

Treatments, side effects ...

... and how to cope.

Introduction

Bladder cancer can be a rollercoaster of tests and treatments, with side effects that can range from “not a problem at all” to “the worst ever”.

At Fight Bladder Cancer, we know that passing on the best tips and advice from other patients and carers can really help if you’ve just been diagnosed, or if you’re having a difficult time with a particular treatment.

You can get really good advice – at anytime – on our **Confidential Forum**, where there are thousands of other patients and carers who are happy to help. It provides information, tips and advice from people who understand what you are going through.

We have organised this advice according to the different tests and treatments, to make it a bit easier to find the information you’re looking for.

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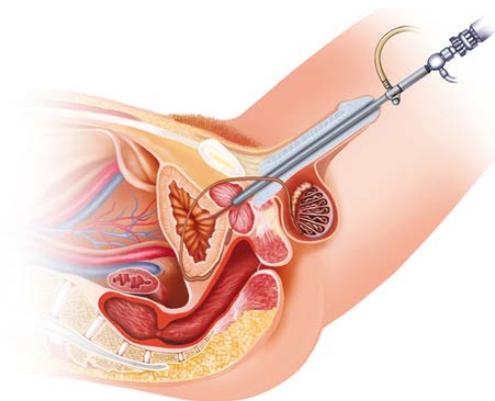
THE INITIAL TESTS (WHEN YOU ARE BEING) DIAGNOSED

The first test that you will have done will usually be a simple wee test that is sent off to the lab for analysis. An ultrasound scan, which is the same as the scan used to monitor pregnancies. will most likely be next to get a picture of you bladder that the medical team can look at. These initial tests also normally will include the important, but more intrusive, cystoscopy.

CYSTOSCOPY

The main test for diagnosing bladder cancer is a cystoscopy. The urologist looks inside your bladder by inserting a small camera through the urethra (the tube that carries your wee out of the body) into the bladder.

The procedure is carried out using a cystoscope, which is a thin fibre-optic tube with a light and camera at one end. Although the thought of this might be embarrassing, it is quite a simple procedure.



Most cystoscopies are done as outpatient procedures, so you'll be able to go home on the same day.

Is a cystoscopy painful?

A flexible cystoscopy is usually carried out using a local anaesthetic or spray to numb the urethra. This will reduce any discomfort when the cystoscope is inserted into the urethra.

A rigid cystoscopy is usually carried out under general anaesthetic (when you're asleep),

or after having an epidural that numbs everything below your waist. However, the procedure may feel uncomfortable for some people, and can lead to mild side effects afterwards, such as muscle pain and nausea.

For a few days after the procedure, you may feel a burning sensation when you wee and you may pass blood in your urine. This is normal and isn't something to worry about, unless it's severe and lasts longer.

Before your cystoscopy appointment you'll be sent information on which type of cystoscopy you will be having and instructions you should follow.

- **If you're having a local anaesthetic** you can eat and drink normally on the day of the appointment. With a spinal epidural or general anaesthetic, you won't be able to eat or drink for several hours before.
- **If you have a local anaesthetic** you'll be able to go home shortly afterwards. It usually takes a few hours to recover from the effects of an epidural or general anaesthetic so you'll need to arrange for someone to take you home. You should rest for 24 hours and avoid driving, operating complex or heavy machinery, and drinking alcohol for 48 hours.

Most prescription medication can be taken as usual on the day of your appointment. However, you may not be able to take aspirin, warfarin or ibuprofen, because they could cause excessive bleeding during the procedure.

Recovering from a cystoscopy

The type of anaesthetic used will affect how long it takes to recover from a cystoscopy. It's normal to have some side effects for a few days afterwards. Most people experience a burning pain when passing urine for the first few days after a cystoscopy. This is normal, and it should stop within a few days.

Having blood in your urine or bleeding from your urethra (the tube that carries urine out of the body) is also common in the first few days after a cystoscopy, particularly when a biopsy was also carried out. Drinking plenty of water can ease both of these symptoms.

Very occasionally, you might be unlucky and have some other side effects, but you should contact the hospital if:

- **your urine becomes so bloody** that you can't see through it
- **you notice clots** or tissue in your urine
- **you experience severe pain while urinating**
- **the pain and bleeding** last more than a few days
- **you're unable to pass urine** more than eight hours after the procedure
- **you develop a high temperature** (fever) of 38°C (100.4°F) or above
- **your urine smells unpleasant**
- **you have nausea or vomiting**
- **you have pain** in your lower back or side

Before being discharged, you'll be given a contact telephone number for the hospital.

Risks of a cystoscopy

A cystoscopy is usually a very safe procedure,

and serious complications are rare. Occasionally, patients may have problems passing urine or an infection may develop.

URINARY TRACT INFECTIONS

Urinary tract infections (UTIs) are infections of the urethra, bladder or kidneys. Symptoms of a UTI can include:

- **a burning sensation** when urinating that lasts longer than two days
- **a high temperature** (fever) of 38°C (100.4°F) or above
- **unpleasant smelling urine**
- **nausea and vomiting**
- **pain in your lower back or side**

Contact your GP or hospital staff as soon as possible if you have any of these symptoms. Antibiotics can be used to successfully treat most UTIs.

PROBLEMS PASSING URINE

Some people find it difficult to pass urine after a cystoscopy. This is known as urinary retention. Urinary retention after a cystoscopy is uncommon in women, but men with pre-existing problems are at a higher risk.

The best advice?

If you're worried about anything, just ask. Don't suffer in silence!



TREATMENT & TIPS – NON-INVASIVE BLADDER CANCER

There are a number of different treatments for non-invasive bladder cancer. The type you may need depends on the particular type of bladder cancer and how aggressive it is (the grade).

The following list is not exhaustive, but it explains most of the treatments available for this form of cancer. If you're having a different treatment, do make sure that your medical team to explain the reason for the treatment, any possible side effects and all the risks.

TURBT (Trans Urethral Resection of a Bladder Tumour)

Generally, after the diagnosis of a bladder tumour, the urologist will suggest that the patient have an outpatient procedure in the hospital to examine the bladder more completely under anaesthesia (general or spinal) and to remove the tumour if possible.

The TURBT is "incision-less" surgery usually performed as an outpatient procedure under a general anaesthetic.

Like the cystoscope, the resectoscope (the instrument used to remove the tumour in the TURBT) is introduced through the urethra into the bladder. Attached to this scope is a small, electrified loop of wire which is moved back and forth through the tumour to cut and remove the tissue.

Electricity is also used to seal off any bleeding vessels. This is sometimes called electro-cauterization or fulguration. The advantages of this procedure is that it can be performed repeatedly at minimal risk to the patient, and with excellent results. There is a less than 10% risk of infection or injury to the bladder, and both are easily correctable.

After surgery, you should be given a single dose of chemotherapy directly into your bladder, using a catheter. The solution is kept in your bladder for around an hour before being drained away.

What actually happens?

You will come into hospital either the afternoon before or the morning of your surgery. Most patients can leave hospital within 48 hours of their procedure.

Do remember take any medicines that you are taking with you when you go into hospital. If you are taking any medicines that thin the blood, for example aspirin, warfarin or clopidogrel, you may need to stop taking them for a short period around the time of your surgery. Your doctor will discuss this with you at your pre-operation assessment. Please do not stop taking any medicine unless told to do so by your doctors.

Your consultant or registrar will see you on the night before or the morning of your operation to discuss the surgery and answer any questions that you may still have.



You will not be able to eat or drink anything for 6 hours before your surgery. This is because you should not have food or drink in your stomach when you are given the anaesthetic. If you do, you are more likely to be sick while you are unconscious, which can lead to complications. The nursing staff will tell you when you will need to stop eating and drinking.

Before the operation you will be asked to put on a gown and some tight-fitting anti-thrombus stockings. These help to prevent blood clots from forming in your legs. You will then be taken to theatre by a member of the ward staff.

Having an anaesthetic

A TURBT is carried out either under a general or spinal anaesthetic. A general anaesthetic is medicine that will make you unconscious (asleep) during your operation, so you will not feel any pain.

A spinal anaesthetic involves a special needle being inserted into your back so that the anaesthetic medication can be injected around the spinal nerves. This numbs the lower half of your body so you will be awake, but will not feel anything from your waist downwards. This can be combined with a sedative, which does not put you to sleep, but makes you feel drowsy. Your doctor will discuss the options with you before the operation.

What are the risks?

Although serious complications are rare, every surgical procedure has risks. Your doctor or nurse will discuss the specific risks for this procedure with you in more detail before asking you to sign the consent form. The risks of having a TURBT include:

- **Blood in your wee** – this is common (in more than 1 in 10 people), and you may experience a mild burning sensation when weeing for a couple of days after your operation. You will be encouraged to drink plenty of water to keep hydrated and flush your system.
- **Infection** – this happens occasionally (in between 1 in 10 and 1 in 50 people). You will be given antibiotics if this occurs.
- **Perforation of the bladder** – this is rare (in less than 1 in 50 people). A temporary urinary catheter or open surgical repair will be needed to fix this problem.

- **Difficulty in weeing** directly after the operation – this is rare, as most patients have a catheter for the first 24 hours after surgery.
- **Deep vein thrombosis** (a blood clot, usually in the large leg veins). The stockings you are given will help to prevent this, and you may also have an injection – the doctors will assess you and discuss whether it is necessary.

What happens during the operation?

When you are anaesthetised your doctor will place a slim fibre-optic telescope (cystoscope or resectoscope) up your urethra and into your bladder. This is a special tube that allows the doctor to see your bladder lining. The visible tumour(s) will be cut away from the lining of your bladder wall using instruments inserted down the side channels of the resectoscope. This can cause some bleeding. Once a tumour has been removed, any bleeding is prevented or reduced by using a mild electric current to cauterise (burn) the area where the tumour was.

If there is a lot of bleeding, you may have a fine tube (catheter) inserted into your bladder to allow it to empty and to remove any debris. Occasionally, the catheter needs to be kept in for several days if the bleeding is persistent. It will be removed when your wee becomes rose coloured or clear, before you leave hospital.

Depending on the size of your tumour(s), the operation may take between 15 minutes and an hour. The tumour(s) will then be sent for examination. Once the operation is over, you will be taken to the recovery room to allow the anaesthetic to wear off. You will be taken back to your ward when you are fully awake, and the nurses will encourage you to drink plenty of water.

As soon as possible after the TURBT operation you should be given a single dose of chemotherapy directly into your bladder, using a catheter. The solution is kept in your bladder for around an hour before being drained away. Because it's put into the

bladder, you don't get the side effects, such as feeling sick or hair loss, that people may get with chemotherapy administered in a vein. With intravesical chemotherapy, hardly any of the drug is absorbed into the blood, which means it rarely affects the rest of the body.

When can I go back to my normal activities?

- You will usually be able to go home about 48 hours after your procedure.
- Speak to your doctor about how much time you will need off work after your operation. This will depend on your recovery and the type of work that you do.
- Usually you will need to take about two weeks off, but if your job involves lifting or heavy work, you may need to take three to four weeks off work.
- You can start gentle exercises about a week after your surgery, but please don't do anything too energetic, such as playing contact sports, for a month.
- Try not to drive again until you feel really comfortable and most importantly are able to perform an emergency stop. Always check with your insurance provider before starting to drive again.

What if I have problems at home?

Some people experience a mild burning sensation when they wee after their surgery. This usually settles after a few days. However, please contact your GP or go to your local accident and emergency (A&E) department if you:

- develop a temperature (over 38°C), have pain and persistent burning when you wee
- are not able to wee for 8 hours (unless you are asleep)
- pass large clots of blood
- have persistent bleeding

If you're worried about anything, just ask.

Your results

All the specimens from the TURBT will be sent to the pathologist for review. The pathologist will confirm the type of bladder cancer and how far it has gone into the bladder wall, if at all. These findings, along with results from imaging (such as CT scans) will determine if further treatment is necessary.

Your results should be available 10–14 days after your operation. You will have an appointment in the follow-up clinic, where your doctor will review your results and discuss your future care. Please make sure you have been given this appointment before you leave hospital after your operation.

The results from your TURBT will determine how much follow-up care you will need.

If you have bladder cancer and do not need any further invasive treatment, you will need to have regular cystoscopies to check the cancer has not returned. These will initially be at three-monthly intervals and then progressively less often if your bladder remains cancer-free. If you need further treatment or your tumour(s) return, your doctor will discuss this with you at your follow-up appointment.

CHEMOTHERAPY TREATMENT

For some forms of non-invasive bladder cancer you will be offered a course of at least six doses of intravesical chemotherapy, where the liquid is placed directly into your bladder, using a catheter, and kept there for around an hour before being drained away.

You should be offered follow-up appointments at 3 months, 9 months and 18 months, and then once every year. At these appointments, your bladder will be checked using a cystoscopy. If your cancer returns within five years, you'll be referred back to a specialist urology team.

Some residue of the chemotherapy medication may be left in your wee after treatment, which could severely irritate your skin. For men, it helps if you wee while sitting

down, and be careful not to splash yourself or the toilet seat. After weeing, wash the skin around your genitals with soap and water.

If you're sexually active, it's important to use a barrier method of contraception such as a condom. This is because the medication may be present in your semen or vaginal fluids, which can cause irritation.

You also shouldn't try to get pregnant or father a child while having chemotherapy for bladder cancer, as the medication can increase the risk of having a child with birth defects.

Are there any side effects?

Chemotherapy will irritate the bladder and produce the sensation of cystitis both during and after the treatment. Sometimes, this is bad enough to stop the treatments. You may also experience pain when weeing or needing to wee more often. Chemotherapy can produce a skin rash or flushing. Ensure you get plenty of rest, drink lots of fluids and take a painkiller such as paracetamol to help alleviate any pain or fever.

Some side effects can be more serious. If you notice any of the following, contact your doctor or nurse immediately:

- Shortness of breath
- Temp above 39 degrees
- Facial or throat swelling
- Persistent joint aches
- Not being able to wee
- White or grey coloured stools

BCG TREATMENT (Bacillus Calmette-Guérin)

BCG is used to treat higher risk non-invasive bladder cancers. BCG treatment has the widest range of experiences from "not a problem at all" through to "that was hell on earth".

What is BCG treatment?

BCG is a live vaccine used to vaccinate against TB (tuberculosis), but it is also used to treat bladder cancer. It is put into the bladder through a catheter to stop or slow down the re-growth of bladder cancer. When it is put into your bladder it triggers an immune response that causes inflammatory changes in the bladder.

BCG treatment is normally given once a week for 6 weeks and continues with a maintenance regime for 3 years.

Are there any reasons why I should not have BCG?

- If you have a UTI.
- If the initial operation to remove the cancer from your bladder (TURBT) was done less than 14 days earlier.
- If you are taking immunosuppressive medication or are immune-compromised
- If you have a bleeding disorder
- If you have active TB and are receiving treatment
- If you are breast feeding. If you are pregnant or trying to conceive, you should discuss this with your doctor before starting treatment.
- If you have had a flu or shingles vaccine within the last 6 weeks.

Is there anything I need to do before my treatment?

You should limit your fluids for 6 hours before treatment. One glass of fluid may be taken with breakfast, and you can eat normally.

By drinking less, your kidneys will produce less wee. This will help prevent the BCG being diluted and will also make it easier for you to hold the BCG treatment in the bladder for 2 hours.

If you normally take water tablets (diuretics), either take them after your BCG treatment is completed or at least 6 hours before your

treatment. This will reduce the amount of wee produced and will enable you to hold the BCG in the bladder.

What happens during treatment?

You will be asked to wee to ensure your bladder is empty.

A catheter will be passed into the bladder through the urethra to drain any remaining wee and insert the BCG.



The catheter will then be removed. In some cases the catheter may be left in the bladder during the treatment. If this is so, the catheter will be clamped to keep the BCG in the bladder. You will be asked to try not to wee for the next 2 hours.

How long will the treatment take?

The treatment takes 2 hours, after which you'll be able to go home. You should feel well enough to drive yourself home after the treatment.

After your first few treatments, if you live within easy reach of the hospital and have your own transport, you may be allowed to go home with the medication in your bladder and wee at home after two hours.

If you are elderly or infirm, you may wish to arrange for a friend or relative to accompany/collect you.

What to do after your treatment

When the BCG has been in your bladder for 2 hours you will be asked to wee into the toilet (men should sit rather than stand to prevent splashing). If the catheter was left in the bladder during your treatment, the BCG will be drained back into a bag before the catheter is removed.

You should abstain from intercourse/oral sex for 2-3 days after each treatment. The use of condoms thereafter is advised, and should continue to be used for several weeks after your treatment has been completed.

The effects on pregnancy are unknown. If you are planning to have children you should discuss this with your doctor, as female patients of child-bearing age are advised to use birth control during treatments and to wait at least 2 years before conceiving (longer if on maintenance treatment). Breast feeding is not advised when having BCG treatment.

You will be able to carry out your normal activities after treatment. There are no restrictions on driving, work, etc.

Are there any special precautions I should take at home?

All the wee you pass during the first 6 hours after treatment should be treated as contaminated. It is recommended that you pour 2 cups of household bleach into the toilet (bleach neutralises BCG) and leave it for 15 minutes before flushing. Ensure no one uses the toilet during this 15 minutes.

Wash your hands and genital area with soap and water each time you wee for 6 hours after your treatment.

Are there any possible side effects from the treatment?

Almost everyone will get side effects from having BCG treatment to a greater or lesser extent. These common side effects include:

- Flu like symptoms what can last for between 1 and 3 days
- problems weeing

- pain when weeing
- feeling the need to wee more often than usual that can last for 2 to 3 days
- bladder infection and discomfort
- blood/scabs in the wee.

These symptoms usually last for a few days or a few weeks. About 30% of us will get a fever (high temperature) which may last one or two days.

A lot less common are side effects that require urgent medical attention.

You should contact your medical team immediately if you experience any of the following symptoms:

- Shortness of breath
- Confusion
- Dizziness or lightheadedness

If you can't contact your medical team for some reason, we would recommend that you went straight to A&E.

There are other less common side effects that might need medical attention, but are not an emergency. With these, contact your medical team within 24 hours of noticing any of the following:

- Fever of 39.5 or higher within 24 hours
- Fever of 38.5 or higher after 48 hours
- Blood in the urine
- Extreme fatigue

Remember that fever, chills, flu-like symptoms, increased fatigue or an increase in symptoms such as burning or pain when weeing are not uncommon. However, if these increase in severity, or last more than 48 hours let your medical team know.

The most important thing to remember is that BCG is very likely to give you a *range* of side effects. Most of these are normal, sometimes quite painful, but usually not dangerous. **However, if you have any doubt, do contact your specialist nurse for advice.**

TREATMENT & TIPS – INVASIVE BLADDER CANCER

There are two basic forms of treatment for invasive bladder cancer: radiotherapy or surgery. Both treatments are commonly offered with chemotherapy either before or after treatment. The current guidelines in the UK state that there is no evidence that one form of treatment is better than the other, so both should be offered to all patients with invasive bladder cancer unless there are specific medical reasons why one form is not suitable.

RADIOTHERAPY

Radiotherapy is used in muscle-invasive bladder cancer.

Radiotherapy involves using carefully measured doses of radiation treatment to target the cancer. These abnormal cancer cells are more sensitive to radiotherapy than normal cells and will be destroyed.

Normal cells can be damaged along with the cancer cells, which is why there are potential side effects, as with any treatment. In general the side effects are linked to the areas of normal healthy tissue that are close to the bladder such as the small bowel, the rectum (lower part of the bowel), the bladder itself and the skin in the area that is treated.

Radiotherapy for bladder cancer is given from outside of the body (external beam radiotherapy). The number and frequency of radiotherapy sessions will depend on the extent, size and type of the tumour. Radiotherapy treatment is painless, and will not make you radioactive!

It is very important that female patients tell their oncologist immediately if they suspect they may be pregnant.

What actually happens?

There is a lot of careful thought put into the detail of your radiotherapy treatment to make sure you get the best treatment for you.

Planning your treatment means exactly that. It is similar to having a designer outfit or suit made – you would want the pattern and finished product to fit you uniquely, and that is what happens with the Planning Scan, which is usually a CT scan done in the radiotherapy department. This is completely different from the other scans you will have had to diagnose the extent of the cancer, so please do not think this is a duplication.

Treatment planning

Designing the radiotherapy treatment specifically for you is very important and ensures that the radiation can be applied as accurate as possible resulting in the maximum benefit. CT scanners and simulators are used to help define the exact area to treat and x-rays are taken as a permanent record of treatment.

During the procedure the radiographers may draw some marks onto your skin. The radiographer will ask your permission to make some of these marks permanent – using a small needle. These tiny permanent marks, together with the measurements taken, will ensure the pinpoint accuracy of your treatment on a day-to-day basis.

This appointment usually takes between 20 and 60 minutes. When you are being given the permanent marks you may feel a slight scratch but otherwise the process is painless. It is important that you lie as still as you can throughout the procedure.

At the end of this appointment you will receive the date and time of your first treatment. You will be given the rest of your dates and times when you attend your first treatment appointment. Your treatment should start as soon as possible, but some treatments require detailed planning and take several days to prepare. Some patients will require further planning appointments before they start their treatment.

What happens when I go for treatment?

On your first day, the radiographers will explain what is going to happen when they take you into the treatment room. The treatment machines are quite big, and you may feel anxious. But remember, the treatment is painless.

The radiographers will help you onto the treatment couch and into the correct position using the measurements and permanent marks from the planning appointment. It may be necessary to remove some clothing to see the treatment area and permanent marks.

It is important to remain very still throughout your treatment, but be sure to breathe normally. The radiographers operate the machine from outside the room, so you will be left alone during this time. Most machines make a noise when they are operating, so you will know when they are switched on. Radiographers monitor you on a CCTV system. If you need the radiographers during this time, raise your hand.

Treatment times vary between 12 and 24 minutes. You will only be alone in the treatment room for some of this time.

What happens when your treatment finishes?

Before you finish treatment, you will receive some personalised advice on how to manage any side effects following treatment and a contact number. Do contact your medical team if you experience any difficulty or are worried for any reason following your course of radiotherapy.

Side effects

Side effects can occur during and immediately after radiotherapy (early reactions), which usually occur during the second half of a course of treatment and can last for some time after the treatment is finished. Several months later, late reactions can occur which may or may not be permanent. Everyone will react differently to radiotherapy, so please ask the radiographers

if you are unsure about anything. You should be given a booklet with specific side effects common to your treatment area, and how to manage them.

SIDE EFFECTS OF RADIOTHERAPY:

EARLY REACTIONS

Fatigue

As radiotherapy can damage normal tissues close to or in the treated area, your body will use a great deal of energy to repair these damaged cells. This means that tiredness is a very common side effect of radiotherapy. If you feel fit enough, gentle exercise can help. Do not force yourself to do things you do not have the energy to do.

Sore, red skin (erythema)

Radiotherapy can make the skin in the treated area itchy, red, and sore. You can minimise this side effect by following the advice of the radiographers.

Bladder symptoms

You may experience changes in the flow of your wee, a need to wee more often, a need to wee urgently, a burning sensation when you wee and/or a small amount of blood in your wee. Your consultant may be able to prescribe you something to help with these symptoms.

Drink plenty of water-based fluids such as cordial. Tea and coffee can make the symptoms worse. Some people find cranberry juice helpful. Tell the radiographers about any of these symptoms so they can ensure you do not have an infection. **Always** report any difficulty in weeing to your medical team.

Bowel symptoms

Treatment may irritate your bowel and make you need to go to the toilet more often. Medication such as Fybogel may be prescribed for you. You may develop tenesmus, which is an urge to open your bowels without passing anything. This can feel like constipation. You may also notice an increase in the amount of wind you pass.

If opening your bowels becomes painful or you notice some spotting of blood, let your medical team know. These side effects are not uncommon so do not be alarmed. Please **do**

not modify your diet or take any medication for your bowels without discussing it with a radiographer or consultant.

SIDE EFFECTS OF RADIOTHERAPY: LATE REACTIONS

Radiotherapy to the lower abdomen in women is likely to induce the menopause. A reaction called vaginal stenosis may occur as a result of scar tissue forming after radiotherapy. Vaginal dilators can be given to those having their pelvis treated to try to prevent this from happening.

For men, radiotherapy can result in a lack of semen or a reduced sperm count, which may result in infertility.

Radiotherapy may lead to more urgent and frequent bowel opening and weeing. Bleeding from the back passage may occur which can require medication or surgery.

Always make sure you let the radiographers know exactly how you feel and whether you experience any side effects.

There are a number of dietary tips that can help during radiotherapy.

It is important to eat well and maintain your weight whilst undergoing radiotherapy.

General tips/advice

- Try to eat small frequent meals and snacks.
- Maintain a good fluid intake. It may be helpful to limit hot drinks and include more cold drinks, but avoid alcohol.
- Choose foods which you enjoy and find easy to swallow.
- Don't worry too much about having foods that are low in fat and sugar for the time being (unless you have another medical condition).
- Some people find that including live yoghurt in their diet can help with diarrhoea.
- Check with a dietician or chemotherapy nurse if you are also having chemotherapy.

Sickness

Try to eat small amounts, little and often. Some people find that food and drink containing ginger helps with nausea.

Bladder symptoms

You may experience changes in the flow of your wee, a need to wee more often, a need to wee urgently, a burning sensation when you wee and/or a small amount of blood in your wee. Your consultant may be able to prescribe you something to help with these symptoms.

Drink plenty of water-based fluids such as cordial, at least four pints or eight mugs a day. Tea and coffee can make the symptoms worse. Some people find cranberry juice helpful. Some patients will have specific advice regarding how much fluid they drink before their radiotherapy treatment. It is important to follow this advice.

Fatigue

As radiotherapy can damage normal tissues close to or in the treated area, your body will use a great deal of energy to repair these damaged cells. This means that tiredness is a very common side effect of radiotherapy. If you feel fit enough, gentle exercise can help. Do not force yourself to do things you do not have the energy to do.

Sore mouth / difficulty swallowing

Avoid smoking which can prevent your body from repairing itself. Avoid drinking alcohol, especially spirits, which can irritate your mouth and make it sore. Avoid food that is very hot, spicy, acidic, hard or crunchy. It may be necessary to move to a softer, more liquid diet in some cases.

Bowel symptoms

Please **do not** modify your diet or take any medication for your bowels without discussing it with a radiographer or consultant.

Dietary fibre

There are 2 types of dietary fibre, and each works in a different way.

Soluble fibre

Foods containing soluble fibre soften the stools and absorb water as they move through

the body. Examples are fruits, vegetables, pulses and oats, which you should include in your diet.

Insoluble fibre

Foods containing insoluble fibre increase the speed at which food moves through the body. Examples are wholegrain cereals and wholemeal bread. **Avoid** these foods whilst you are experiencing diarrhoea.

If you are having problems with excessive wind and bloating, you might find it helpful to cut down on peas, beans, lentils, cabbage and fizzy drinks.

Always make sure you let the radiographers know if you experience any side effects. They need you to tell them about your general well being.

RADICAL CYSTECTOMY (RC)

A Radical Cystectomy or RC is a surgery to remove your bladder as a treatment for invasive bladder cancer.

It also involves removing the nearby lymph nodes, part of the urethra, the prostate (in men) and the cervix and womb (in women). It is a major operation, lasting at least 6 hours. Recently, some RCs have been carried out using robotic surgery, but currently there is limited evidence about whether this is better than the traditional surgeon's method as far as long term prognosis is concerned.

However, we do know that this surgery is very important for some patients for whom traditional surgery would be dangerous due to other health issues as it is better for blood loss and generally you will have a quicker recovery.

What does the operation involve?

The operation is performed under a general anaesthetic. This means that you will be asleep for the whole operation, so you will not feel any pain. The anaesthetic is given through a small injection in the back of your hand.

The type of cystectomy you will have would depend on your individual circumstances.

For a man, the surgeon will usually remove your bladder, prostate gland, seminal vesicles (where semen is stored) pelvic floor muscle and lymph glands within the pelvis. In some cases, your surgeon will also remove your urethra.

For a woman, the surgeon will remove your bladder, urethra, ovaries, uterus (womb) and the upper part of your vagina. Internal lymph glands that lie within your pelvis are usually removed during the operation as well.

Your surgeon will discuss the operation with you in more detail. It is important that you understand what is going to happen, so please ask questions if you are uncertain.

Why should I have a cystectomy?

The benefits of this operation will be discussed with you in more detail, but your doctor may be recommending this surgery for you because:

- You have cancer in your bladder which would be best managed by completely removing the bladder.
- Your bladder may have developed a tumour after radiation treatment.
- Your bladder may be bleeding after radiotherapy.
- Your bladder may be damaged or bleeding uncontrollably from other causes or treatments.

How will the surgery affect me?

This is a major surgical operation, and you are likely to be in theatre for between 8 and 10 hours. There is a long recovery period before you can think of going back to work, but you can be home afterwards from as early as 5 or 6 days after the surgery!

To give an idea of the scale, a radical cystectomy is similar in many ways to a heart bypass but is much bigger than a hip replacement, back surgery or a hysterectomy.

To understand the operation you are going to have it is helpful to have an idea of how the normal system should work.

The urinary system consists of the kidney, the ureters, the bladder and the urethra. The kidneys are responsible for filtering the waste products from your blood. These waste products are excreted by the kidney as wee. The wee passes from your kidneys, down the ureters, to the bladder. The production of wee is continuous, although you may notice that you produce less wee at night.

The bladder acts as a reservoir for the wee. A sphincter muscle at the base of the bladder prevents the leakage of wee when closed. The sphincter opens when this muscle relaxes. To empty the bladder the sphincter opens, the bladder contracts, and wee passes out of the bladder and through the urethra to the outside. Females have a short urethra, while in males it is much longer and wee has to pass through the prostate gland and down the penis before reaching the outside.

If you have a radical cystectomy, your body will still need a way to get rid of your wee. As part of the same surgery as removing the bladder, they will create an alternative way for this to happen. There are two ways of doing this:

- **Formation of a urinary stoma** (ileal conduit), where your wee is passed through a channel into a bag attached directly to your body.
- **Some form of bladder reconstruction**, where a pouch is made from part of the bowel, to store wee. The pouch is emptied either by passing wee via the urethra in the usual way, or by using a catheter that is passed into the pouch.

This is a major operation, which permanently changes your body in several ways. It affects how you wee, your ability to have children, to have sex and to some extent, your bowel function. Bladder reconstruction takes longer than having a stoma formed, and recovery can take longer.

Preparing for surgery

It is very important that you understand your operation and the implications for your life after surgery. Your medical team will do their

best to explain all aspects, so that you know what to expect. Please ask them any questions that you may have. It is a good idea to write questions down before you come to see the surgeon, to help you remember and get the most out of your appointments.

We recommend that you speak to, or meet, someone who has had this type of operation so you can talk with them about their experiences. You can do this through our [Confidential Forum](#) or [Bladder Buddy Service](#).

In the days before your operation, your medical team will discuss the plan for your hospital stay with you in detail. They will also let you know what to eat and drink before your admission. Unless you have diabetes, they will often recommend that you have special high carbohydrate drinks the night before surgery and early on the morning of the surgery. These help restore the function of your stomach and intestines after surgery. If these drinks are suitable for you, you will be given them at a clinic visit to keep at home for just before your surgery.

You'll need to go to your hospital for a pre-assessment appointment, where some investigations and a check for MRSA are done. You should let your medical team know if you have:

- an artificial heart valve
- a coronary artery stent
- a heart pacemaker or defibrillator
- an artificial joint
- an artificial blood vessel graft
- a neurosurgical shunt
- any other implanted foreign body
- a prescription for warfarin, aspirin or Clopidogrel (Plavix)
- a previous or current MRSA infection

A specialist nurse will see you, either before you come into hospital for surgery or on the day of your admission. If you are having a urinary stoma, they will mark the place where your stoma will be. If you are having a bladder

reconstruction, they will still make a mark. On rare occasions, during surgery it becomes clear that a planned reconstruction is not possible. If this happens a stoma will need to be created for you, so they need to prepare for this.

During surgery

A radical cystectomy is a major operation and takes several hours.

You will be given a full general anaesthetic and an epidural to help with the pain after the operation. Special drips are placed into large veins and into an artery, so that you can be carefully monitored during and after surgery. You will be positioned very carefully on the operating table to minimise the effects of pressure on your skin. Your breathing is done for you with a machine called a ventilator.

You will be covered almost completely (apart from your abdomen) with operating drapes that ensure a sterile area for surgery and help to keep you covered and warm. A warming air blanket is used.

During surgery the anaesthetic team will check you very carefully, monitoring your temperature, heart rate, blood pressure and how the breathing machine is working. Blood tests are done during surgery to check on your body's response to the procedure. You will be given fluid through the drips, to replace fluid that is lost, and a few patients are given a blood transfusion during surgery.

The operating theatre team will check your body position carefully during surgery and move your arms gently from time to time, to help prevent them becoming stiff after surgery. Inflatable boots are used to squeeze your calves very gently at intervals during surgery, to reduce the risk of a blood clot in the veins.

If you are a woman, and have been through the menopause (change of life) and have not previously had surgery to remove your womb, the surgeons will usually remove:

- the bladder
- the womb

- both ovaries and fallopian tubes
- the top part of your vagina

Part of the vagina will be left in place, so that if you wish to be sexually active after the surgery, this should be possible.

If you are a man, the surgeons will usually remove:

- the bladder
- the prostate
- the sperm sacs (seminal vesicles)
- in some cases, the urethra

If the position of your cancer permits, the surgeons may try to preserve the nerves that are involved in producing erections. These run very close to the prostate, and they usually suffer some damage during the operation.

This means that almost all men who have a cystectomy will not have spontaneous, usable erections after the operation. Do talk to your medical team about this in detail before you have surgery, as they will be able to explain the available treatments that may help.

Following the removal of your bladder, your surgeon will either create a urinary stoma or perform a bladder reconstruction.

Recovery in hospital

After surgery you are most likely to wake up in the recovery area of the operating theatre. The following day you will be moved to the urology ward. In a few cases, if there are certain problems following surgery, you may spend some time in a high-dependency unit before moving to the ward.

Most patients spend from 7 to 10 days in hospital after their operation. They will carefully monitor your recovery. Your epidural is important and if it works well, you should have very little or no pain, and you should be able to move your legs normally.

Sometimes the epidural does not work as well, and the Acute Pain team help to get it working as well as possible. A few patients need a pump that allows them to give themselves

doses of painkilling medication via a drip. Their epidural will be left in place for a few days after surgery, and then replaced by other pain-killers.

You should also be offered at least three special nutritional drinks a day, to help combat the loss of weight and muscle that can follow surgery.

The nursing staff and physiotherapists will help you to get out of bed and start moving as soon as possible. This will reduce the risk of blood clots forming in your legs and lungs, and will also help to prevent chest infections. They will also give you compression stockings to wear to encourage the blood to drain from the legs, and daily injections to make the blood less likely to clot. These injections should be continued for up to 6 weeks after surgery. Your team will teach you how to do this when you are on the ward, so that you can give yourself the injections after you go home.

Being more mobile will also encourage your bowel to start working, which normally takes a few days. During this period you will need to find a balance between eating and drinking enough to regain your strength, but not overfilling your stomach, which may make you feel sick.

One sign that the bowel is starting to work is that you fart. Although it is not something that is generally discussed outside hospital, it is a simple and helpful indication of how the gut is working, so you will need to get used to talking about this delicate matter after your operation!

It may take up to 6 weeks for the bowels to get back to normal after surgery. Five to ten percent of people find that their bowel habits change permanently after surgery. If this does happen, typically the bowels will work once or twice more each day than before, and the stools may be a bit looser.

Walking is an important activity following your operation, and you will be strongly encouraged to walk as much as (and as soon as) possible afterwards. The nurses and

physiotherapists on the ward will help you become more independent, rather than lying in bed all day, even though this may seem daunting at first.

Being upright and mobile helps your body to get back to "normal business" and helps to reverse some of the changes that happen following such a major surgery.

Before you are ready to go home, you will be expected to be able to walk at least 100m and climb one flight of stairs. This means getting moving quickly after surgery. Many patients walk a good deal further than this.

This exercise will also require you to rest well in between, so a mixture of resting in bed and walking is good.

While you are on the ward, the nurses will help you to get the hang of how to look after your stoma, bladder substitute or catheterisable reservoir, depending on which operation you have had. Although it will be very unfamiliar at first, you will quickly learn how to manage it. The specialist urology nurses will help whilst you are on the ward and in the clinic afterwards.

Recovery at home

Once you leave hospital, it is usual to feel tired. Your body will continue to react to the surgery for several weeks. Also, in hospital, the ward staff will have been playing a big part in your care. Even small tasks at home like going to get yourself a drink, will seem to be more of an effort than usual.

Your physical recovery will progress in the weeks that follow your surgery, although this may be in fits and starts rather than a steady improvement. After a relatively quick start, it is normal for recovery to slow down and be more gradual.

You may have bad days where it feels as if things are getting worse, rather than better, but this is not usually a sign of a problem. It is important to try not to get downhearted. Your energy, appetite, how food and drink goes down, how your bowels work, how you sleep and your mood, will all get better over time.

When you get home, you will need to ensure that someone is able to accompany you out of the house every day, increasing your walking distance each time as much as you can manage, so that by 2 or 3 weeks after getting home you are walking at least half a mile each day, and preferably more. Many patients find that after their operation they are walking further than they have done for years, and feeling much better for doing so. Some patients come back to clinic a month after their surgery and are walking 2 or 3 miles each day.

The following are important milestones in your recovery, if your wound heals normally:

- heavy lifting: for the first 6 weeks after surgery, you should avoid lifting anything heavier than a full kettle – your wound will need to be checked in clinic first
- recovering your energy: your energy should be starting to return by 6 weeks
- driving: you should be able to make a gradual return to driving from around 6 weeks – your wound will need to be checked first, and you should feel confident that you can make an emergency stop. We recommend that somebody accompanies when you first return to driving

Full recovery is likely to take from 3 to 6 months. If you had chemotherapy before your surgery, you can expect the recovery to be around 6 months. By this time most people will have returned to their normal activities without feeling more tired than usual.

After effects

Any major surgery will mean changes for your body, and can affect how you feel about yourself. This is completely normal, and we can help. Your specialist nurse can give you advice and answer questions.

Don't forget that there are hundreds of other patients who have been through this surgery on our [Confidential Forum](#), or we can put you in touch with someone through our [Bladder Buddy Service](#).

It will also be helpful to talk to your partner, a family member or a friend about the possible side effects of surgery. As well as helping them to understand more about how you are feeling, it can also provide you with extra reassurance and give you more confidence as you prepare for your operation.

There are also specific side effects relating to the different ways in which your bladder may be replaced.

Your sex life

In all cases, having a cystectomy will affect your sex life. For men, it can cause problems getting an erection, whereas women often find it makes sex uncomfortable.

There are a variety of things that can help, such as tablets like Sildenafil (Viagra®), injections and vacuum pumps for men or, in women, extra lubrication or a dilator which can help stretch the vagina. You will be able to see a specialist nurse who is experienced in helping people overcome these problems, so please don't feel embarrassed about discussing them.

Discovery of further cancer

When men have their bladder removed, around 30% are found to have unsuspected prostate cancer. In almost all of these men, the prostate cancer that is found is confined to the prostate gland and because that has been removed, together with the lymph glands around the bladder and prostate, no further treatment is needed.

Complications

Every operation has possible complications, which means that things can go wrong. This risk needs to be weighed against the risk of the cancer and the benefit of surgery. The types of cancer for which the bladder may be removed are all high risk. The benefits of having the surgery are therefore considerable. You may need, however, to consider other treatments which may also have both risks and benefits, for example radiotherapy. Weighing up the risks and benefits of different treatments is often difficult.

In general, the bigger the operation, the more likely it is that there will be complications.

There are two sorts of complications that can happen with surgery:

- general complications: these can happen after any surgery – the bigger the operation, the more likely they are to occur
- specific complications: these only happen after particular types of surgery, so in this case they are the complications which follow bladder cancer surgery – these will be different to the complications from heart surgery, hysterectomy, etc.

There is also a distinction between minor complications and major complications. This depends on the type of complication, which part of the body is affected and what the consequences of the complication could be.

Major complications are common after cystectomy, whichever form of urinary drainage is used afterwards. The likelihood of complications depends on how healthy you are going into surgery and whether you have other health problems like heart or chest disease, diabetes, high blood pressure, kidney disease or being considerably overweight, or combinations of these problems.

- 25 to 30% of patients whose general health is good before the operation will have at least one major complication after their surgery
- at least 30 to 50% of patients whose general health is not good will have at least one major complication after their surgery.

General complications

Some examples of common general complications after cystectomy are:

- blood clots in the legs (thrombosis) or the lungs (pulmonary embolism)
- chest infection
- wound infection or breakdown
- slow recovery of bowel function (ileus)

- abnormal heart rhythm, angina or heart attack (myocardial infarction)
- a mini-stroke or stroke

Specific complications

The specific complications of removing the bladder relate mainly to the surgical joins made in the bowel, where a part of the bowel is removed to make the urinary drainage system, or the joins between the tubes that drain the kidneys (ureters) to the bowel form the drainage system. These are examples of possible specific complications:

- blockage or leakage of the joins in the bowel
- blockage or leakage of the joins between the ureters and the bowel
- injury to the lowest part of the bowel (rectum)
- injury to the bowel (more likely after previous abdominal surgery or radiotherapy to the abdomen or pelvis)

As indicated above, the risks of surgery need to be weighed against the risk of the cancer and the benefits of surgery.

Follow-up

For almost all patients who have surgery to remove their bladder, follow-up for life is sensible.

You have follow-ups to check that

- there is no sign that the cancer has come back
- there are no long-term side effects from the surgery

It is likely that you will be seen

- every 3 months in the first 2 years after surgery
- every 6 months in the next 2 years
- then annually for life

The follow-ups consist of checking how you are and how you feel, together with combinations of blood tests, chest x-rays and scans.

Your new way of weeing

Most people will get a choice of how they will wee (type of urinary diversion) when they have their bladder removed.

The three main types are:

- urinary stoma (urostomy)
- reconstruction (neo-bladder)
- continent diversion

HAVING A STOMA

A urostomy (when they create a stoma) is the most common operation for invasive bladder cancer. It has been done since the 1950s and is also called an ileal conduit.

When your surgeon removes your bladder you have a small piece of your small bowel removed and the cut ends are joined together. The tubes carrying your wee from the kidneys (the ureters) are sewn into one end of the piece of bowel the surgeon removed. And they seal this end of the removed bowel. Next, the surgeon cuts a small hole in the surface of your tummy (abdomen). The open end of the piece of bowel is put into this hole. This makes a stoma. The stoma is usually put to the right of your tummy button. But you can talk to the surgeon about where it would be best to put it for you.

When the operation is finished, your wee will run down the ureters, through the piece of bowel and out through the stoma. You will need to wear a waterproof bag (urostomy bag) over the stoma to collect the wee. You can empty the bag as often as you would normally go for a wee.



A specially trained nurse called a stoma care nurse will show you how to look after your stoma, and can help you cope with any problems. You may also find it helpful to talk with someone who has already learned to live with a stoma. As well as talking to people on our [Confidential Forum](#), your nurse or doctor may be able to arrange for you to meet and talk with another patient about how they coped. This kind of advice can be very helpful, especially in the first few months after your operation.

Most people who have a stoma can get back to a normal life. Many go back to work and take up their favourite pastimes again, including swimming. Your stoma nurse can give you information and advice.

Before your operation, the doctor or nurse will carefully plan the position of your stoma so that your bag will stay in place whether you are sitting, standing or moving about. The stoma is usually located in the abdomen, and it may be placed on the right or left of the belly button (navel).

Sometimes the stoma can be tailored to a person's particular need. For example, a keen right-handed golfer may prefer a left-sided stoma so that it doesn't interfere with playing golf.

For the first few days after your operation, your nurse will look after your stoma for you. They will make sure that the bag is emptied and changed as often as necessary. At first your stoma will be slightly swollen, and it may be several weeks before it settles down to its final size. The stoma will also produce mucus (a thick white substance), which appears as pale 'threads' in your wee. The amount of mucus produced will decrease over time.

As soon as you feel ready, the nurse will show you how to clean your stoma and change the bags. It may be helpful for a close relative or friend to be shown as well in case you ever need help at home.

There are different types of bags available. Your nurse will help you choose one that suits you best. When you're changing your bag, allow yourself plenty of time and privacy

so you can do things at your own pace and without interruptions.

Stoma (urostomy) bags are flat so they won't be noticed under your clothes. The size and position of the stoma is the most important factor in how noticeable the bag is. Many people with a stoma can wear their tightest clothes without anyone knowing they have a stoma bag. Although you may be very aware of your stoma, people won't usually notice it unless you choose to tell them.

Before you leave hospital the nurse will make sure you have a supply of stoma bags. When you're at home, you can get all your supplies from your chemist. As some chemists don't have a very large stock, it's often a good idea to give them your order well in advance. Sometimes it's better to order directly from a specialist supplier. Your stoma nurse will be able to recommend suppliers.

You will need to empty your stoma bag several times a day and change it every two to three days. You may have some problems to begin with, especially at night when the stoma may leak. A district nurse will visit you at home to help while you get more familiar with your stoma and how it works.

You may have difficulties with leaks or skin rashes, which may mean that your bag isn't a good enough fit. Your stoma nurse will be able to give you different bags to try until you find one which works best for you and will also be happy to give you any further support and advice you may need.

Once you're at home, you'll still be able to phone your hospital stoma care nurse for advice, and you may also have contact with a community stoma nurse.

Living with a stoma

Most people who have a urinary stoma are able to return to a normal life. Having a stoma is not a bar to working or to most activities, even swimming. People will not be able to tell that you have a stoma. The bag is flat and will not be visible through your clothes.

However the first few months after surgery can be very difficult. You will need to learn how to take care of your stoma and use the bags and fittings. In addition, you will have had major surgery and will be dealing with changes affecting, for instance, your sex life and ability to have children. Many people find that they have difficulty adjusting emotionally and in terms of their body image. It is not unusual to feel quite depressed in the weeks immediately after surgery.

You will probably find it takes a little time to get used to living with a stoma. It can take a while to find the bags and fittings that suit you, and you will need to learn new routines around emptying and changing your bags. Your specialist nurse will advise you about how to obtain supplies of bags and fittings.

Although many people are able to go back to wearing the clothes they did before the operation, the position of your stoma may make it difficult to wear certain items. Clothing which may cause problems includes pants, skirts or trousers with a tight waistband or belt which presses directly onto the stoma. Other patients are often the best source of information about where to find sources for comfortable, practical and stylish clothes. We are happy to introduce you to other patients who will be able to help and advise about the practicalities of day-to-day life.

Can there be problems?

After an operation to form a stoma, most people have few or no problems whatsoever. However, some do experience difficulties, which may give rise to concern.

You are entitled to impartial advice on the stoma pouches most suited to your needs from your stoma nurse.

LEAKS

Some people experience occasional leaks, but if they are frequent something is wrong. A simple adjustment to the stoma pouch may be all that is necessary, so talk to your specialist nurse as soon as possible. If the leak is caused by a faulty stoma pouch, inform the supplying company so they can correct the problem.

URINARY TRACT INFECTION

Bacteria are commonly present in a stoma, but are usually flushed away if you drink plenty (approximately 2–3 litres per day). Antibiotics should only be prescribed if you have cloudy, unpleasant smelling urine, accompanied by discomfort or pain around the stoma or kidney area and a raised temperature.

MUCUS IN YOUR WEE

The intestine (bowel) naturally secretes mucus to assist the passage of waste products. Your stoma is made from a piece of bowel, and will therefore continue to produce mucus, but this usually decreases with time. This mucus usually looks like thin white threads in your wee.

HERNIAS

A hernia is a weakness in the abdominal wall often at a site where the abdomen has been opened surgically. This can occur either around the stoma or at the incision site, and a small bulge develops. A hernia support belt may be worn to help prevent a hernia from developing or to support an existing hernia.

Discuss any concerns you may have with your specialist nurse. Surgical correction is only advised if the hernia is causing great discomfort or obstruction. Mesh may be inserted during the operation to repair the hernia to strengthen the abdominal wall, as recurrent surgery may weaken the abdominal wall further.

BLEEDING FROM THE STOMA

The stoma has many tiny blood vessels, so it is not unusual to see specks of blood when cleaning it. This is quite normal. Bleeding may also occur if the stoma pouch is rubbing against the stoma, so this should be fixed to prevent ulceration of the stoma. If the bleeding is excessive, seek medical help as soon as possible, as a large blood vessel may have been damaged. If any bleeding comes from inside the stoma, this should be investigated urgently. Sometimes urine infections and stones can cause slight bleeding.

BLEEDING AND DISCHARGE FROM THE URETHRA

If your urethra was left in place after surgery,

it is important to report any bleeding that may occur as soon as possible.

STONES

One cause of stones is recurring UTIs, but a high fluid intake can help prevent them. If you do pass a stone, save it and give it to your GP, who can arrange to have it analysed. Further investigations may then be required.

DIET

People with a stoma can normally enjoy a completely normal diet. It is helpful to create an acidic urine pH, which helps to prevent infection. Cranberry juice, cranberry capsules or any fruit juice and bio or live yoghurt help in this process. However, cranberry juice or capsules should be avoided if you are taking warfarin. If you have any doubts ask your nurse specialist.

Our top tip is to drink lots and lots of water!



NIGHT DRAINAGE SYSTEMS

Your stoma bag will only be able to contain a certain amount of wee before you will need to empty it. This isn't usually a problem during the day, but at night you will need to connect your bag to a night bag which will hold up to 2 litres of wee.

These usually work very well, but here are some tips that will help prevent any problems.

- To avoid an airlock in the night drainage system, connect the night drainage bag to a stoma pouch that already has some wee in it. Squeeze the wee through into the night drainage bag and the stoma pouch should then remain empty overnight.
- Reusable night drainage bags must be washed thoroughly after each use. Vinegar or disinfectant can be inserted using a syringe or small funnel, and then agitated and flushed through with warm water. However, it is acceptable to use just water. A night drainage bag should only be used for a maximum of 5–7 nights before replacing it.
- The simplest method of night drainage is to use disposable bags, which are emptied and thrown away after each use.
- To avoid twisting of night drainage bags during the night, use an anti-twist strip, fastening the tube of the bag to your leg.
- Some people find a leg bag more convenient than a night drainage bag for additional capacity.
- Flat pack night drainage stands can be either free-standing or slid between the mattress and the base of the bed, and are ideal for travel.
- Place the night drainage stand in a plastic bowl or inside a large plastic bag (ensuring there are no holes in the bottom) for extra security.

TRAVELLING

Always keep a night drainage bag in the glove compartment of your car to empty your pouch in case you are held up in traffic. But don't forget the connector between the two!

GENERAL TIPS FOR A STOMA POUCH

- Warm the flange (the pieces that you stick onto your body) against your body before applying, as this can help make it more flexible.
- After fitting a new bag, if you're using a two-piece system, give the pouch a 'yank'

to ensure it is clipped onto the flange securely.

- Stoma pouches with a bendy/fold-up tap can occasionally be hard to open and close. If this is the case, rub a small amount of Vaseline around the bung to solve the problem.
- When using paste, or similar products, wet your finger to avoid it sticking during application.
- Sore places around your stoma can be healed with many different products available on prescription. If problems persist, see your specialist nurse.
- To remove wee smells from carpets, beds or furniture after a leak, use either bicarbonate of soda or one of a range of deodorizing products, usually available free from your stoma supply company.
- A range of mattress protectors is available from most medical equipment shops, department stores and larger chemists.

HAVING A NEOBLADDER

Throughout the world neobladders are the main alternative to having a stoma with a bag attached to your abdomen. The first ever neobladder operation was performed in 1959, so there has been a lot of experience in this procedure. Some surgeons favour this option, whilst others are quite happy to advise both neobladders and stomas. Some people are very suited to a neobladder operation, but others aren't. Do talk to your consultant about what is right for you. Before a final decision is made, there will need to be blood tests and scans to make sure that a neobladder is the best option for you.

What actually happens?

Forming a neobladder is carried out at the same time that you have a cystectomy and your bladder is removed. This means that the operation is the same as described above but the surgeon will form the neobladder rather than the stoma.

This is a slightly more complicated operation than creating a stoma, so it is likely that you

will be longer in theatre and your recovery might be longer before you can go home.

The neobladder is formed by removing a piece of your bowel (larger than that used to make a stoma), and sewing the remaining bowel back together again. The section of bowel that has been removed is opened lengthways and then stitched together to make a new 'bladder'. This is then joined to your ureters (the pipes that bring your wee down from your kidneys to your bladder). This new bladder, the neobladder, is then connected to your urethra, so that your wee is expelled through the normal route.

Please remember that if your cancer has spread to the urethra, then this is not a suitable operation for you as the urethra will have to be taken out to ensure all the cancer is removed. This means there will be no urethra left to attach the neobladder to. In these circumstances your surgeon will form a stoma.

The muscles of your neobladder will not work in the same way as in a normal bladder. Initially, you will not have complete control of the new bladder, so you will be shown how to do pelvic floor exercises to strengthen your muscles. It is quite common to have some incontinence in the early days following surgery, especially at night. After surgery, the capacity of your neobladder will be limited, so you will need to set an alarm to wake yourself up at night in order to go to the loo before it becomes too full.

It will take between 3 and 6 months post surgery for your neobladder to stretch to the same size as a normal bladder. You will probably need to empty it every 1 to 3 hours to start with, and then gradually build up the time between loo visits as your neobladder stretches and you get used to the new sensations.

This surgery is a major undertaking, and it is likely that you will need to stay in hospital for 2 to 3 weeks. Your urology team will keep a close eye on you to make sure that no complications occur. You will be given lots of fluids through a drip until you are able to drink enough normally. Make sure you get

enough pain relief – if it's not working, ask for some more. Do not suffer in silence. Your consultant should provide you with all the information you need to know about your operation. If you are not clear on something, do ask. Make sure you know about all the permanent changes to your body as well as the temporary ones. Talk to your consultant about sex and make sure you get any specialist advice and aftercare you need.

Straight after the operation you will have a catheter in the new bladder and a drain in your abdomen. These will normally be removed after a couple of days, but you will also have two fine tubes which will be draining the kidneys that will normally have to stay in for 7 to 10 days. Whilst you have the catheter in, it is important that this isn't blocked by mucus so you will be shown how to flush your new bladder to remove any excess.

How do I empty my neobladder?

The nerve supply to your new bladder will have been interrupted, so you will not get the same sensation as you did with a normal bladder when you need to wee. You will need to learn a new way to feel and understand when you need to go to the loo, as well as learn a new technique to empty your new bladder.

The 'feeling' you get when you need to empty your new bladder varies between people. Some people experience a feeling of fullness, while others report that they feel like they need to pass wind! Don't worry, your body will find a way of telling you when it's time to wee. You will also have to learn a new way to have a wee. You will need to relax your pelvis and strain your abdominal muscles to squeeze your wee out. Most men find that they need to sit down to do this rather than trying to do it standing up.

It is important not to strain too much as this can cause problems, so take your time and don't try to force it out at all costs. While you are still in hospital, you will be shown how to use a thin catheter in case you need to rely on one to empty your bladder completely. Wee left in your bladder can make you more prone to

infections and could cause problems for your kidneys. If in doubt, ask for help and then ask for help again.

It is important that you have good bladder control and do not suffer from incontinence before having this surgery. Since all of the bladder and part of the urethra are removed during surgery, this may affect your continence afterwards. The surgeon will leave behind the section of the urethra where the sphincter muscles are located. These are the muscles which work to help keep you dry. The surgeon will also attempt to preserve as many of the nerves in this area as possible.

The bladder can often be emptied in the normal way. However you must be aware that you may be incontinent at first. Daytime continence should return over a period of 4 to 6 months, though you may be incontinent at night for up to a year following surgery. Unfortunately a small percentage of patients may continue to be incontinent during the day and/or night even after this time has elapsed.

Some patients find they are unable to empty their bladders adequately or at all. This can happen immediately after surgery or later on. The only way to empty the bladder in these cases is by clean intermittent self-catheterisation. This means inserting a narrow hollow plastic tube called a catheter up the urethra and into the neobladder. Once the urine has drained out, the catheter is removed. This procedure is taught to all patients who are having a neobladder before surgery in case they need to use it afterwards. Your surgeon will discuss this with you and refer you to a nurse specialist who will make an appointment to teach you how to do it.

The first few months are all about getting used to this new way of having a wee. Remember you are learning a brand new skill, and very few people get it right first time. Don't feel like a failure if it takes longer than average to get it all sorted, and be prepared for some incontinence in the beginning. Some people are lucky and it just 'clicks' and they are sorted within a couple of months. Many take

longer, sometimes a lot longer, but you *will* get there. Do have a chat with people in our **Confidential Forum** who have neobladders – they will happily give you their best advice. We can also put you directly in touch with someone who has a neobladder that you can talk to through our **Bladder Buddy Service**.

What are the risks of having a neobladder?

All treatments and procedures have risks, and your medical team will talk to you about the risks of having a neobladder. The most common complications are:

- urine infections
- mucus build-up (which may cause stones to form)
- blood may become too acid (known as hyperchlorimic acidosis).
- incontinence by day and/or night
- inability to empty the new bladder completely and the need for self-catheterisation.
- erectile dysfunction (in male patients)
- sexual dysfunction (in female patients)

If you get any serious problems, like not being able to empty your bladder at all, even with a catheter, do go straight to hospital. If you are having difficulties in any way, contact your specialist nurse.

Life after surgery

Your medical team will give you any specific instructions you need to live with a neobladder. If you don't understand something, do ask them to explain it again. It will take several months before you regain your strength. Remember, you have just had a major operation. Do try and keep to a healthy diet with plenty of liquids. These extra liquids are very important in the early days to prevent constipation. You have just had a length of your bowel cut out and what is left needs some tender care!

The best tips

Take your time getting used to your new bladder. Don't panic if it seems to be taking a while to get the hang of it all. Try not to do any heavy lifting for about 6 months. And remember, in the beginning it will leak. But it will stop leaking and life will be good.

HAVING A CONTINENT URINARY DIVERSION

These are less common in the UK, but you might be offered this type of operation by your surgeon. The most common of these types of surgery are the Mitrofanoff and the Mainz Pouch.

THE MITROFANOFF

There are three main parts of this diversion:

- the reservoir to hold the urine
- the channel or tunnel to let the urine flow out of the reservoir
- the continence mechanism to keep the urine in until it is convenient to empty the reservoir

The reservoir for the urine can be made using a completely new bladder made entirely of bowel. This is connected to the outside of the body by a tunnel, which forms a small opening (a stoma) on the surface of the skin.

The tunnel can be made of various parts such as your appendix, ureter or bowel depending on what surgical technique the surgeon has decided would work best for you.

The reservoir is emptied of urine by using a plastic tube called a catheter. This is inserted into the stoma, through the tunnel and into the pouch. Once the pouch is empty, the catheter is removed. You do not need to wear a bag over this opening, as this stoma is continent and does not leak in between catheterisations.

For the best advice on the Mitrofanoff, information about any complications and great tips, we recommend that you get in touch with [Mitrofanoff Support UK](#).

THE MAINZ POUCH

With this type of urinary diversion after surgery the patient is able to pass urine via the rectum (the back passage). The ureters are plumbed into the rectum, which has been changed surgically so that it is now a reservoir for urine.

Unlike urinary diversions, you do not need to use a device to either empty the bladder or collect your wee (stoma bag). With the rectal bladder you will be able to wee and have your bowels open through the same opening (the anus).

The main complications are:

- Incontinence: it may take several months for you to regain continence, especially at night. Though you will be able to tell if you need to pass urine or if you need to have your bowels open, your stool is likely to be very soft because it will be mixed with urine. This means that you may also leak stool until you regain control.
- Offensive odour: the bacteria which live in the bowel will give a pungent odour which some patients may find offensive. This may mean you have to carry deodorising spray when using public conveniences.
- Acidosis: the bowel may absorb some of the urine, making your blood acidic. This may not give you symptoms and can easily be put right with medication.
- Incomplete emptying: you may find you are unable to empty all the contents of your rectal bladder. This means you will always have some urine and/or faeces in your bladder which may cause acidosis, urine infections and incontinence.

If you are unable to empty your rectal bladder and as a result have acidosis and/or recurrent infections, your surgeon may advise that further surgery is needed. This may mean changing to an alternative urinary diversion.

CHEMOTHERAPY

This section is about chemotherapy treatment for bladder cancer injected into the bloodstream. These treatments, which can also be called systemic chemotherapy, reach all areas in the body that have a blood supply.



Neoadjuvant

Chemotherapy may be given before radiation therapy for invasive bladder cancer and also before radical cystectomy. This is called neoadjuvant treatment, meaning before the main treatment.

Neoadjuvant chemotherapy in suitable patients has been shown to improve survival by 5%. This means for example, that if the cancer has spread through into the muscle lining of the bladder and the chance of being alive and well five years after the cancer treatment is 60%, neoadjuvant chemotherapy would increase this to 65%.

Adjuvant

This form of chemotherapy is an extra after the main treatment such as radical cystectomy, to try and reduce the chance of the cancer returning. This is not usually given if you have had neoadjuvant treatment.

Palliative

This means that your medical team cannot cure the cancer but can give you treatment to improve symptoms and extend life – hopefully of good quality. It does not mean that you are terminal. Doctors use the phrase terminal to mean someone for whom there is no treatment available that targets the cancer.

Remember when you are quoted statistics that they apply to a group of patients, some of whom may do much better than the average, although some will do not quite as well. You are an individual patient.

You can find more detailed information on chemotherapy regimens [here](#). This gives information on the commonly used drugs. There are also a number of treatments that are used in clinical studies. As these change often, it is better just to get the patient information sheet that is given for that particular trial.

When looking at any of these information sheets, show them to family members, friends or a bladder buddy. Write down any questions that you have and **buy a thermometer** (and know how to use it), as this will be needed during any chemotherapy treatment to check your temperature if you feel unwell in any way.

Finally ...

We hope that we have provided most of the information that you need with regard to your tests and treatments for bladder cancer, but we do know that it is very likely that talking to someone else who has been through exactly what you are going through is often the best way to learn things, get advice and really understand.

Do join our [Confidential Forum](#) where there are many people who can help you in so many ways. Or we can help find someone who can chat with you on a one-to-one basis through our [Bladder Buddy Service](#).

We are patients and carers ourselves so please get in touch if you have any questions or just want to chat.



About Fight Bladder Cancer

Fight Bladder Cancer is the only patient and carer led charity for bladder cancer in the UK.

At Fight Bladder Cancer, we take great care to provide up-to-date, unbiased and accurate facts about bladder cancer. We have a very supportive medical advice panel made up of some of the best professionals working with bladder cancer, and hope that our information will add to the medical advice you have had and help you to make decisions.

To donate, go to our Just Giving page:

[justgiving.com/fightbladdercancer](https://www.justgiving.com/fightbladdercancer)

or text **FBCD00 £5 to 70070**

Registered charity **1157763**

Please note that our services are not intended to replace advice from your medical team.

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YOU CAN FIND A WEALTH OF INFORMATION, SUPPORT
AND ADDITIONAL DOWNLOADS ON OUR WEBSITE:

[fightbladdercancer.co.uk](https://www.fightbladdercancer.co.uk)