

Understanding issues that may arise with a urostomy

For people with a new urinary diversion

The idea of having a urinary diversion can be a bit daunting. You'll be pleased to know that after an operation to form a urostomy, many people have few or no problems whatsoever. However, some do experience difficulties, and we hope that this leaflet helps you understand some of the issues that may occur.



An example of a one-piece urostomy bag
Photo courtesy Hollister Ltd

Urostomy pouches

You are entitled to impartial advice on the urostomy pouches most suited to your needs. We recommend that you discuss this with your stoma nurse.

Leaks

Some people experience occasional leaks, but if they are frequent then something may be wrong. A simple adjustment to your urostomy pouch may be all that is necessary, so talk to your stoma nurse as soon as possible. If the leak is caused by a faulty urostomy pouch, inform the supplying company, with details of the batch number. Also, please do let us know as we record any incidents in our Appliance Issues Log to monitor whether there are any recurring problems.

Urinary tract infections (UTIs)

Bacteria are commonly present in a urostomy, but are usually flushed away if you drink plenty (approximately two to three litres per day). You may need antibiotics if you become unwell with any of the following symptoms – cloudy, offensive smelling wee, accompanied by discomfort or pain around the stoma or kidney area, and a raised temperature. Speak to your GP or specialist nurse, who will probably send a specimen of your wee to be analysed so that the appropriate antibiotic can be prescribed.

Taking a specimen of wee directly from your stoma, using a sterile catheter, is the ideal way of collecting a non-contaminated specimen. If this is not possible, you should clean your stoma and hold a specimen container just below it to collect drops of urine. A urine specimen to detect infection must NEVER be taken from a urostomy pouch which has been on for some time, as it will contain stale urine and give a false result.

Note: It is important to ensure that a note is sent along with your wee specimen, stating that it is from a urostomy, not a bladder.

Mucus in your wee

The intestine (bowel) naturally secretes mucus to assist the passage of waste products. The urostomy (ileal conduit) is made from a piece of bowel and will, therefore, continue to produce mucus, but this usually decreases with time.

Hernias

The muscles in the abdominal wall should form a snug fit around the stoma opening, but if the muscles in this area become weak a hernia can form, resulting in a small bulge.

You can wear a hernia support belt to help prevent a hernia developing, or to support an existing hernia.

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

Kidney stones

One of the causes of kidney stones is recurring urinary tract infections, so increase your fluid intake as a preventative measure. If you do pass a stone, save it and give it to your GP who can arrange to have it analysed.

Bleeding from your stoma

Your 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 your urostomy pouch is rubbing against your stoma, so take care as ulceration of your stoma may develop.

If the bleeding is excessive, seek medical help as soon as possible, as one of your large blood vessels may have been damaged. If any bleeding comes from inside your stoma, do get this investigated urgently. Sometimes urine infections, and kidney stones, can cause slight bleeding.

Bleeding and discharge from the urethra

If the bladder has been removed, but the urethra (the tube leading to the outside) has been left in place, it is important to report any bleeding as soon as possible.

If you have a urostomy because of a non-malignant condition, your bladder may well be left in place and will usually shrivel in time. Some people find that they experience discharge from the redundant bladder. This can become infected and you'll find that antibiotics are necessary. Regular washouts may also be recommended. In women, if the problem persists, a minor operation might be offered to make an opening from the bladder through the vagina to drain the fluid. Men may need to have the bladder removed.

Diet

You are likely to be able to enjoy a completely normal diet. You may find it helpful to create an acidic urine pH, to help prevent infection. You can do this by drinking cranberry juice or take cranberry capsules (unless you're taking Warfarin); similarly any fruit juice and bio or live yoghurt are excellent. The top tip, however, is to drink lots of water.

Night drainage systems

To avoid an airlock in your night drainage system, connect your night drainage bag to a urostomy pouch with a quantity of urine in it. Squeeze the urine through into the night drainage bag and the urostomy pouch should then remain empty overnight.

You should wash your reusable night drainage bags thoroughly after each use. You can insert vinegar or disinfectant, using a syringe or small funnel and then agitate and flush through with warm water. However, you can just use water. You should only use your night drainage bag for five to seven nights before replacing it with a new one.

You may find that the simplest method of night drainage is to use disposable bags, which you can empty and dispose of after each use.

To avoid twisting of night drainage bags during the night, you may want to use an anti-twist strip, fastening the tube of the bag to your leg.



Night bag arrangements of two Urostomy Association supporters.

You may find that the need for a night drainage bag can be eliminated entirely while at home by using the U-Drain system. Speak to your stoma nurse about this.

Some people find a leg bag more convenient than a night drainage bag for additional capacity.

You may want to explore flat-pack night drainage stands. These can be either free-standing or slid between the mattress and the base of the bed, and they are ideal for travel.

You might want to put 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.

If you experience any issues with nighttime urostomy products, contact your stoma nurse or stoma equipment supplier.

Travelling

There is no reason for your urostomy to hold you back from travelling. It is usually safe to fly four to six weeks after your surgery, but seek advice from your consultant first.

Always keep a night drainage bag in the glove compartment of your car to empty your pouch into when held up in traffic. However, we don't recommend that a full urostomy pouch, fitted with an emptying bung, rather than an open/closed tap, is emptied this way.

To make seat belts more comfortable over your stoma, you may prefer to use one of the following devices:

- A cam plate allows your seat belt to be locked in a comfortable position, but will release instantly when required.
- A clip designed to lower the position of the seat belt, which is particularly useful for shorter people, where the diagonal would cross the neck.
- A simple sleeve addition to the belt for people who cannot reach the top anchorage point.
- A device designed to ease belt tension across your chest and reduce any restriction in breathing, which can also reduce pressure on the abdomen.

These devices are available from most car accessory shops. You may also like to see our '**Directory of suppliers**' leaflet.

When flying on long journeys, if you are concerned that your pouch will overfill and you cannot easily access the plane toilets, connect a night drainage bag concealed in a carrier bag, which you can then discreetly empty later. For more travel advice, plus stories from globetrotting urostomates, do **visit our website**.



Top tips suggested by Urostomy Association supporters

- Warm your flange against your body before applying, as this can help flexibility.
- 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.
- Urostomy pouches with a bendy/fold-up tap can occasionally be hard to open and close. If you have this difficulty, 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 stoma nurse.
- To remove urine odour from carpets, beds or furniture after a leak, use either bicarbonate of soda, or one of a range of deodorising products, available from supermarkets and pet shops.
- A range of mattress protectors are available from most medical equipment shops, department stores and larger chemists. You may want to check out our 'Directory of suppliers'

Please remember that just because some people with a urostomy have asked us to produce this leaflet, it does not mean that everyone will develop problems. If you are concerned about any aspect of your life with a stoma, just remember that help is only a telephone call away.

About the Urostomy Association

This leaflet is just one in a series. You can see the full list on our website in the resources section. There you can also find our blogs, videos and webinars.

We know that sometimes you just want to talk things over, so we have specially trained buddies who have had their own urinary diversions and are happy to help. There is also a private Facebook group where you can ask questions and share your experiences with other people living with a urinary diversion.

We're also here to raise awareness of all matters around urinary diversions, and we run campaigns and appeals, liaising with like-minded organisations, policy makers and health professionals. Our aim is to build a supportive community around your needs.

Please remember that this leaflet is for information only, and you should contact your own stoma nurse about questions relating to your own care.

Lastly, we can only continue to support members of our community live their best lives, before and after surgery, thanks to charitable support.

Kind donations enable us to run our helpline and keep members up to date through our regular magazine, e-newsletters, group meetings, social media and fact sheets. Thanks to donors, we can inform and support stoma care professionals, increase awareness across healthcare and the general public, and influence urostomy policy and practice.

All of this, and much more, is possible because people choose to donate, fundraise and say thank you to our charity. If you would like to make a donation or support us in other ways, please visit our website at urostomyassociation.org.uk.

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