



University Hospitals Birmingham
NHS Foundation Trust



Cystectomy and Urinary Diversion (for women)

Patient Information

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Introduction

It is essential that you read this booklet carefully and if there are any areas that are not clear or there are questions you need answering then there are telephone numbers at the back of this booklet for you to contact the urology nurse specialists. It is important that you understand the operation and its effects on you.

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

Why do I need this operation?

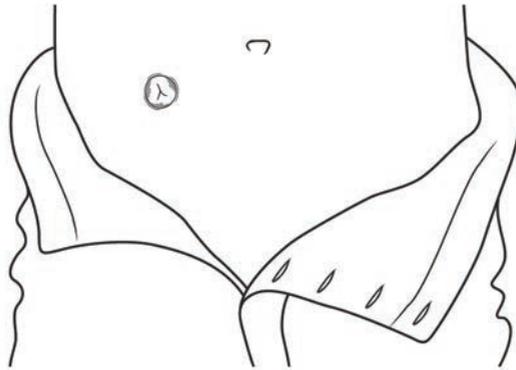
Your doctor will have discussed with you the need for a cystectomy and ileal conduit. This operation is the removal of the whole bladder and diverting the urine. The womb (hysterectomy) and both ovaries (bilateral salpingoophorectomy) are often removed at the same time. It may be necessary to remove the top part of your vagina as part of the hysterectomy. This is called a radical cystectomy.

This operation is nearly always performed for women who have been treated for bladder cancer. You may or may not have had other forms of treatment for your bladder cancer before the decision for a cystectomy was discussed with you.

What does the operation entail?

The operation is the removal of your bladder, and rediverting the flow of your urine through a urinary diversion or urostomy (stoma). The stoma is an opening on the abdomen which is made using a small piece of bowel to act like a drainpipe. Your kidneys and ureters are plumbed into one end

of the bowel and the other end is brought onto your abdomen (tummy) as a small spout. A bag or appliance is then worn over the stoma to collect the urine that drains through the stoma.



For women undergoing this operation who have not yet gone through the menopause, then your consultant and specialist nurse will discuss with you the possibility of needing hormone replacement treatment following the surgery.

If you have not had contact with a specialist nurse, then they can be contacted on 0121 371 6926 (answer machine available). They will be able to discuss the operation with you and answer any of your initial questions.

“Buddy” system

No matter how many leaflets and booklets you will 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 to 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-screening clinic before your operation, to see the specialist nurse and so all of the necessary investigations can be done in preparation for your surgery. The specialist nurse will see you again before your operation (possibly when you attend for the pre-screening appointment). They will go through any questions you may still have and decide with you where the stoma should be placed. It is important that the stoma will be in a place that you can easily see it, to enable you to care for it when you finally go home.

If you are admitted the night before your operation, a member of the 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).

This incision will be down the front of your abdomen.

You will also be asked to wear some special (TED) stockings whilst on the ward. These are designed to help prevent deep vein thrombosis (DVT) from occurring. After the operation you will also be given daily injections to help prevent the DVT happening.

On the day of your operation, you will be helped into your operation gown in preparation for surgery. TED stockings will be given to you to wear. This is to reduce the risk of clots forming in your legs (Deep Vein Thrombosis/DVT). A theatre porter will collect you and take you to theatre. A nurse will go to theatre with you and stay with you until you are asleep.

After your operation

What care will you need after the operation?

Your consultant will want you to be nursed in the Intensive care Unit for a short time immediately after the operation. Once you have recovered, then you will be transferred back to the urology ward for the rest of your hospital stay. The need to be nursed on critical care depends on the surgery and any other health issues you may have.

If there is no need for critical care then after the operation you will wake up on the ward in your own bed. There will be certain tubes attached to you, but each tube serves a purpose and helps you to recover. These are listed below.

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 and will be done by a machine connected to your arm with a Velcro cuff.

You will remain nil-by-mouth 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 drip 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 drip will be removed. You will then be able to eat.

You may have a fine tube into your nose and down into your stomach (nasogastric tube). This helps to stop you feeling sick, and is easily 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 anaesthetic, without the need for further pain relieving injections. The anaesthetist will discuss this with you before you go to theatre. This will stay until you are drinking again. Then you will be given pain relief in the form of a tablet or suppository. Please ask the nursing staff if you need anything 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 your operation and sit in a chair. This is to help reduce the risk of developing a DVT and to help prevent developing a chest infection. Mobilising you as soon as possible helps 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 and the specialist nurse during your pre-clerking session in the prevention of a DVT.

Your wound will have dissolvable sutures (stitches). These can take up to 3 months to completely dissolve. You may experience 'itching' until then. To begin with you will have a dressing over the wound. 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 wound pain.

The ward nurses will care for your stoma until you are over the operation. You will then be taught, in stages, how to care for the stoma yourself. There are many types of bags or appliances available. Please ask the specialist nurse if you wish to try other types of appliances during your hospital stay. For

the first ten to fourteen days, your stoma will have one or two tubes coming out of the middle. These tubes are called “ureteric splints”.

They help to keep the tubes draining the kidneys (ureters) open or patent until the new urinary diversion heals inside your abdomen. They are easy to remove and will come out before you go home.

Going home

What aftercare will you require?

You need to expect to stay in the ward for 10-14 days after the operation. You will not be discharged until you are happy to care for your stoma and be able to change the bag / appliance by yourself. You will need to convalesce (take things easy) for a while. It may take you up to 12 weeks to fully recover. You should avoid heavy housework, shopping, gardening and active sports for the first 6 weeks. Exercise such as walking at a steady pace will do no harm. Your activity can be gently increased after the 6 weeks. You may need to involve family and friends during this period if you live alone. You may be entitled to some home help and meals-on-wheels for the first few weeks at home. If you feel that this applies to you or you are worried about how you will cope on discharge, then mention it when you see the specialist nurse during your pre-clerking appointment.

You will be able to care for your stoma, but a specialist nurse will be visiting you before discharge to ensure you can look after it yourself. You will be given supplies to go home and they will show you how to order and obtain further supplies once at home.

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

find that your stoma is draining urine with “bits” in. Do not be alarmed. This is normal, as the piece of bowel that has made the stoma, continues to make mucus. If you find this is disturbing, drinking cranberry juice can help alleviate the problem.

You will be able to wash, dress and cope with the stairs on discharge, but remember – you will become tired quicker than is usual for you. You will need to slowly build up your strength. It is not unusual to need to rest for a few hours each afternoon. As you recover from the operation, you will gradually return to your normal activity. Expect to need to rest for up to 6 weeks following this type of surgery.

You are not to drive for 6 weeks following the operation or until you can comfortably wear the seat belt and are able to do an emergency stop if necessary. It is advisable to check with your insurance broker as different insurance companies have varying policies regarding the length of time following surgery before they are happy to provide cover.

You may find 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 operation. This will settle as you begin to do more during the daytime. However, you may seek the need for a sleep / nap during the day.

Your appetite may be small to start with. Do not worry – having 3-4 smaller meals as opposed to 2 large meals will be easier to eat and digest. As your activity increases, you will be able to go back to your normal eating habits.

You may find that your bowels are sluggish to begin with. This is because you are not as active as is normal for you, and your appetite is smaller than is usual for you. Do not worry. Drink plenty of fluids, and try to eat some fibre a day. You should avoid straining to open your bowels, if this is becoming a problem, contact your GP, who will prescribe a gentle laxative. You can help yourself by drinking natural fruit juices, brown bread, vegetables etc. If you are worried about your diet,

please ask the specialist nurse. They will be happy to discuss this before you go home.

You will be seen about 12 weeks after the operation and regularly after that. Your appointment will be sent through the post to you. If you have not received your appointment please contact your consultant's secretary or your specialist nurse.

Going back to work will depend upon what type of job you do. Please discuss this with your consultant and nurses before going home. You can get a sick note from the ward staff whilst you are in hospital. Your GP can then give you any more.

Gentle exercise in the early weeks following discharge is encouraged. Walking is excellent to begin with as it puts no pressure upon your wound as it continues to heal. After approximately 4-6 weeks, you may gradually begin to return to normal activity. You should refrain from heavy housework, heavy lifting, gardening, and sports activities until this time. Remember, you should be seen in the out patients clinic for review at around this time, Therefore, please feel free to discuss this with your consultant and your specialist nurse. They will be happy to discuss any concerns with you.

Your sex life afterwards

You should remember that you have recently had major surgery, and should allow time to recover from this. Several factors will determine whether or not sexual intercourse will be possible. During the operation, it may have been necessary for the top part of your vagina to be removed as part of the hysterectomy. This is unavoidable in this type of surgery. If you (or your partner) have any worries or concerns regarding this, do not be afraid to raise these questions with your consultant or stoma care nurse. They will understand and be able to offer help and advice. There will be treatment that we can offer you – so please ask.

Further advice

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 or potions. Bathe the wound with plain water, and pat gently dry. If it is not responding, seek advice from 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.
- You are at risk of developing a Deep vein thrombosis (DVT) if you are inactive following the operation. Try not to sit down for long periods, potter around the house until you feel strong enough to go outside. Remember to practice your 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 on 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.
- Seek the advice of your GP if you experience sudden breathlessness. This may be caused by a Pulmonary Embolus (PE) and would require admission to hospital to correct. This is a blood clot that has formed in the veins in your legs, and has travelled to your lungs.
- You will have received specific information regarding your stoma care in the additional information booklet given to you before your surgery. The stoma nurse will discuss this with you again before you home. Please remember that you have had a major operation. You will need time to recover

from this operation. Do not be surprised that it can take 6 weeks afterwards, before you feel up to doing normal activity and possibly another 6 weeks before you regain strength and stamina. This time during the postoperative period can be frustrating and you may feel upset and depressed. Please feel free to talk to your specialist nurse.

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

- You may wish to take a short break. This is acceptable within the UK. Please remember that driving long distances is tiring. You may need to plan to take extra breaks in your journey.
- Holidays abroad are OK once you have fully recovered. Previous patients have commented that they were not ready for this type of travel until approximately 3 months after the operation. This is something to bear in mind. Travelling before this may pose problems in obtaining travel insurance.
- Wherever you decide to go on holiday, please remember to take all of your appliances with you in your hand luggage, and to take enough supplies with you to last your length of stay.
- If you are flying for a long length of time, it is important to take precautions. Drink plenty. Try to mobilise during the flight. If at all possible, wear some support stockings (similar to those you wore after the operation) whilst flying.

Contact numbers

For further advice please contact the specialist nurses on the contact numbers listed below.

Urology specialist nurses
Telephone: 0121 371 6926

Urology, Queen Elizabeth Hospital Birmingham
Telephone: 0121 371 6240

Urostomy Association 0870 770 7931

Macmillan cancer line 0808 808 2020
Website www.macmillan.org.uk

CancerHelp UK
<http://cancerhelp.cancerresearchuk.org>

'The Patrick Room' at the outpatients department of the cancer centre or the Queen Elizabeth Hospital
0121 472 1311 Ext 8417

Glossary of terms

Cystectomy	an operation to remove the whole bladder.
Urethra	the tube or waterpipe within the penis that drains the urine from the bladder.
DVT	Deep Vein Thrombosis (clots in the deep veins of leg).
PE/Pulmonary Embolus	a blood clot that has formed as a DVT and travelled to the lungs.
Intravenous Infusion (IVI)	commonly called a 'drip' it is a method of giving fluid into a vein in the arm to provide hydration.
Salpingo-oophrectomy	removal of one of both ovaries and fallopian tubes.
Hysterectomy	removal of the womb.
NBM	nil by mouth.



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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