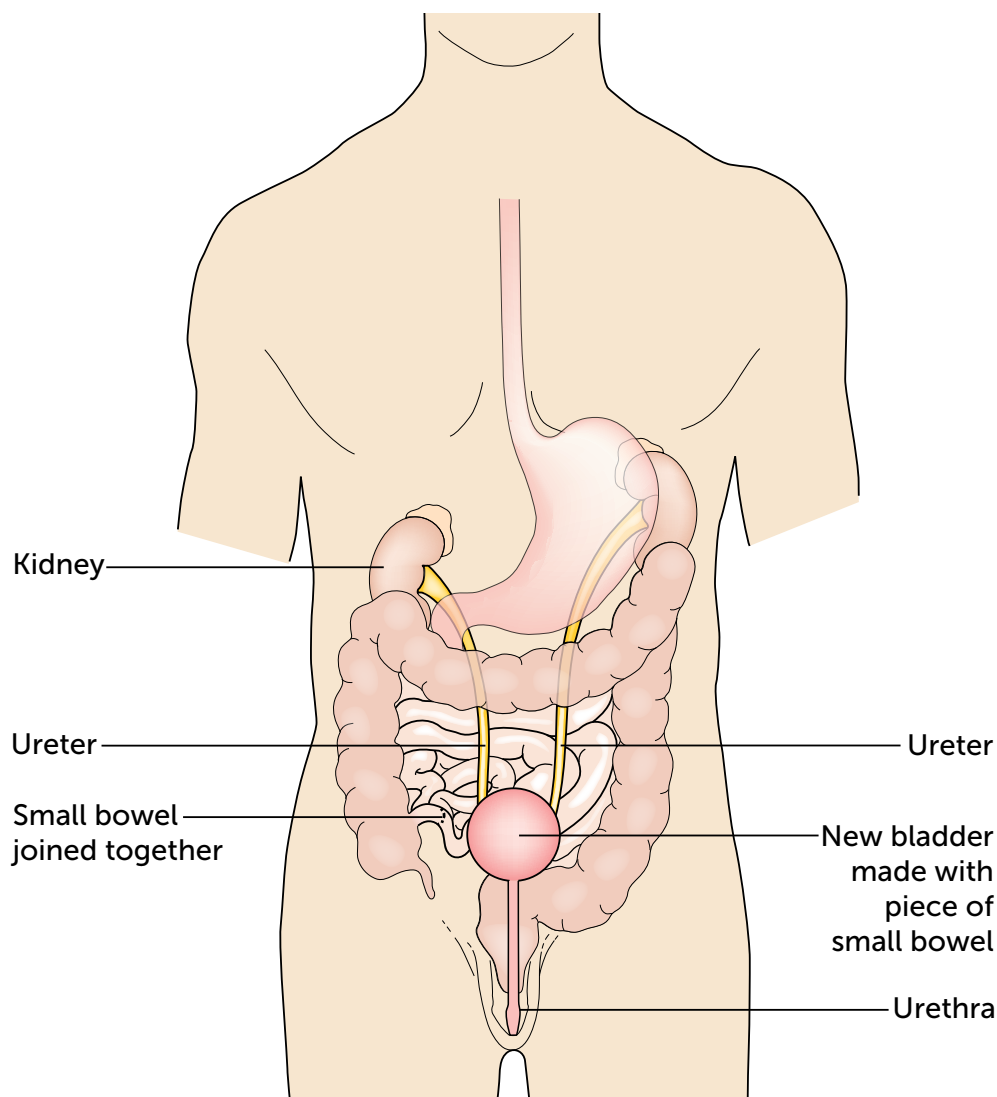


Life with a neobladder

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



If you've had a bladder reconstruction or a neobladder, you'll have a new bladder made out of a piece of your small 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.

After the operation

You will have a catheter in your new bladder to remove your urine, and this will be connected to a bag. Other tubes will be in place to help drain the site and keep the kidneys working. Your nurse will look after you after the operation, and will keep everything flushed and clean. You'll be shown how to wash out the bladder, use the catheters and change the bag. It's important to be as hygienic as possible, to reduce the chance of an infection.

Flushing out the neobladder will help prevent mucus, which is produced by cells making up your new bladder, from blocking your catheter tube. The mucus needs to be flushed out to stop it from building up on the lining of the pouch and possibly leading to infections.

At home

After surgery, you'll go home with a catheter inserted for a few weeks so everything can heal. If your wound becomes red, inflamed, swollen, discharges fluid and becomes smelly or more painful contact your hospital. The catheter will connect to a leg bag (see Box ①).

At night, you can use a larger night bag so you don't have to get up to empty the bag before morning.

You'll need to flush out your new bladder to remove mucus. It is important that the catheter does not become blocked. If you notice that there's a plug of mucus blocking the tube, try to dislodge it. If you can't unblock the catheter, contact your nurse specialist or the ward you were on straight away.

Using a leg bag

Some medical teams recommend different ways of using a leg bag – follow their advice if it's different.

- Put the soft backing of the bag against your skin, and adjust the straps until they're comfortable
- Wear the leg bag below your knee so the catheter can drain efficiently
- Make sure the valve at the bottom of the bag is closed before you connect it to your catheter (flip the valve upwards towards the bag until it snaps in place)
- Attach the bag to the end of the catheter by inserting the connector into the catheter port
- You don't have to disconnect the leg bag from the tubing to empty it – just open the valve and use the outlet tube to direct and control the flow into the toilet
- Wash the connector with soap and water and cover it with the cap provided – you can soak the cap in soap and water when it's not in use – rinse it with warm water before you put it back on the connector
- Your nurse specialist should be able to advise you how many times you can re-use your bag and on keeping reusable urinary collection bags clean and free of bacteria odour.
- Catheter care is so important – you need to keep things as clean as possible to avoid infections or problems. Your nurse specialist will be able to advise if you need some help.

①

Passing urine

When everything has healed, you'll return to hospital so the catheter can be removed. You'll be shown how to empty your bladder. To pass urine, you hold your breath and use your abdominal muscles to push down into your abdomen (see Box 2). You'll need to do this regularly as your body will no longer tell you when your bladder is full. Men may find it easier to sit on the toilet to pass urine, rather than stand.

It's important to empty the bladder completely, as any urine that stays there for a long time can cause infections, irritation or stones. Your stoma nurse will help you with how to check that your new bladder is fully empty. At first, empty your bladder every 1–3 hours. Gradually increase the time between visits to the toilet. The bladder will be able to hold more urine over time – by about 6 months, it should be able to hold about 1 pint.

Don't be alarmed by the thick, jelly-like white mucus in the urine. It's produced naturally by the section of bowel that's been used to make the new bladder.

Problems passing urine

If you find it difficult to pass urine naturally, talk to your medical team. It may be easier for you to use a catheter to empty the new bladder.

Pelvic floor exercises

You'll also be shown some pelvic floor exercises to help strengthen the muscles supporting your new bladder. These need to be done regularly, so find a way of building them into your everyday routine.

Leaks

You will still leak urine during the day for a few months after the operation, and it might take a year to become completely continent during the night. Wearing incontinence pads and using a waterproof mattress, protector or sheet can help.

Some people find it helps to set an alarm during the night so they can empty their bladder.

Some tips for emptying your neobladder

- Sit all the way back on the toilet seat and support your feet on a low footstool – don't hover over the seat
- Relax and release your pelvic floor muscles while breathing deeply – try not to rush or strain
- Lean forward so that urine comes out
- Wipe, stand up, shake your hips, sit down, lean forward again to see if there's any more urine to come
- Keeping your lips, jaw and mouth open while urinating to help your pelvic floor relax
- Breathe in through your nose and out through your mouth – direct the air down and forward towards your abdomen, and as you do this, contract your abdominal muscles
- Try whistling, as this might increase the pressure in the abdomen

From the University of Michigan Health System Treatment Handbook on Neobladder Surgery and Recovery, available from www.med.umich.edu/cancer/files/neo-bladder-handbook.pdf, accessed 21 June 2018



Medical alert

Consider wearing a medical information bracelet or tag so that, if you become unconscious, responders can see the type of operation that you've had.

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 have information about the operations and life afterwards that may be helpful, too.

- **The British Association of Urological Surgeons (BAUS)** has produced some helpful leaflets, including ones on radical cystectomy with bladder replacement (separate information for men and women) 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>
- **Disability Rights UK** sells the Radar Key at www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key

The key opens about 9000 locked accessible toilets across the UK. Disability Rights UK can also provide details of where the toilets are located.

- **Macmillan Cancer Support** at www.macmillan.org.uk/information-and-support/bladder-cancer/invasive-bladder-cancer/treating/surgery/surgery-explained

Macmillan also produce a toilet card to show to staff in shops, pubs and other places. It lets you to use their toilets without questions (though there's no guarantee). You can order this from Macmillan at <https://be.macmillan.org.uk/be/p-22493-generic-toilet-card.aspx>

- **MedicAlert** at www.medicalert.org.uk is a charity that supplies medical alert items, such as bracelets

Shops and Suppliers

- **Live Better With Cancer** at <https://livebetterwith.com/> is an online shop that also has blogs and information.
- **SOS Talisman** at www.sostalisman.co.uk supplies medical information jewellery.