

Cystectomy (bladder removal) and bladder substitutes

There is more information on bladder cancer and its treatment on our website at actionbladdercanceruk.org

When you have your whole bladder removed (in a radical cystectomy), the nearby lymph nodes are also removed. Women may need to have their uterus (womb) and ovaries taken out. Men have their prostate gland removed, too.

The surgeon will also create a new way for urine to leave your body. There are different options, but they may not all be suitable for you. If you do have different options, talk to your medical team about the pros and cons of each one.

The three main ways of urine removal after a radical cystectomy are:

- to have a **stoma** created by using a piece of your bowel to form a tube. This tube provides an outlet for your ureters to pass through an open hole (called a stoma) that has been made in your abdomen. This tube makes a small 'spout' which protrudes slightly from the abdomen so that urine can freely drain into a bag that lies flat against your abdomen – the procedure is usually called a urostomy (sometimes ileal conduit or urinary diversion).

- to have an **continent urinary diversion**, or **Mitrofanoff**, by having an internal urine pouch (sometimes called a new bladder or neobladder) made from a section of your bowel and a channel created using your appendix and/or a piece of bowel which joins the pouch to the skin of the abdomen – urine doesn't freely drain but is removed by inserting a thin tube (catheter) into the bladder through the channel.
- to have a **new bladder** (or neobladder) made and connected to your body's urinary system so that you pass urine in much the same way as before.

Straight after the operation

When you wake up, you'll probably have a number of tubes attached. These will be drains to remove fluid from your abdomen and catheters to collect urine. Urine will drain through one or two catheters into a bag while the area heals. Your medical team will talk to you about what to expect – it varies from person to person and some surgeons also use slightly different techniques.

Urostomy (stoma and bag)

If you have a urostomy, a piece of your bowel will be used to make a tube carrying urine from your ureters through an opening on your abdomen. This is called a stoma (see picture). The ureters are the tubes that normally carry urine from the kidneys to the bladder (see picture). Urine is collected in a bag that attaches to your abdomen.

How the bag works The bag that collects urine from the stoma lies flat against your skin, so it shouldn't be noticeable to those around you. It sticks onto your abdomen around your stoma. Urine passes from your ureters, through the piece of bowel, out through the stoma and into the bag. The bag has a non-return valve that stops urine washing back. This helps prevent urinary infections. A tap at the bottom of the bag lets you drain the urine into a toilet.

Different types of system The bag and attachment come in one-piece and two-piece versions.

A one-piece system has a built-in adhesive patch that sticks to your skin. You'd need to change the whole thing every 2–3 days.

With the two-piece systems, the adhesive patch is separate from the bag. The bag clips on to or seals with the adhesive patch. The adhesive patch can be left in place for around 5 days.

You could also ask your nurse for a bag and practice wearing it.

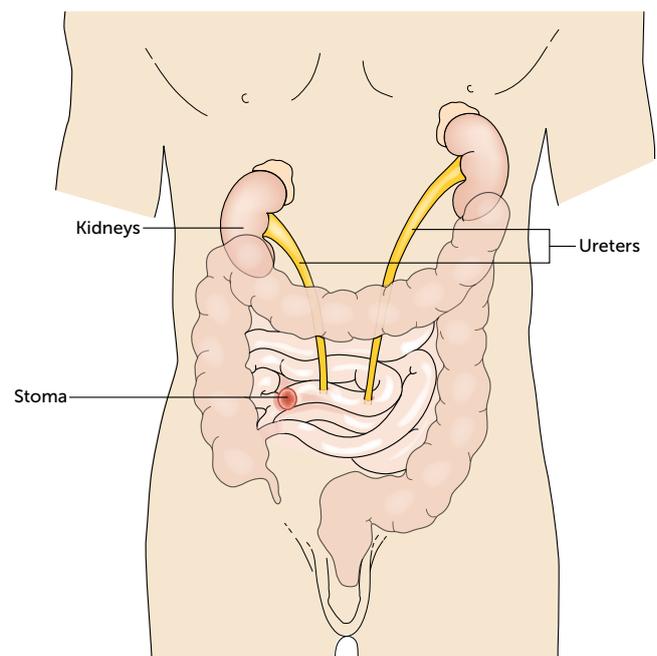
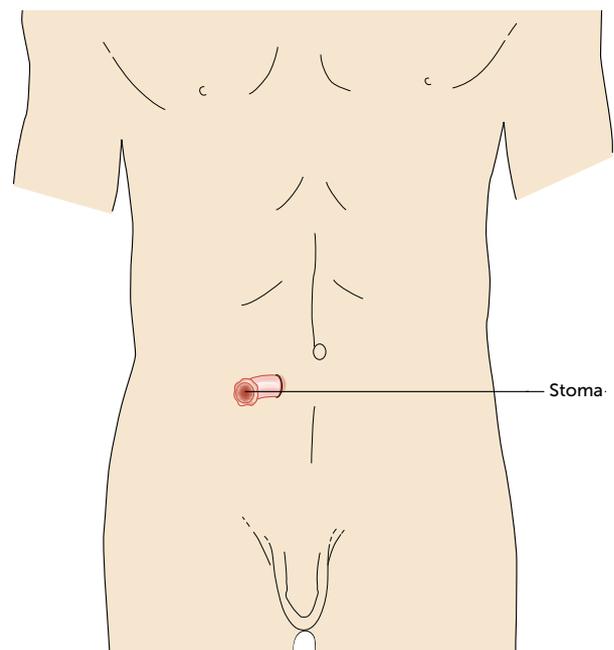
Practicalities You'll need to empty the bag regularly. How often depends on how much you drink. You'll probably need to do it more often than you had to empty your bladder before your operation.

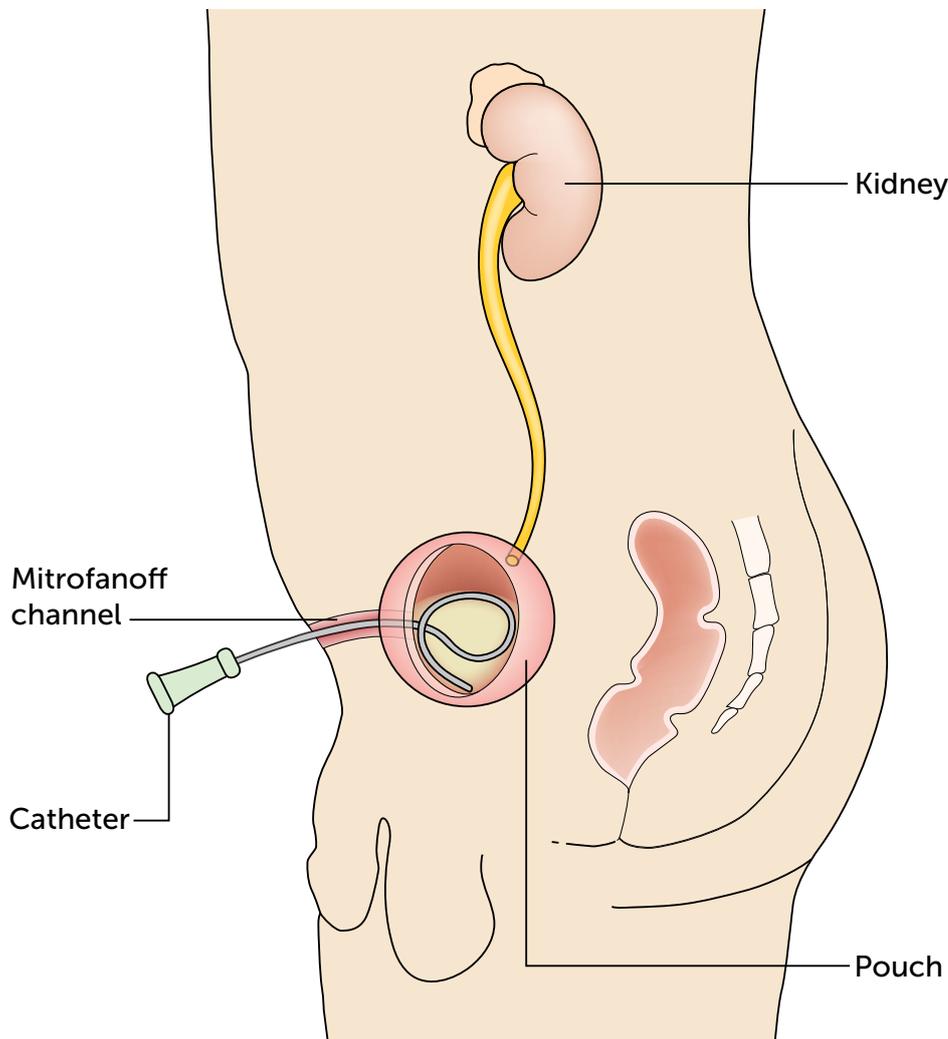
At night, you can use a night bag, which is bigger than a normal bag. You shouldn't need to get up to empty your bag in the night. You might find it reassuring to use a waterproof sheet under your own sheets in case of any leaks.

You'll need to clean the stoma area regularly and change the bag and patch.

The bag shouldn't normally leak, but most people will have a leakage at some time, most commonly during the early days. For this reason, it's sensible to take spare supplies when you go out.

There's much more information on living with a urostomy on our website at actionbladdercanceruk.org





Continent urinary diversion

If you have a continent urinary diversion, sometimes called a Mitrofanoff, you'll have an internal urine pouch (sometimes called a new bladder or neobladder) made from a section of your bowel. A channel will be made to link the new bladder to the surface of the abdomen. Unlike the urostomy, urine doesn't freely drain out of the stoma. The surgeon makes a valve between the channel and bladder during the operation, and this keeps the channel closed to urine until you want to empty the bladder. To empty the bladder, you put a catheter into the channel (see picture).

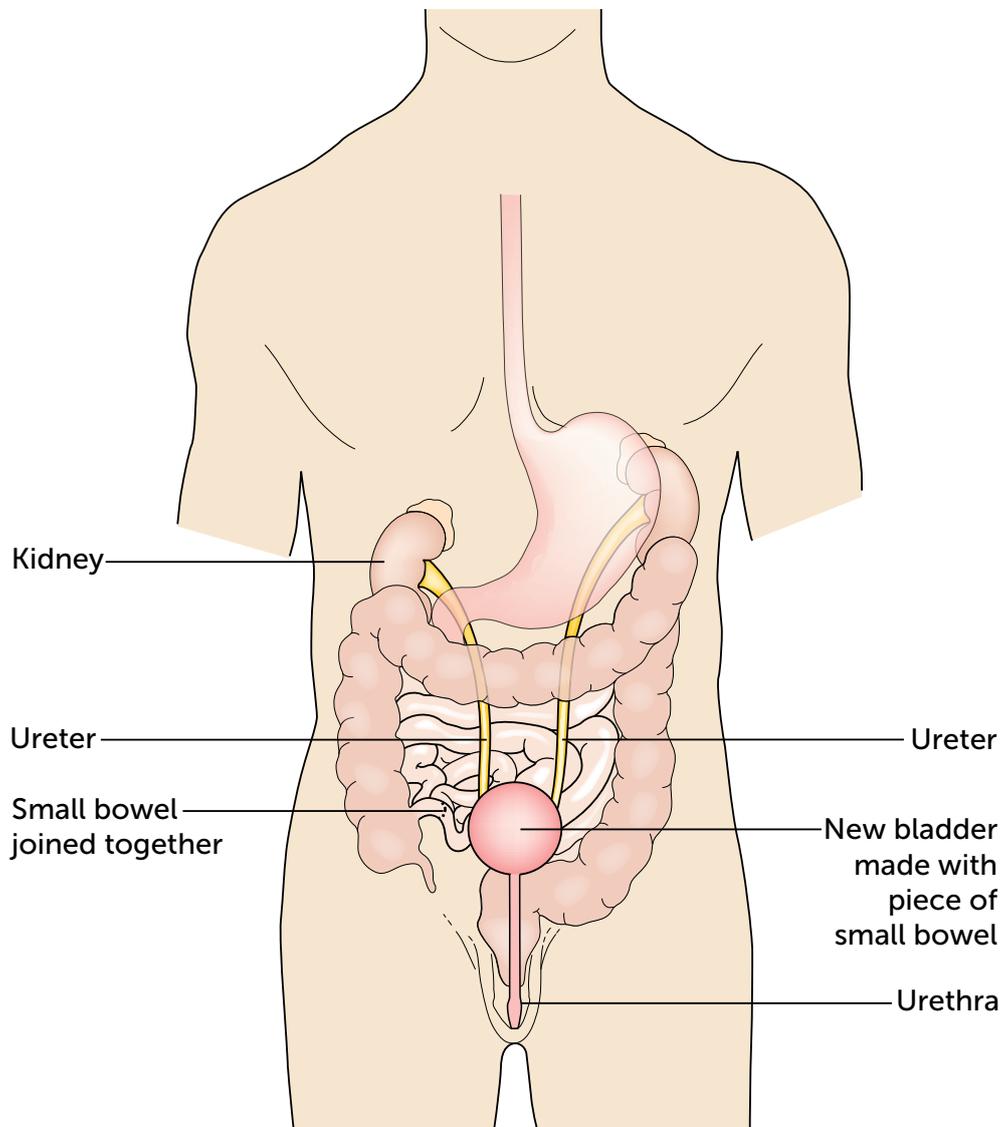
Practicalities You'll probably have to drain urine every couple of hours at first, but eventually this will reduce to four or five times a day and settle to being

more like a normal, voiding habit. You need to be as clean as possible when you do this so you don't get infections. You'll need to wash out the new bladder regularly.

At first, you'll leave a catheter in place overnight, and this will be connected to a night drainage bag. Over time, you may find ways to reduce the amount of urine produced during the night so you can sleep without a catheter.

You don't need to cover the stoma unless it gets sore or irritated. It doesn't need to be covered when you bathe, shower or swim, either, though some people like to put a waterproof dressing over it.

There's much more information on living with a continent urinary diversion on our website at actionbladdercanceruk.org



Bladder reconstruction or neobladder

If you've had a bladder reconstruction, you'll have a new bladder made out of a piece of your bowel. During the operation, this will be joined to the ureters, which are the tubes that carry urine from the kidneys to the bladder, and to the urethra, which is the tube that runs from the bladder to the exit from the body.

Practicalities You'll have a catheter inserted after the operation to drain urine. But this will be removed when the area is healed. You'll be shown how to pass urine by using your abdominal muscles to push down on the new bladder. As you won't have any

sensation telling you that it's time to go to the toilet, you'll have to find a way to ensure you go regularly.

You'll need to do pelvic floor exercises every day to help strengthen the muscles supporting your new bladder.

It will take months for you to become continent during the day, and possibly longer for complete night-time continence to return. Some people find it helps to set an alarm during the night so they can empty their bladder.

There's much more information on living with a neobladder on our website at actionbladdercanceruk.org

Changes after surgery

Cystectomy and the creation of a new urine system is major surgery. As with all major surgery, there are risks with the operation itself and afterwards. Your medical team should discuss these and how they may affect you as an individual. If you're not clear about anything, ask.

Below, we have included a brief description about some of the changes likely to happen after your operation. Your medical team will be able to provide more information that's tailored to your individual circumstances.

Bowel problems In the weeks after your surgery, you may find it difficult to empty your bowels. Eating healthily and a high fibre diet can help. In a few people, this can carry on for longer. Ask your medical team for advice.

Sex life Having your bladder and nearby organs removed will almost certainly affect your sex life. It will cause problems with erections for men. Women may find sex uncomfortable if they've had their bladder removed. And sometimes the vagina is affected by the surgery – it may need to be made shorter, for example, and this affects sex. Your medical team should discuss the effects of surgery on your sex life and the ways to help overcome the problems.

Finding another cancer It's not unusual to find prostate cancer in men having their bladder removed. If the cancer is within the prostate and nearby lymph nodes and these are removed during the cystectomy, no further treatment is needed. Blood levels of prostate-specific antigen (PSA) will be checked regularly.

Fertility If your operation involves removing your sperm sacs (men) or ovaries (women), you won't be able to have children afterwards. A woman who has her ovaries removed will go through the menopause after the operation.

Help and support when you leave hospital

Stoma Nurse

Your local stoma nurse or nurse specialist will give you support and advice once you return home (the name may be different – in some areas, they may work as part of the colorectal service, for instance). They can help arrange supplies of your equipment and provide guidance about caring for your urinary diversion. Talk to your nurse if you have any problems.

The arrangements and amount of support available varies from place to place. Some stoma nurses will visit your home, but usually you will need to go to a clinic. Clinics are held regularly.



More information

As well as information about bladder cancer and treatments, our website has other information sheets that you might find helpful. You can also find your nearest bladder cancer patient support group.

Other charities and organisations also have information about the operations.

- **The British Association of Urological Surgeons (BAUS)** has produced some helpful leaflets – you can find them at www.baus.org.uk/patients/information_leaflets/category/3/bladder_procedures
- **Cancer Research UK** at <http://www.cancerresearchuk.org/about-cancer/bladder-cancer/treatment/invasive/surgery>
- **European Association of Urology Nurses (EAUN)** at <https://patients.uroweb.org/bladder-cancer/>
- **Macmillan Cancer Support** at www.macmillan.org.uk/information-and-support/bladder-cancer/invasive-bladder-cancer/treating/surgery/surgery-explained
- **Mitrofanoff Support** at www.mitrofanoffsupport.org.uk/
- **Stomawise** at www.stomawise.co.uk
- **Urostomy Association** at <https://urostomyassociation.org.uk/>