should be closely monitored. Urinary infections may be more of a problem than usual.

This surgery does not affect male sexuality or fertility.

Returning to work

You may return to work approximately 8 weeks after the operation but you may need longer if you need to establish a confident programme of clean intermittent self-catheterisation.

Playing sports

Contact sports such as rugby, football or hockey are best avoided. There are no restrictions with swimming.

Going on holiday

There are no restrictions when going on holiday but do not forget to take an adequate supply of catheters, appropriate equipment and antibiotic course if you suffer from urinary tract infections. Always carry equipment in your hand luggage as well as in your suitcases in case these go missing.

You should drink a 1.5 – 2 litres of fluid in hot weather and during long flights. Catheterise yourself immediately before any long journey.

Some patients prefer to have an indwelling catheter, a tube that remains in place in the bladder by means of a deflatable balloon connected to a leg bag for long flights or journeys. Please carry a letter from your doctor with you explaining the operation you have undergone and the need to carry equipment with you.

It is advisable to wear a medical information bracelet or necklet as a safety precaution. Should you ever be in the unfortunate position of being taken to hospital and not be able to communicate with the hospital staff for whatever reason, they may not realise what type of operation you have had. The information they can obtain from such bracelets or necklets may stop any damage or unnecessary treatment being carried out.

Long term follow up

It is very important that you are followed up regularly by the Urology Department, your appointments will be made by the medical or nursing team. Once stable you will have an annual ultrasound scan of your Kidneys and blood samples taken.

Points to remember

You should contact your GP, the Ward or your nurse specialist if:

- You think you have a urine infection
- Your operation scar becomes hard, reddened, inflamed or begins to ooze discharge
- You have persistent abdominal or back pain
- You suffer persistent nausea or vomiting

Contact numbers

If you have any questions regarding the content in this leaflet, please contact the Urology Team via the number below.

Urology Nurse Specialists

Tel: 0121 371 6932 or 0121 371 6929

The following contact details are for recommended suppliers of medical identification jewellery.

Medic Alert Foundation

Tel: 01908 951045 www.medicalert.org.uk

SOS Talisman Ltd

Tel: 020 8554 5579 www.sostalisman.co.uk

Acknowledgements

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The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm

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