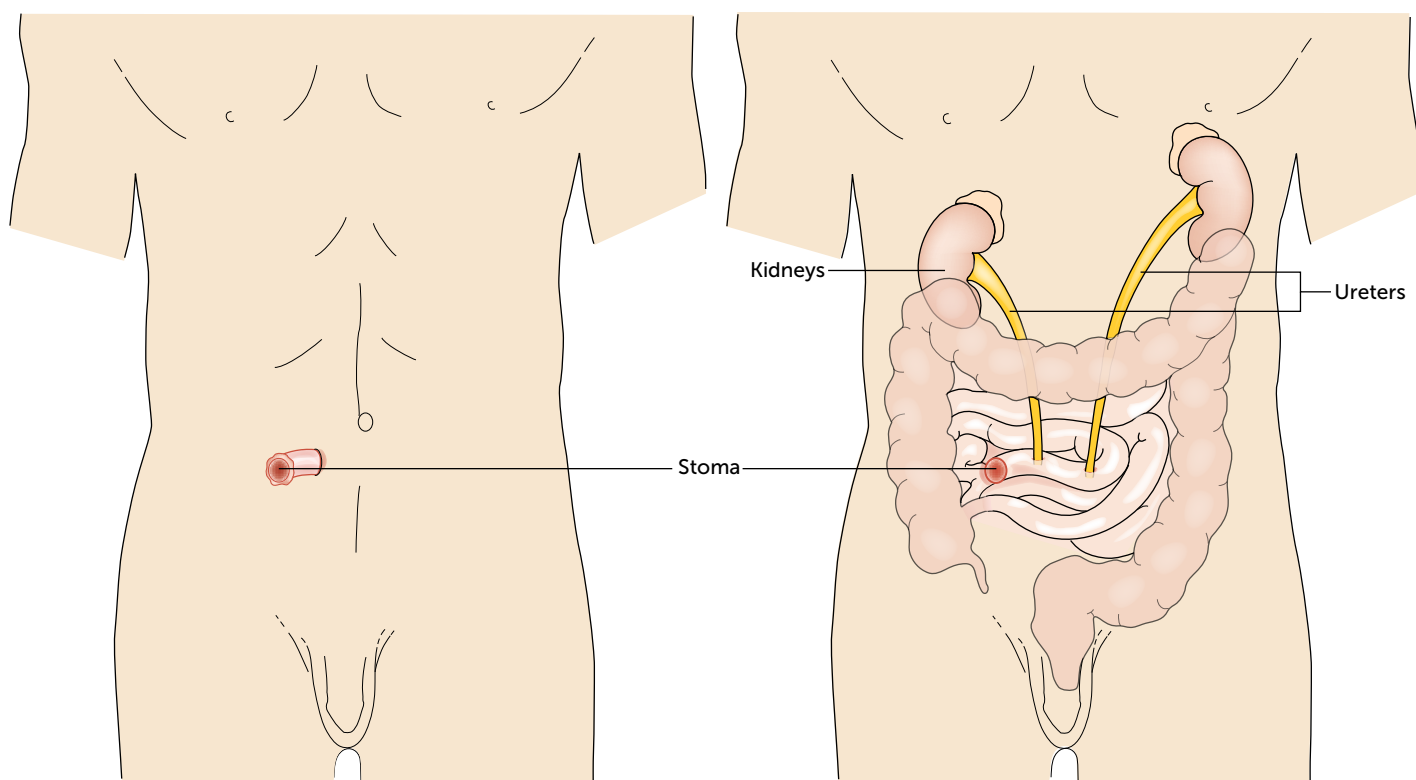


## Life with a urostomy (urinary stoma)

There is more information on bladder cancer and its treatment on our website at [actionbladdercanceruk.org](http://actionbladdercanceruk.org)



If you have a urostomy, a piece of your bowel will be used to form a tube that provides an outlet for your ureters that passes through an open hole called a stoma that has been made in your abdomen. It makes a small 'spout' which protrudes slightly from

the abdomen. The ureters are the tubes that normally carry urine from the kidneys to the bladder. Urine is collected in a bag that attaches to your abdomen.

## After the operation

Immediately after the surgery you will have a catheter or catheters that are collecting urine. They will drain into a collection bag. They will be removed once any swelling has improved.

The nurse will look after your stoma and bag after the operation. He or she will make sure it's kept clean and your bag is emptied at the right time. Over the coming days, the swelling around your stoma will lessen, though it may take a couple of weeks to get to its final size. Pale strands or threads in your urine are nothing to worry about – they are mucus made by the stoma.

In hospital, you'll be shown how to clean your stoma and change your bag. You'll be able to choose the system that fits you best. The two main types of system, or appliance as they're sometimes called, are one piece and two piece (see Box ①).

## Using the bag

**How the bag works** The bag is flat and lies against your skin, so it shouldn't be noticeable to those around you, even when it fills. If you're worried, wearing slightly looser-fitting clothes might help you feel more confident.

The bag sticks onto your abdomen around your stoma. Urine passes from your ureters, 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.

**Wearing an ostomy belt or using tape** Some people like to wear a belt to help hold the bag in place. The belt attaches to the system and wraps around the waist. It can help support the bag, which can get heavy if it becomes very full with urine. If you use a belt, make sure you don't have it too tight – you should be able to put two fingers inside the belt. Other people use tape around the outside edge of the adhesive patch to help hold it in place.

## One piece and two-piece systems

### ONE-PIECE SYSTEM

The bag has a built-in adhesive patch that fits firmly around the stoma. You normally change them every 2 or 3 days.



### TWO-PIECE SYSTEM

The bag is separate from the adhesive part, which is sometimes called the flange or skin barrier. The adhesive patch sticks to the body and can stay in place for around 5 days. The bags clip on or seals with it, and can be removed without pulling the patch from the skin.



## Emptying the bag

You are likely to need to empty your bag more frequently than you had previously needed to empty your bladder. How often you need to empty it may also be influenced by types of drinks (for example caffeine and alcohol). You can also get different sizes of bag, your stoma nurse can help you decide which suits you best. You will need to empty it before it gets very full and heavy, it is easy to check this discreetly. A good tip is to take advantage of opportunities to empty your bag, particularly before things like going to the cinema or a meal.

**To drain the bag** Cough a few times before you drain the bag as it encourages urine to empty into the bag. Sit on the toilet or stand beside it. Unfasten the tap at the bottom of the bag and

empty the urine into the toilet. Most men are able to stand in the usual way, although sitting can be helpful (particularly if you are not steady standing, or on a train or a plane). It is also possible for men to use urinals, although a toilet cubicle is more discreet for those who would prefer more privacy.

## Changing the bag

The standard advice is to change it every second day, although some people change it every day. How often you need to empty or change your bag will be personal, as it varies. You'll soon be able to establish a routine. Many people change their bag in the morning when you have less urine in your system, some people do it at night. The steps to follow to change your bag are shown in Box 2.

### Removing the bag

- Make sure you have everything you need
- Empty the bag
- Wash your hands or use an antibacterial hand cleanser
- If you are using a one-piece appliance, support the skin with one hand and with your other hand gently and slowly ease the bag off. You can use an adhesive remover to help remove it more easily
- If you're using a two-piece, unclip or unseal the bag from the adhesive patch or skin barrier
- Place the used bag with any wipes into a plastic disposal bag (it's usual to be provided with plenty of disposal bags)

### Cleaning the stoma area

- Use warm tap water and a dry wipe to gently clean around the stoma. Don't rub hard or you will make the area sore
- Dry thoroughly with a dry wipe, and pat gently
- Place used wipes in the disposal bag with the used bag
- Wash your hands

### Putting on the next bag or adhesive patch (two piece)

- Some people use a barrier cream or spray to protect the skin – gently wipe or spray around the stoma area. Massage any cream in well and leave the cream or spray to dry for a few seconds
- If you need to, cut a hole in the patch. It can be useful to do this in advance, some people do a batch at a time.
- Warm the new bag against your body
- **Make sure the tap is closed**
- Remove the protective cover from the adhesive patch. Fit the bag over the stoma and smooth from the centre to the edges, making sure there are no creases that could allow a leakage
- Hold the bag against your abdomen with your hands for 30–50 seconds to increase adhesion to your skin. This is important as it helps the bag mould to your body.
- If you're using a two-piece system, clip or seal the bag
- When it's done, give the bag a tug to check that it's fitted properly
- Seal the bag and put it in the bin
- Don't flush bags down the toilet as they will block pipes
- Wash your hands

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## Stoma care

If the hole in your bag is much bigger than the stoma, the urine will come into contact with your skin and make it sore. Having bags with pre cut holes can help avoid this.

If the hole is too small, your stoma may become damaged.

Treat the skin around the stoma with care. It can become sore if you remove the adhesive patch too often or use some strong cleansers. If it does get sore, you can get a prescription for something to help the area heal quickly.

If this keeps being a problem, or your stoma has been damaged or the skin is very sore, ask your stoma nurse or nurse specialist for advice.

## 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.

**Bleeding** Don't worry if there's a small amount of bleeding around your stoma when you're cleaning the area. But if the bleeding is coming from inside the stoma, contact your stoma nurse urgently. It will probably mean you've got a urinary tract infection, but you need to get it checked out.

**Mucus** The piece of bowel that was used to create the stoma will still produce mucus. It will look like a white sticky substance on the tube or in the bag. It might form a blockage in the tubing – if this happens, gently squeeze the tube to push the blockage through.

**UTI Symptoms** After a urostomy, you may still get a urinary tract infection (UTI). If you get any of these symptoms, seek medical advice:

- dark, cloudy or strong-smelling urine
- back pain (where your kidneys are located)
- loss of appetite, nausea or vomiting

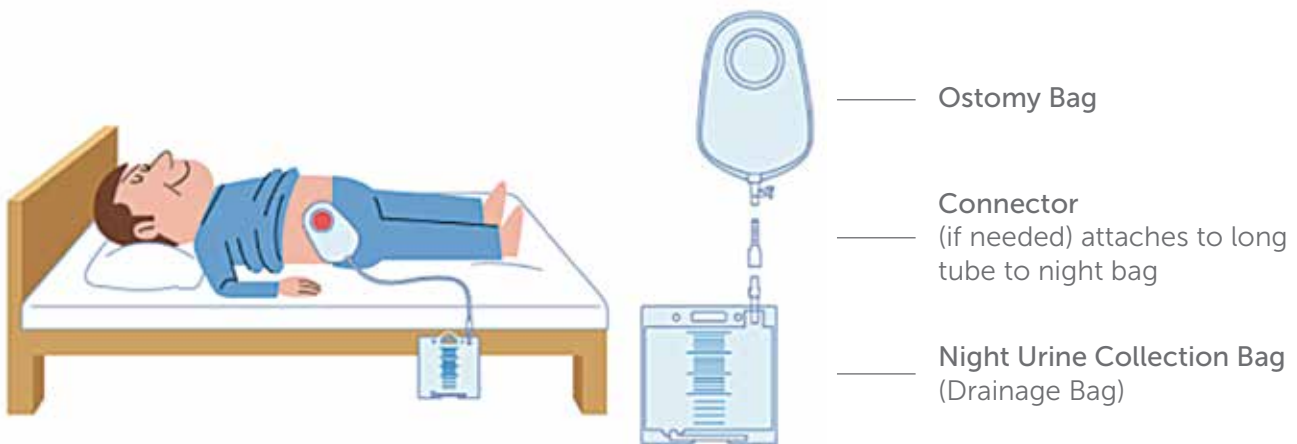
## Leakages

Urine shouldn't usually leak from your bag. But most people will have a leak at some time. Always carry a pack of spare items with you.

At night, a waterproof mattress, mattress protector or sheet will help protect your mattress against the occasional leak. You may find this reassuring and it can avoid inconvenience.

If you have several leakages, there may be something wrong. Talk to your stoma nurse or nurse specialist. It may be that:

- your appliance isn't fitting you properly because your stoma has changed shape or you've lost or gained weight
- the appliance you're using doesn't suit you
- your skin wasn't dried properly before you applied the bag



## Nights

At night, you can use a night bag. This is bigger than your normal bag, and it connects to it to increase the amount of urine that can be collected. You shouldn't need to get up during the night to drain it. You can get reusable night drainage bags and disposable ones. Using a plastic sheet to protect your mattress can be a good idea.

**Reusable bags** have to be washed thoroughly after each use and the longest they can be used for is seven days. If the night bag or tubing starts to look cloudy or change colour, replace them. This isn't because they'll be less effective but that bacteria may be growing, and this can lead to infection.

Clean the night bag and tubing by flushing it through a couple of times with warm water – hold the end of the tube under the tap, partly fill the bag with water, swish the water around, empty it and then repeat the process. Instead of water, some people prefer to use diluted vinegar (one part vinegar to three parts water) or an antiseptic liquid such as Dettol. Use a syringe, a small funnel or an empty washing-up-liquid bottle to direct the liquid into the tubing. Swish the fluid around, let it drain out and then rinse with warm water. Some people prefer to let the cleaning fluid stand in the bag and tubing for an hour before draining and rinsing. Hang the bag and tubes up to air dry. Keep the catheter cap and apply after use.

**Disposable bags** are emptied and disposed of each morning.

**Avoiding air locks** Sometimes urine doesn't drain because there's an air lock. To avoid this, leave some urine in your bag. As you connect your bag to the night bag, squeeze your bag to get the urine to flow into the night bag.

If the urine doesn't drain, try disconnecting and straightening the tube then reconnecting.

**Arranging the night bag** You can hang the night bag on the side of the bed or put it on a special stand. Some people put the night bag in a bowl or large plastic bag to safeguard against spills.

Keep the tubing and night bag below the level of your normal bag. The urine won't drain if it has to travel uphill.

Some people find an anti-twist strap helpful. It fastens the tube of the bag to the leg and so avoids everything getting twisted during the night. Some night bags have extra-long tubing to allow more movement, and some have special tubing that's less likely to kink.

If you're travelling, you might want to consider a flatpack stand. Some are freestanding and some are designed to slide between the mattress and bed base.

**If you go into hospital** It's a good idea to take your night bag and any connectors with you, as it's unlikely the hospital will have supplies of your specific type.

## Practicalities

### Travel

It's a good idea to keep a night drainage bag in the car so you can empty your bag if you find yourself in a traffic jam.

**On a long flight**, if you're worried about not getting to the toilet, you could connect to a night drainage bag concealed in a carrier bag. The bag can be emptied discreetly when it's convenient. You might also want to book an aisle seat so it's less disruptive to make several trips to the toilet.

**Making seatbelts comfortable** Seatbelts can press down on a stoma. Some people use a device that locks the seatbelt in a comfortable position but releases safely when necessary. And you can also buy seatbelt ostomy protectors. Some devices marketed for pregnant women also work to reduce the pressure on the abdomen. A simpler solution is the humble spring-type clothes peg, which you can use to make a fold in the belt. Another option is to place a small cushion between your belt and your abdomen.

### Providing a urine sample

Sometimes it isn't possible or convenient to take a urine sample from a catheter direct from your stoma. What you can do is remove the bag and then clean your stoma well with water. Hold the clean receptacle for the sample under your stoma so that you catch the urine as it comes out. Don't let the receptacle touch the stoma. Write on the sample container or tell whoever you pass it to that the sample was taken from a urostomy.

### Drink lots of water

Drinking lots of water can help avoid urinary tract infections (UTIs), which are more common in people with a urostomy. 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 (unless you take warfarin regularly).

### Supplies (such as stoma bags)

You'll be given a supply of the items you need from the hospital. All your stoma products will be available on prescription. Unless you already have one, you'll be given an exemption certificate for your GP to sign. The certificate entitles you to free prescriptions.

The procedure for getting your supplies might depend on the hospital or area where you live. You may be given a card with the prescription code(s) for your stoma equipment. When your GP sees this, he or she can give you a prescription for the pharmacist or delivery company (keep hold of the prescription – don't leave it with the GP). In other areas, the stoma nurse will make your first order via one of the delivery companies and then write to the GP to tell them what needs to be prescribed. You can then talk to your stoma nurse or nurse specialist and make any changes to your prescription as you try out different products.

**From the pharmacy** If you use a pharmacy to get your supplies, your pharmacist will probably have to order them in, so make sure you arrange this well before you start to run out (it may take up to a week). If there are any problems, ask your stoma nurse or nurse specialist for advice.

**From a delivery company** You can register with a company over the phone or on the internet. You'll either have to send them your prescription or they will write to your GP. Once your stoma has reached its final size (usually after around 6 weeks), you can ask the delivery company to cut your bags to fit your stoma if this is something that you've been doing at home. You'll need to send a template. Your stoma nurse or nurse specialist can help with this if necessary.

### 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** 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 – you can find them at [www.baus.org.uk/patients/information\\_leaflets/category/3/bladder\\_procedures](http://www.baus.org.uk/patients/information_leaflets/category/3/bladder_procedures). The leaflet called 'Living with a urostomy' lists some delivery companies
- **Cancer Research UK** at <http://www.cancer-researchuk.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](http://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.
- **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](http://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](http://www.medicalert.org.uk) is a charity that supplies medical alert items, such as bracelets
- **Stomawise** at [www.stomawise.co.uk](http://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](http://www.sostalisman.co.uk) supplies medical information jewellery.