

What is a radical cystectomy and formation of ileal conduit?

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This is an operation to remove your bladder and the cancer that it contains. It is major surgery and usually involves removal of other structures close to the bladder in order to give the best chance of removing all of the cancer.

Once the bladder is removed, your urine is diverted using an isolated section of bowel which is brought up to the skin of your abdominal (tummy) wall as a urostomy, otherwise known as an ileal conduit.

Why do you need this surgery, and what are the benefits?

You have been diagnosed with a type of bladder cancer that cannot be controlled with operations to scrape away the tumours as they grow. The scans carried out have shown that there is no obvious evidence of cancer outside the bladder, but nearby lymph nodes will be removed during the operation.

The removed lymph nodes will be inspected by the pathologists to look for signs of cancer spread. The doctors feel that this surgery is in your best interest with the aim of curing your bladder cancer.

Alternative treatments: These will have already been discussed with you.

Radical cystectomy with formation of a neobladder or construction of a catheterisable pouch.

This is a radical cystectomy, but without an external ileal conduit. The bladder is replaced with a pouch made out of small bowel. Your surgeon may offer this depending on the nature of your cancer and your general health. Details are covered in a separate leaflet.

Radical radiotherapy

This may be suitable if a decision has been made that you should not undergo surgery, or if following discussion with a surgeon and specialist nurse, you decide that a cystectomy is not your preferred treatment option. It is important to note that a certain type of bladder cancer, called *carcinoma in situ (CIS)*, is not responsive to radiotherapy.

Systemic chemotherapy

This involves taking medication by mouth, or given in a drip in to your bloodstream. Depending on your pre-existing health conditions, this may be used before radical cystectomy or radiotherapy.

What does the operation involve?

You will have a general anaesthetic (be fully asleep) for the operation. It is usually carried out using a keyhole approach with robotic assistance, and can take up to 6 hours.

For **women**, this means removal of your womb, ovaries, part of your vagina, and nearby lymph glands. Most of your vagina will remain in place, and sexual intercourse should still be possible once you have recovered. You can ask your surgeon or clinical nurse specialist (CNS) if you would like more detail.

For **men**, this means the removal of your bladder, prostate gland and nearby lymph glands. For some men, it may be possible to save the nerves that control your erections, but this is not always possible. Your surgeon will discuss this with you, and there is help available to you if you suffer with erectile dysfunction after surgery.

The tubes that drain your kidneys (ureters) are stitched to a separated piece of small bowel and brought out on to the surface of your abdomen as an ileal conduit.

There will be 6 small scars centred around your belly button. Rarely, the operation will be carried out through a larger incision on your abdomen (open cystectomy).

What happens before the operation?

You will have had a discussion with your surgeon and met with the cancer nurse specialist to go over what the surgery entails, and to discuss any particular concerns that you may have.

We offer you the option to talk with a 'buddy' patient, this is someone who has already undergone the surgery. You will also meet the stoma nurses, who will discuss with you how to look after your stoma. They support you with caring for a dummy stoma, to practice attaching and removing the drainage bags to your tummy. This will also happen even if the plan is to carry out the formation of a neobladder.

Due to the complexity of the surgery, depending on any existing health conditions you may have, your surgeon may arrange an exercise test and a meeting with one of the anaesthetic doctors. This is to assess how your heart and lungs will cope with the physical stress of surgery.

You will have an appointment with the Preparation for Surgery nurses, this will involve:

- Blood tests
- A tracing of your heart (ECG)
- Measuring your blood pressure, height and weight
- Checking that your health history and any medications are up to date
- Provision of information with advice on when to last eat and drink, what to bring in to hospital, and any alterations to your usual medications (especially if you are on blood thinners or medication for diabetes)
- Provision of pre-op carbohydrate drinks, and when to take them.

On the day of surgery

You will be admitted to the pre-op ward (Knapp ward), where you will meet your admitting nurse, anaesthetist and surgeon.

You can wear your glasses, but do not wear contact lenses. It is important that you wear any hearing aids, these will be given back to you in the recovery room.

The anaesthetist will discuss what the anaesthetic will involve and the planned pain relief after your surgery. You will be asked to take a strong, long-acting pain killer tablet called oxycodone.

You will have your blood pressure, pulse and temperature checked and blood sugar level if you are diabetic. A finger prick test to check your blood clotting (INR) will be done if you have been taking warfarin.

You will be asked to change into a hospital gown and put on elasticated surgical stockings (your nurse will check that it is safe for you to wear these).

What should I expect after the operation?

At the end of the operation you will be taken to the recovery room where you will be closely monitored. Your nurse will ensure that you are comfortable, check your blood pressure, pulse, urine production and monitor your surgical wounds.

Depending on your individual circumstances, you may go to the high dependency unit for close observation. Usually this will have been booked in advance by the anaesthetic doctor.

On return to the ward following your operation

Day 0:

Eating and drinking

A section of bowel has been removed from your small bowel to make your urostomy. This means that your bowel takes a few days to recover. Immediately after the operation you will be offered only water to drink. You do not need to over drink as you will have fluids administered via a tube into a vein in your arm. If you are feeling sick tell the nursing team and they will give you some medication to help. The amount of oral fluids you drink will increase over the coming days. We are waiting for your normal bowel sounds (gurgling noises inside your tummy) to return.

Pain control

Your ward nurses will ensure that you have good pain relief by ensuring that you receive pain killer tablets on a regular basis. Please let your nurse know if you feel that your pain is not well-controlled.

Good pain control is essential in allowing you get up and about, take deep breaths and sleep well, which will aid recovery. You may notice some pain in your shoulders; this is not unusual. It is caused by the gas that is used to inflate your abdomen during the operation to assist with the surgery. The gas is removed at the end of the operation, but can irritate the nerves in this

area. This will resolve over a day or so and you can assist this process by getting out of bed and walking as soon as you feel able.

Activity

You may choose to stay in bed on the first night following surgery, but you will be encouraged to take deep breaths and change position. You will have calf pumps around your lower legs that inflate and deflate. These help blood to circulate and prevent blood clots forming (Deep Vein Thrombosis). If you have surgical stockings on, we will assist you with changing them every 3 days. You only need to wear them whilst you are in hospital.

Wound

The cuts to your abdomen will have been dressed with skin glue, with dissolvable stitches under the skin. You may have a tube to drain fluids in your tummy or a urinary catheter inserted via your water pipe (urethra), to drain any excess fluid.

Urostomy

You will have a thin thin drainage tube (stent) in either kidney. These run along the whole length of your kidney drainage pipes (ureters), and the lower ends drain in to your stoma. The lower ends of the stents will be visible in your urostomy bag. These help by ensuring that the urine drains into your urostomy. They also protect where the ureter has been stitched into your stoma, allowing it to heal. The nurses will check your urostomy regularly and your urine output every hour. The stents will be removed by your stoma nurse between 5 -10 days after your surgery, after any swelling has settled down. This will be carried out in your own home.

Day 1:

Eating and drinking

You may have clear fluids today. This includes water, coffee or tea without milk. We will also provide you with clear protein drinks and we would like you to try to drink 3 of these throughout the day. The Doctor will listen with their stethoscope to your abdomen every day. They are listening for bowel sounds and they

will ask you if you have passed wind. These are both signs that your bowel is starting to recover. If you are able to drink enough fluids then the fluids via the drip in your arm can be removed. This depends on whether you feel sick, and the amount of urine you are producing. You must ask your nurse for anti sickness medication if you feel sick.

Activity

Following assistance with a wash, you will be assisted to get out of bed to sit in your chair. You will need to pace yourself as this may make you feel tired. It is usually better to sit out for several short periods rather than sitting out for a long period. You will also be encouraged to take a short walk with some assistance. This physiotherapy is the first step to getting back to normal, and is very important.

Wound

The nurses will check your wounds to check that they are healing. We do expect there to be some bruising and some slight redness initially.

Urostomy

You will be visited by the stoma care team today. They will change your bag and you will be encouraged to get involved with the care of your stoma. You will be guided every step of the way until you feel confident with this. We recognise that this can be quite challenging initially, but the nursing staff will help you to gain confidence over the next few days. Your urine production will be monitored 1-2 hourly.

Low Weight Molecular Heparin (LWMH)

During your pre-assessment you will have received information about giving yourself a daily injection of this drug for 28 days. This is designed to assist in the prevention of blood clots forming in the leg veins. If a deep vein thrombosis (or blood clot) forms in the leg, there is a small risk of the clot travelling up to the lungs which can be dangerous. Your nurse will teach you how to give the injection to yourself (a shallow injection under the skin). You may prefer someone close to you to be taught how to do this, the choice is yours. Your nurse will need to know that you will get your injections safely before you go home.

Day 2:

Eating and drinking

You may have whatever type of drinks you like today. We will also provide you with clear or milky protein drinks, and encourage you to manage three of these during the day. If your bowel is starting to work you will be allowed soup and a light dessert. Remember if you are feeling sick the nurse can give you something to help. If you are feeling bloated tell your nurse. Walking and moving around can help you to pass wind.

Activity

You will be encouraged to be more independent with a wash today. You should aim to sit out for longer periods. You will still need to pace yourself as this may make you feel tired. It is usually better to sit out for a few short periods rather than a prolonged period. You will also be encouraged to walk more today, if you need assistance, the ward staff can accompany you.

Wound

Your urethral catheter and abdominal drain tube may be removed today if the amount of fluid draining into the bags is low enough. You are likely to leak fluid from your penis or vagina and need to wear a pad. It is a normal part of the healing process and will gradually decrease over the coming weeks.

Urostomy

You will be visited by the stoma care team. They will help you to get involved with the care of your urostomy and change your bag. The large drainage bag will be removed and you will be taught how to empty your urostomy bag. The nurses will assist and supervise you to do this, as they will be still monitoring how much urine you are producing.

You will be assisted daily with this change of your urostomy bag to help you gain confidence. Any of the ward nursing team will help at any time. At the weekend it is okay to remind the nurses that you need to change your bag and they will happily help you.

Day 3 and beyond:

Eating and Drinking

You may be able to eat more solid foods, but still aim for a light diet today. Your nurse will give you advice on what you can try to eat. We will continue to offer the protein drinks. If you feel bloated or sick let your nurse know. You may need to stay on fluids only for a little longer until things settle.

Activity

You should be walking independently and be spending most of the day in the chair. Start thinking about how you will move about at home.

Wound

Your wounds will continue to be checked, and if your abdominal drain tube or urethral catheter has been removed you might like to try to have a shower.

Urostomy

You should be changing your urostomy bag with minimal supervision. When the ureteric stents have been removed it is easier to manage the bag changes, however the stoma care team will show you the best way to manage for now.

Everybody is different and so the way they react to surgery is different too. The goal is for you to be well enough to go home between days 5-7 but do not be discouraged if you are not ready by then.

Before you are discharged we like to know that you are:

- Eating regular meals
- Having your bowels open
- Moving around independently and able to manage stairs
- Having good pain control
- Able to care for your Urostomy
- Able to inject yourself with your low molecular weight heparin independently (or have someone close to you trained to do this).

Leaving Hospital:

You will need to arrange transport to get home. It is best if someone can pick you up directly from the ward

You will be given a copy of your discharge summary when you leave hospital. A copy will also go to your GP.

When you are at home:

Drinking and eating

You may find you do not have an appetite for a large meal. Continuing to try small portions of what you fancy is much easier to manage. You can continue to drink the protein drinks three times a day but we would not expect you to need these if you are able to eat normal foods. You would need to purchase these drinks after your discharge home if you wish to continue with them, but it is not essential.

It is important for you to be able to drink enough fluids. A useful way to check if you are drinking enough is to look at the colour of your urine. You are aiming for the urine to be a pale yellow or straw colour.

Pain Control

You may need to take pain killers for a few weeks. If that includes an anti-inflammatory medication, you will be given a tablet to prevent stomach irritation. Some painkillers can cause constipation so you will be given a laxative medication to help to keep the stool soft and make it easier to open your bowels.

Activity

Resume normal activity around your home and then gradually increase the amount of walking you do each day. Do not be surprised if you feel very tired it can take up to three months to feel back to normal again. Continue to do deep breathing. You will need help with shopping and cleaning and should avoid heavy lifting for 6-8 weeks.

Wound

You may still have some bruising where the wounds on your abdomen are but this will resolve over the next few weeks. You may also have some bruising and swelling of the genitals which will also resolve. Try to wear supportive pants if you can tolerate the waistband, as this will help to manage the discomfort and reduce the swelling. You may shower but try to avoid rubbing the abdominal wounds.

Leakage from the penis or vagina is still quite common in the first few weeks, but will gradually dry up.

Urostomy

The stoma care team will provide you with your supplies and prescription to take home. They will arrange for your local community team to visit you at home. If you are recovering elsewhere please make sure they know where you have gone.

A stoma nurse will visit you at home to remove the stents from your ileal conduit approximately 10 days after your surgery. This is not usually painful.

You will have been provided with a dose of antibiotics to take just before the stent removal. Your stoma nurse will tell you exactly when to take this.

Driving

You should feel comfortable enough to resume driving 2 weeks or so after your surgery. It is advisable to check with your insurance company that they are happy with this.

You need to be able to do an emergency stop. Try sitting in your car and going through the motions. If anything feels uncomfortable, leave it a little longer.

Problems that may occur:

If you get a temperature or start vomiting, especially if you have unexpected abdominal pain, contact your GP immediately (or 111 if it is out of hours).

Swollen tummy, constipation or bloating

Make sure you are taking your laxative as directed and are drinking adequate amounts of oral fluids. If you are struggling to have your bowels open ask your GP for advice. The GP may advise you to increase the laxative or may add in other medication.

Signs of infection

This could be very red tummy wounds and occasionally there may be a yellow/green fluid coming from your wound.

If your urine becomes very smelly and cloudy it may indicate a urine infection.

If you notice you feel unwell or develop a temperature please contact your GP as you may need treatment.

Signs of a Blood clot

Deep vein thrombosis; this is a blood clot in the legs. If you have pain in the back of the thigh, calf or groin, swelling of the leg or warmth and redness – please contact your GP or nurse specialist.

Swelling of feet and legs

This is quite common and should get better in a week or two. Walking can help with this. To help reduce any swelling you could try raising your legs on a cushion or a foot stool when you are sitting down.

Follow-up care

You will have an out-patient appointment to meet with your Urology Consultant approximately 6 weeks after your operation. This is to check on your progress and go through the bladder and lymph node histology results.

Sexual issues

There are specialist clinics available to you if you are having difficulty with sexual function. These are available for men with erectile dysfunction, and ladies with vaginal narrowing. You may choose to access this with your local team if you are outside of the Exeter area. Your cancer nurse specialist can help arrange this.

If you need any advice after you have been discharged, you can call:

Dart ward (available 24 hours/day)
01392 402735

Urology clinical nurse specialists
at the Royal Devon (Monday-Friday)
01392 402747

Or you can call your local specialist nurse team if your follow-up care is planned in a different Hospital.

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