

PATIENT INFORMATION

RADICAL CYSTECTOMY (IN WOMEN) WITH FORMATION OF AN ILEAL CONDUIT



Department of Urology

What is the evidence base for this information?

This publication includes advice from consensus panels, the British Association of Urological Surgeons, the Department of Health and evidence-based sources. It is, therefore, a reflection of best urological practice in the UK. It is intended to supplement any advice you may already have been given by your GP or other healthcare professionals. Alternative treatments are outlined below and can be discussed in more detail with your Urologist or Specialist Nurse.

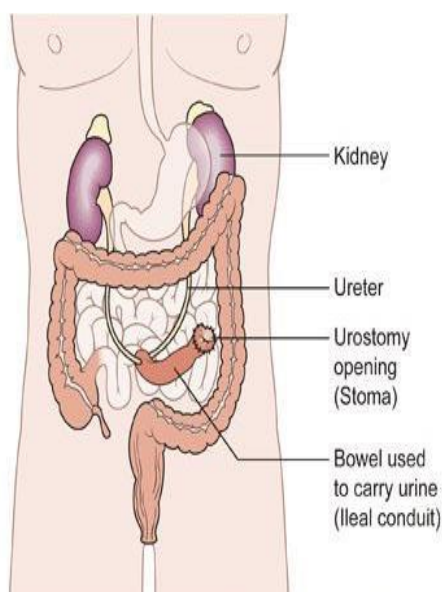
What does the procedure involve?



This involves removal of the entire bladder, the uterus(womb), the ovaries, your vagina and local lymph nodes with permanent diversion of urine to the abdominal skin using a separated piece of bowel as a stoma (called urostomy).

What happens during the procedure?

A full general anaesthetic will be used and you will be asleep throughout the procedure. In some patients, the anaesthetist may also use an epidural anaesthetic to minimise post-operative pain.



In the operation, the bladder, the uterus, ovaries, upper part of the vagina and local lymph nodes are removed. Most of the vagina is left in place and for women who are still sexually active, intercourse should be possible.

The ureters (the tubes which drain urine from the kidneys to the bladder) are then sewn to a separate piece of small bowel which is positioned on the surface of the abdomen as an opening this is called a urostomy. The ends of the small bowel, from which the urostomy is separated, are then joined together again.

What happens immediately after the procedure?

In general terms, you should expect to be told how the procedure went and you should:

- ask if what was planned to be done was achieved
- let the medical staff know if you are in any discomfort
- ask what you can and cannot do
- feel free to ask any questions or discuss any concerns with the ward staff and members of the urology team
- ensure that you are clear about what has been done and what is the next move

After your operation, you may be in the High Dependency Unit (HDU) or Intensive care unit (ITU) before returning to the ward; visiting times in these areas are flexible and will depend on when you return from the operating theatre.

You will have a drip in your arm. You will usually have two tube drains in your abdomen and two fine tubes which go into the kidneys via the stoma to help with healing. Normally, we use injections and elastic stockings to minimise the risk of a blood clot (deep vein thrombosis) in your legs. A physiotherapist will come and show you some deep breathing and leg exercises, and you will sit out in a chair for a short time soon after your operation. It will, however, take at least 3-6 months, and possibly longer, for you to recover fully from this surgery.

We will encourage you to get up and about as soon as possible. This reduces the risk of blood clots in your legs and helps your bowel to start working again. You will sit out in a chair shortly after the procedure and be shown deep breathing/leg exercises. We will encourage you to start drinking and eating as soon as possible.

Benefits

This operation is performed to cure your cancer and control symptoms such as bleeding, frequency of passing urine and discomfort.

Serious or frequent risks

- Everything we do in life has risks. Surgery to remove your prostate is a major operation and there are some risks associated with it, including problems with:
 - breathing (for example, a chest infection);
 - the heart (for example, abnormal rhythm or, occasionally, a heart attack); and
 - blood clots (for example, in the legs or occasionally in the lung).
 - Stroke
 - Death

Those specifically related to a radical cystectomy and ileal conduit may include:

- Common risks (Greater than 1 in 10):
 - Discomfort or difficulty with sexual intercourse due to narrowing or shortening of the vagina (100%)
 - Menopausal symptoms because your ovaries have been removed (almost 100%)
 - Paralytic ileus (failure of your bowel to work) for several days causing nausea, bloating, vomiting requiring intravenous drip, stomach drainage (10-50%)
 - Bleeding requiring blood transfusion or further surgery (10-50%)
 - Your cancer may not be cured by the procedure and may need further treatment (10-50%)
- Occasional risks (Between 1 in 10 and 1 in 50):
 - Need to remove your urethra (waterpipe) (2-10%)
 - Decrease in kidney function over time (2-10%)
- Very rare but serious complications (Less than 1 in 50):
 - Scarring, narrowing or hernia around your urostomy requiring revision (0.4%-2%)
 - Diarrhoea/vitamin deficiency due to shortened bowel requiring specific dietary supplements or other treatment (0.4%-2%)
 - Late scarring or stricture of the bowels or ureter requiring further surgery (0.4%-2%)
 - Damage to rectum or fistula requiring temporary stoma (0.4%-2%)
 - Need to return to theater for reoperation due to bleeding, bowel leakage, urine leakage or bowel obstruction (0.4%-2%)
 - Numbness & weakness due to nerve compression caused by position during surgery, vascular damage or nerve damage while remove cancer (<0.1%)
 - MRSA bloodstream infection (0.02% - 1 in 5000)
 - Clostridium difficile bowel infection (0.01% - 1 in 10,000)
 - Colonisation with MRSA (0.9% - 1 in 110)

The risks of not having the operation are:

- The tumour will continue to grow and then spread around the body.
- The tumour may cause further bleeding and discomfort.
- Avoidable death from bladder cancer.

Alternative treatments

The alternative treatments available are:

- **Radical radiotherapy** – if, for any reason, a decision has been made that you should not undergo surgery
- **BCG instillation into bladder**– only indicated for high-grade non-muscle invasive cancer; not for muscle-invasive disease
- **Radical Cystectomy with formation of a neobladder or construction of a catheterisable pouch**– radical bladder removal but without an external urostomy
- **Systemic chemotherapy** – drugs given by mouth or into your bloodstream; sometime before radiotherapy or radical cystectomy

These will be discussed with you by your surgeon and your clinical nurse specialist (CNS) – sometimes called a key worker. You may also wish to discuss these treatments with an oncologist prior to your surgery. This will be arranged for you.

Buddy system

Sometimes it is helpful to talk to a patient who has undergone this operation. If you feel that you would like to talk to someone who has had the same operation, please ask your CNS to put you in contact with them. All ‘buddies’ have volunteered their services to help other patients through this process.

Your pre-surgery assessment visit

You will receive an appointment letter to attend a pre-admission clinic before your operation where you will be seen by members of the medical and nursing teams of the urology unit. The aim of this visit is to record your current symptoms and past medical history, including any medication you are taking. Your heart and lungs will be examined to check that you are well enough for surgery. Blood tests and x-rays will usually be taken or arranged during this clinic.

You will also be given dietary instructions and told when you will need to stop eating and drinking. If you are insulin dependent diabetic, or on blood thinning medication you will need special instruction, please discuss this with your nurse/doctor at pre-admission clinic.

You will be seen by a Urology Nurse Specialist before your operation and she can discuss and answer any questions you may have. If you wish, you will be given the opportunity to meet someone who has previously had this procedure.

You will also be seen by the Colorectal/stoma CNS to mark the site where your stoma will be positioned and to try the various drainage pouches available. You will also be given the opportunity to discuss life with a urostomy.

The members of the urology team will check that you agree to have the planned surgery.

Being admitted to the ward

You will either be admitted on the day of surgery or a day before your surgery so you and we can prepare for the surgery. We will welcome you to the ward and check your details. We will fasten an armband containing your hospital information to your wrist.

To reduce your risk of blood clots in your legs after surgery, we will usually give you clexane injections and ask you to wear support stockings before and after your surgery. You may also have a drip inserted to give you fluids straight into your veins before your operation. We will usually ask you to continue with your normal medication during your stay in hospital, **so please bring it with you.**

Before you come into hospital

There are some things you can do to prepare yourself for your operation and reduce the chance of difficulties with the anaesthetic.

- If you smoke, consider giving up for several weeks before the operation. Smoking reduces the amount of oxygen in your blood and increases the risks of breathing problems during and after an operation.
- If you are overweight, many of the risks of anaesthesia are increased. Reducing your weight will help.
- If you have loose or broken teeth or crowns that are not secure, you may want to visit your dentist for treatment. The anaesthetist will usually want to put a tube in your throat to help you breathe. If your teeth are not secure, they may be damaged.
- If you have long-standing medical problems, such as diabetes, hypertension (high blood pressure), asthma or epilepsy, you should consider asking your GP to give you a check-up.

Your anaesthetic

We will carry out your surgery under a general anaesthetic. This means that you will be asleep during your operation and you will feel nothing.

Your pre-surgery visit by the anaesthetist

After you go into hospital, the anaesthetist will come to see you and ask you questions about:

- your general health and fitness;
- any serious illnesses you have had;
- any problems with previous anaesthetics;
- medicines you are taking;
- allergies you have;
- chest pain;
- shortness of breath;
- heartburn;
- problems with moving your neck or opening your mouth; and
- any loose teeth, caps, crowns or bridges.

Your anaesthetist will discuss with you the different methods of anaesthesia they can use. After talking about the benefits, risks and your preferences, you can then decide together what is best for you.

Also, before your operation a member of the theatre nursing staff may visit you. He or she will be able to answer any questions you may have about what to expect when you go to theatre.

The day before surgery

Your stoma and specialist nurse will usually see you on the ward before your operation. The nurse will go through any questions you may still have and decide with you where the stoma should be positioned so that you can easily care for it.

You may have an intravenous infusion (drip) started on the ward before your operation. This is to keep you hydrated whilst you are nil-by mouth (i.e. whilst you are not allowed to eat or drink anything).

On the day of your operation

Nothing to eat and drink (nil by mouth)

It is important that you follow the instructions we give you about eating and drinking. We will ask you not to eat or drink anything (including chewing gum or sucking sweets) for six hours before your operation. This is because any food or liquid in your stomach could come up into the back of your throat and go into your lungs while you are being anaesthetised. You may take a few sips of plain water up to two hours before your operation so you can take any medication tablets.

Your normal medicines

Continue to take your normal medicines up to and including the day of your surgery. If we do not want you to take your normal medication, your surgeon or anaesthetist will explain what you should do. It is important to let us know, before you are admitted, if you are taking anticoagulant drugs (for example, warfarin, dabigatran, apixaban, aspirin or clopidogrel).

We will need to know if you do not feel well and have a cough, a cold or any other illness when you are due to come into hospital for your operation. Depending on your illness and how urgent your surgery is, we may need to delay your operation as it may be better for you to recover from this illness before your surgery.

Your anaesthetic

When it is time for your operation, a member of staff will take you from the ward to the operating theatre. They will take you into the anaesthetic room and the anaesthetist will make you ready for your anaesthetic.

To monitor you during your operation, your anaesthetist will attach you to a machine to watch your heart, your blood pressure and the oxygen level in your blood. General anaesthesia usually starts with an injection of medicine into a vein. A fine tube (venflon) will be placed in a vein in your arm or hand and the medicines will be injected through the tube. Sometimes you will be asked to breathe a mixture of gases and oxygen through a mask to give the same effect.

Once you are anaesthetised, the anaesthetist will place a tube down your airway and use a machine to 'breathe' for you. You will be unconscious for the whole of the operation and we will continuously monitor you. Your anaesthetist will give you painkilling drugs and fluids during your operation. At the end of the operation, the anaesthetist will stop giving you the anaesthetic drugs. Once you are waking up normally, they will take you to the recovery room.

Pain relief after surgery

Pain relief is important as it stops suffering and helps you recover more quickly. Your anaesthetist may suggest that you have an epidural. The nerves from your spine to your lower body pass through an area in your back close to your spine called the 'epidural space'. An epidural injects local anaesthetic drugs into the epidural space using a fine plastic tube placed between the bones of the lower spine. This means that the nerve messages are blocked.

This causes numbness and removes the pain. Epidurals may be used during and after surgery for pain relief. They can be inserted when you are conscious, sedated or during your general anaesthetic. The benefits of an epidural are:

- better pain relief than other methods;
- reduced complications of major surgery; and
- you may recover more quickly.

Following an epidural, you may experience some side effects. Side effects are common but are normally minor and easy to treat. Serious complications are rare.

Common side effects include itching from the drugs used and headache. There is a small risk of having a bad headache (one in 100) and of temporary nerve damage (1 in 10,000).

Permanent nerve damage and paralysis are very rare indeed. Your anaesthetist will discuss these issues with you.

Another alternative for pain relief is to have a PCA (patient-controlled analgesia). This allows you to control your pain relief yourself. Morphine is the drug normally used, and the PCA machine allows you to press a button and give yourself a small amount of pain medication.

Some side effects are sickness, constipation and drowsiness. Larger doses can cause breathing problems and low blood pressure. However, you can never give yourself too much medicine by this method.

We may also give you tablets or injections to make sure you have enough pain relief. Once you are comfortable and have recovered safely from your anaesthetic, we will take you back to the ward. The ward staff will continue to monitor you and assess your pain relief. They will ask you to describe any pain you have using the following scale.

- 0 = No pain
- 1 = Mild pain
- 2 = Moderate pain
- 3 = Severe pain

It is important that you report any pain you have as soon as you experience it.

What are the risks of anaesthetic?

Your anaesthetist will care for all aspects of your health and safety over the period of your operation and immediately afterwards. Risks depend on your overall health, the

nature of your operation and how serious it is. Anaesthesia is safer than it has ever been. If you are normally fit and well, your risk of dying from any cause related to anaesthetic is very small.

Side effects of having an anaesthetic include drowsiness, nausea (feeling sick), muscle pain, sore throat and headache. We will discuss with you the risks of your anaesthetic.

After your surgery

Once the medical team are happy with your progress, we will usually take you from the recovery room to the intensive care unit. You will need to rest until the effects of the anaesthetic have passed. You will have a drip in your arm to keep you well hydrated.

Stents/Stoma

The constant flow of urine at the point where the ureters (tubes from the kidneys) are attached to the bowel makes the join heal slowly; therefore, two temporary tubes called stents are inserted. One end of the stent sits in the ureters and the other comes out of the stoma through the abdomen. The stents empty urine into the watertight pouch attached to the abdominal wall. The nurse will check this regularly.

Your stents may be removed during your stay in hospital. If they are not, the colorectal/stoma nurse will arrange for them to be removed at home, this is painless and the stents will be simply pulled out of the stoma.

Nasogastric or Gastrostomy tube

This is a small tube which drains fluid out of your stomach into a small bag attached at the end of the tube. When your bowel is not working, fluid collects in your stomach and can make you feel sick. The tube is inserted either through your nose or small opening on your tummy into your stomach; this will help reduce the feeling of sickness. You will gradually take fluids by mouth starting with sips of water and increasing slowly over the next few days until you are taking a light diet. The tube is normally removed 2-3 days after your operation unless you continue to feel sick.

Wound

You will have a dressing over the wound for a few days after the operation. Where your doctor made the cut, clips will have been used to keep the two edges of the skin together. These look just like staples. They are normally removed about 10 days after the operation. The wound will heal and over time the scar will fade.

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.

Leaving hospital

❖ Length of stay

How long you will be in hospital varies from patient to patient and depends on how quickly you recover from the operation and the anaesthetic. Most patients having this type of surgery will be in hospital for 10 to 20 days.

❖ Medication when you leave hospital

Before you leave hospital, the pharmacy will give you any extra medication that you need to take when you are at home.

❖ What aftercare will I need?

You will be seen regularly by your stoma/specialist nurse who will ensure you are happy to care for your stoma and are able to change the bag/appliance by yourself. You will be given supplies to go home with and you will be shown how to order and obtain further supplies once at home. Any difficulties that you may have once home or questions please contact your CNS or GP practice.

❖ Convalescence

How long it takes you to recover from your surgery varies from person to person. It can take up to three months. You should consider who is going to look after you during the early part of this time. You may have family or close friends nearby who are able to support you or care for you in your home during the early part of your recovery period. You might consider going to stay with relatives or you may want to make your own arrangements to stay in a convalescent home while you recover. After you return home, you will need to take it easy and should expect to get tired to begin with. You may need to involve family and friends during this period if you live alone.

❖ Stitches

We will take out any clips or non-dissolving stitches that seal the wound after about 10 to 14 days. You may also have stitches around your stoma-these will either dissolve or be removed by the Community Stoma Nurse if you have left hospital before this time, we will arrange for a community nurse to do this.

❖ Heparin Injections

During your stay, you will have had daily injection into your abdomen. You will need to continue these for four weeks. We will give you instructions on how to do the injections, but should you not feel comfortable we can arrange a district nurse to see you.

❖ **Personal hygiene**

You will normally bathe or shower while you are in hospital, and this can continue as normal after you leave hospital.

❖ **Diet**

You do not usually need to follow a special diet. If you need to change what you eat, we will give you advice before you go home.

❖ **Exercise**

We recommend that you avoid strenuous exercise and heavy lifting for up to six weeks. You should do lighter exercise, such as walking and light housework, as soon as you feel well enough.

❖ **Sex**

As mentioned above this type of surgery has an effect on your sexual and reproductive organs. We recommend you do not attempt sexual intercourse for at least six weeks after surgery.

This will then be discussed with you at your post-operative appointment.

❖ **Driving**

You should not drive for at least six weeks after surgery. After this time, you may drive if you feel confident that you could perform an emergency stop without discomfort. It is your responsibility to check with your insurance company.

❖ **Work**

How long you will need to be away from work varies depending on:

- how serious the surgery is;
- how quickly you recover;
- whether or not your work is physical; and
- whether you need any extra treatment after surgery.

Most people will not be fully back to work for three months. Please ask us if you need a medical sick note for the time you are in hospital and for the first three to four weeks after you leave.

❖ **Holiday advice**

Holidays abroad are okay once you have fully recovered. Previous patients have commented that they were not ready for this type of travel until approximately three 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 any 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.

❖ **Outpatient appointment**

Before you leave hospital we may give you a follow-up appointment to come to the outpatient department, or we will send it to you in the post. This appointment is normally 10-12 weeks following your surgery.

We ask that you have your bloods tested one week before you attend your clinic appointment (a blood request card is normally sent in the post to you).

Contact details

If you have any specific concerns that you feel have not been answered and need explaining, please contact the following.

- Urology Nurse Specialist Helpline 01905760809
(Monday - Thursday 08.30 - 16.30 and Friday 08.30 - 13.00)
- Alexandra Hospital:
 - Secretaries: 01527 512155
 - Ward 17 Nursing Staff: 01527 512045 or 01527 503030 ext: 44045 or 44046
 - Ward 14 Nursing Staff: 01527 507967 or 01527 503030 ext: 44032 or 47967
 - Sharon Banyard, Laura Grazier Urology Nurse Specialist
 - Jackie Askew, Uro-oncology Macmillan Nurse Specialist
- Kidderminster Hospital and Treatment Centre:
 - Secretaries: 01562 513097
 - Penny Templey, Aimee England, Urology Nurse Specialist
 - Sarah Holloway and Kerry Holden, Nurse Specialist – Survivorship Programme: 01562 512328
- Worcestershire Royal Hospital:
 - Secretaries: 01905 760766
 - Helen Worth, Emma Hurton, Lisa Hammond, Urology Nurse Specialists

Bladder Cancer Support group:

- Jackie Askew, Uro-oncology Macmillan Nurse Specialist: 01527 503030 ext: 44150

Colorectal/Stoma Care Nurse Specialists:

- Alexandra Hospital:
- Jane Gascoigne (phone 01527 512196 or call 01527 503030 and bleep 0199)
- Sandra Chambers (phone 01527 512195 or call 01527 503030 and bleep 0198)

Other information

The following internet websites contain information that you may find useful.

- www.patient.co.uk
Information fact sheets on health and disease
- www.rcoa.ac.uk
Information leaflets by the Royal College of Anaesthetists about 'Having an anaesthetic'
- www.nhsdirect.nhs.uk
On-line health encyclopaedia
- www.uagbi.org
Urostomy Patient Information Website
- www.worcestershirehealth.nhs.uk/acute_trust
Worcestershire Acute Hospitals NHS Trust

For more patient information visit 'The British Association of Urological Surgeons' website: <http://www.baus.org.uk/>

REFERENCES

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National Cancer Institute (2008). Bladder Cancer PDQ. Available online: <http://www.cancer.gov/cancertopics/pdq/treatment/bladder/healthprofessional>.

Nieh PT, Marshall FF (2007). Surgery of Bladder Cancer. Campbell-Walsh Urology, 9th ed., vol. 3, pp. 2479-2505. Philadelphia: Saunders Elsevier.

Rosenberg JE, et al. (2009). Bladder. Everyone's Guide to Cancer Therapy: How Cancer is Diagnosed, Treated, and Managed Day to Day, MO: Andrews McMeel.

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PET@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.