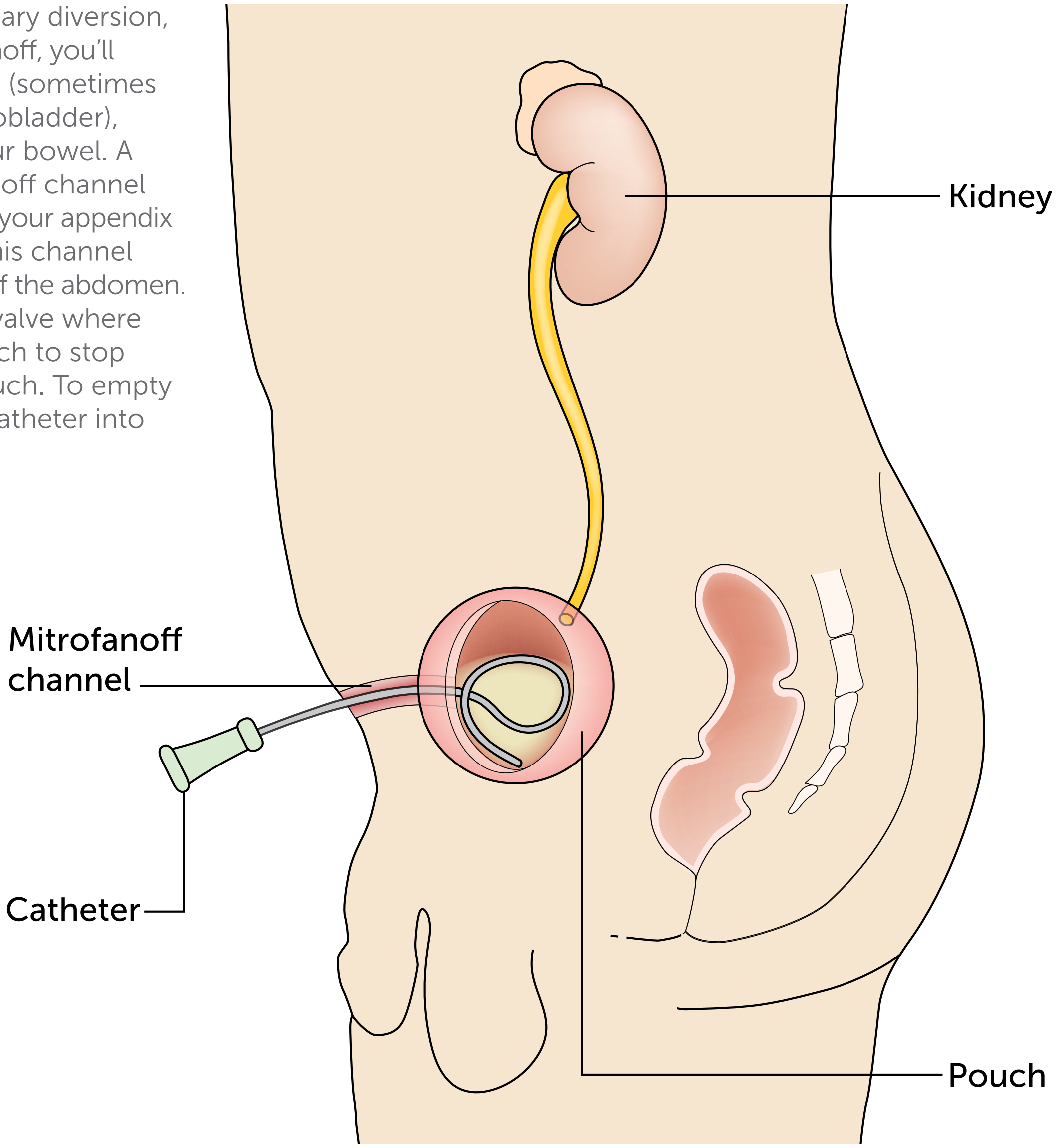
Action
Bladder Cancer UK

Life with a continent urinary diversion

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

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 – called a Mitrofanoff channel – will then be created using your appendix and/or a piece of bowel. This channel joins the pouch to the skin of the abdomen. The surgeon also makes a valve where the channel meets the pouch to stop urine leaking out of the pouch. To empty the pouch, you put a thin catheter into the channel (see picture).



After the operation

You'll have a number of tubes connected to you when you come round from the operation – these will be catheters and drains that remove fluids so the area can heal properly. You may have three catheters going into the pouch: one through the Mitrofanoff channel, one through your urethra (see picture) and one through an opening in your tummy (this one is called a suprapubic catheter). Urine will drain freely through one or two of these catheters, and the third will be capped so that urine doesn't come through it. This third catheter is a safety catheter that can be uncapped and used if there's a problem (your medical team will explain this to you).

Your nurse will look after the channel, pouch and catheters after the operation. When you're feeling a bit better, you'll be shown how to wash out your catheters and pouch. This is important because the pouch and Mitrofanoff channel are made from bowel, which naturally produces mucus. Although this mucus is harmless, it can block the catheters and build up in the pouch.

The catheter or catheters that are collecting urine will be taped in place. They will drain into a collection bag worn on the leg. They will stay in place until the channel has completely healed when you'll return to hospital to have them removed. You'll need to empty the bag and change it regularly. You'll be shown how to do this, but the main points are described in (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.

If urine stops collecting and you can't get the catheter to flow again, contact your stoma nurse, nurse specialist or the ward you were on straight away.

If you have a catheter through your urethra, this will be removed after 3–7 days. The other catheters will stay in place for around 6 weeks.

Blood in the urine You may see some blood in your urine in the weeks after the procedure. This is normal.

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

①

When the area is healed

When the channel is completely healed, you'll go back to hospital so the remaining catheters from the operation can be removed (sometimes the suprapubic one is left in place while you get used to the procedure for emptying the pouch – see overleaf).

You'll be shown how to empty urine from the pouch (see Box ② opposite) by putting a catheter into it through the Mitrofanoff channel.

You'll probably have to empty the pouch every couple of hours at first, but eventually this will reduce to four or five times a day. Aim to catheterise every 2–4 hours. Never leave it longer than 6 hours for emptying. Overfilling the pouch can stretch and weaken it.

If you can't get the catheter into the bladder, don't keep trying. Have a break for a few minutes, and don't drink anything. Try again. If it's still unsuccessful, try with a smaller catheter than the one you use normally. If you are still having trouble, contact your stoma nurse, nurse specialist or the ward you were on straight away for advice.

Washing out the pouch

Some surgeons recommend different ways of cleaning out the pouch – follow their advice if it's different.

- Use boiled and cooled water, bottled water or sterile saline solution (which you can buy) to wash out or irrigate the pouch; we'll call this irrigation liquid
- Empty the urine from the pouch with a catheter, but leave the catheter in place afterwards
- Pull up the irrigation liquid into the syringe
- Fit the syringe onto the end of a catheter
- Gently push the syringe plunger in so that the irrigation liquid is pushed into your pouch
- Slowly pull the plunger back to pull the liquid back into the syringe
- Remove the syringe from the catheter and empty the used irrigation liquid into the toilet
- Refill the syringe with fresh irrigation liquid and repeat
- Keep repeating the procedure until the used irrigation fluid is clear of mucus

②

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.

Practicalities

Caring for the pouch

As the pouch is made from a piece of bowel, it doesn't behave exactly like a bladder. The bowel produces mucus, which can build up in the pouch. To stop this happening, wash it out regularly. You'll be shown how to do this in hospital, but the steps are outlined in the Box below (Box ②). You might find that you don't need to do this quite so regularly after a while.

At night At first, you'll leave a catheter in place overnight, and this will be connected to a night drainage bag. Eventually, you may find that if you cut down on how much you drink a couple of hours before you go to bed, and completely empty your pouch just beforehand, you can sleep as normal without a catheter. If you have a lot to drink in the evening or find that your pouch fills overnight, you may have to set an alarm to wake you during the night so you can empty your pouch.

Looking after the area

You don't need to cover the opening 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.

If the area becomes red or painful, or it leaks or bleeds, see your GP or contact your stoma nurse, nurse specialist or ward for advice.

Drink lots of water

Drinking lots of water can help avoid urinary tract infections (UTIs) and irritation. Aim for 2–3 litres of fluid a day. You may also hear that drinking cranberry juice or taking cranberry juice capsules is beneficial, too. Newer research seems to be showing that cranberry juice isn't particularly helpful, but you can still drink a glass a day just in case (unless you take warfarin regularly). Avoid too many fizzy drinks and drinks with caffeine, such as coffee.

Travel

Empty your pouch before you set off on a long journey.

If you're going abroad, take plenty of spare catheters and the things you need to wash out the pouch (pack some in your hand luggage just in case your larger bags go missing). You can use bottled mineral water to washout the pouch. Carry a letter from your doctor that explains the operation you have had and why you need to carry equipment with you.

General advice

Supplies (such as catheters and bags)
You'll be given a supply of the items you need from the hospital. Once you're at home, you can get all your supplies from your pharmacy through a repeat prescription. Give them your order well in advance of when you'll need the products. Alternatively, you can get your supplies direct from a local stockist or online. Your medical team can advise you about what you need and the best way of getting your supplies.

Disposal of catheters Put used catheters (and bags, in the weeks after your operation) in a plastic bag and place in the dustbin.

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.

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, including one on the Mitrofanoff procedure – 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
- **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
- **Mitrofanoff Support** at www.mitrofanoffsupport.org.uk/
- **Stomawise** at www.stomawise.co.uk
- **Urostomy Association** has information and a list of suppliers at https://urostomyassociation.org.uk/

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.