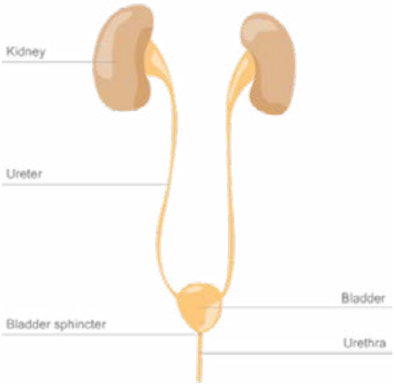
B|BRAUN
SHARING EXPERTISE

YOU ARE A UROSTOMATE

UROSTOMATE PATIENT GUIDE

A urostomy is a surgically created opening made to drain urine from the kidneys after a part of the urinary tract has been damaged (bladder cancer, trauma...). This is usually a permanent stoma. There is a continuous output of urine flowing, so you will need to use a drainable urostomy collection pouch.



- Kidney: In humans, bean-shaped organs which ensure blood filtration and produce urine.

- Ureter: Conduits that allow the flow of urine from the kidneys to the bladder.
A reflux of urine towards the kidneys is responsible for severe infections.

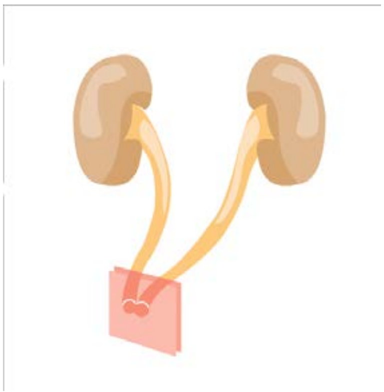
- Bladder sphincter: the bladder sphincter is an annular muscle at the bottom of the bladder that allows the bladder to close when contracted.

- Bladder: The bladder is a reservoir for urine. The emptying is controlled by the sphincter. Correct functioning of the muscles and nerves in the bladder wall is essential for full voluntary emptying.

- Urethra: The canal which urine passes through which starts at the bladder to leave the body, therefore allowing the bladder to empty.

The two most frequent types of urostomies:

The ureterostomy cutanous (UC)



Urethers are moved to the outside of the body.
When the stoma is just formed, it will have one or two thin tubes (drains) attched to the stoma pouch. These are positioned in theatre, and are there to help the operation heal inside. They will usually fall out into your stoma pouch within 10 - 14 days after the operation .

The trans-ileal cutanous uterostomy

This operation is usually longer as there are two steps:

Step 1: consists of isolating a part of your ileon (~15cm).

Step 2: one end of the ileo part will be closed and the other part will be placed outside of the body as a stoma.

The ureters will be connected into this ileo part. Urine can pass through the ileo part and leave the body.

Managing your urostomy

The selection of your appliance depends on the following:

- the location of your stoma
- stoma irregularities
- skin integrity
- your comfort
- cost
- your ability to manage the system
- your preference

In the case of a urostomy the output is a continuous flow of urine, and if your urostomy contains a segment of intestine, as it is the case with an ileal conduit, then the output will also contain some mucus. In any case, you will need to use a drainable pouch with an anti-reflux valve, which can be, connected to a drainage bag at night. In a drainable bag the bottom of the bag is open, allowing the bag to be emptied regularly. It is sealed using a clip which is usually built into the bag.

When deciding which pouch best fits your needs, you will have the possibility of choosing between two types of systems: a one-piece system or a two-piece system. In a one-piece system the pouch and the skin protector are bounded together. In a two-piece system the pouch and the base plate are separated and attached to each other by the patient thanks to a mechanical or adhesive system. With this type of system you can keep the same base plate on for several days and only change, when needed. The pouch doesn't irritate the skin.

Frequently Asked Questions

Theme 1: Equipment/Appliance

1. Can I change my appliance on my own?

Yes! You will need a little bit of training at first, but changing it on your own will enable you to remain completely independent. This will also help you if you are faced with a small leakage problem as you will know what to do. Cleaning with water and soap is best in this situation if help is not readily available.

2. How often should I empty my pouch?

This varies according to the person (based on ones urine production), but on average every 2 to 3 hours. Emptying the pouch on a regular basis is a must. This way, the pouch stays discreet under your clothes and you will limit the risks of facing leak issues (if the pouch is too heavy then it may unstick itself away from the skin or the base plate). Remember to empty your pouch before any sport activity, or sex...

3. When should I change my pouch?

Don't wait until there is a leak to change it! Change your pouch on a regular basis. The following time periods are recommended:

-for the one piece system: every day or every other day
-for the two-piece system: every two to four days for the base plate and every other day for the pouch
-for night bags: every day otherwise rinse it

However each individual is different. In time you will find your own routine.

When removing your appliance, check the gum. If the gum is thinned out then change your appliance more often.

4. Where can I throw out the pouches and used appliances ?

Do not try to flush a pouch down the toilet as it will block your plumbing system!

The pouches aren't biodegradable so they shouldn't be thrown somewhere outside.

To dispose of your pouch, start by emptying it before putting it into a closed plastic bag. You can then throw it all away in the garbage.

5. Can I customize my pouch ?

Of course! You can customize your pouch any way you want using different materials (duct tape, tissue, ..). You can even find videos and tutorials on the web by searching “fashionable ostomy”, or “homemade ostomy pouch”.

Theme 2 : food and drinks

1. What can I eat ?

Having a urostomy doesn ‘t mean that you have to follow a specific diet, eating must remain a pleasure. The best way of staying healthy is to have a good food hygiene, try to eat regularly, slowly and calmly. Know that some foods can color urine (for example beets) or give them a specific odor (asparagus or cabbage). Be careful, plum juice or cranberry juice make urines more acid.

2. Should I drink a lot?

Yes! One important rule is to drink a lot of water each day (between 1,5 liters to 2L). This is especially the case for a trans-ileal cutaneous urostomy where the output can contain mucus and therefore block the catheters. You can drink coffee, tea, juices as well as water on a daily basis.

You can drink alcohol but in moderation.

Theme 3: Every day life/ Coming home

1) The recovering phase

When you go home at first you may feel tired and should take a rest each afternoon. Try to avoid staying up all day as this can tire you out of the point where you cannot sleep at night. When you do start to exercise again it's advisable to start gently, for example going for daily walks or swimming is good. If you don't exercise, but would like to start housework again, then start with the lighter tasks and take frequent breaks.

An E.T. nurse can give you more advice.

2) Driving

Start driving when you feel comfortable performing an emergency stop without hurting your abdominal muscles or wound (this can take up to 8 weeks.) To be safe, the first time you start driving either start with a short distance or ask another insured driver to come with you in case you are unable to continue.

If you are concerned about this, please consult your doctor.

3) Showering or bathing

As the equipment is fully waterproof you can shower or bath. Keep in mind that the heat of the water can have an impact on the adhesive power of the skin protector (1-piece system) or the base plate (2-piece system).

In all cases avoid using products such as shower gels or bubble bath as they leave a greasy film on the body making it harder for the equipment to hold properly. This can lead to possible irritations. Choose products with a neutral pH, preferably without fragrance and without colorant.

4) Psychological adjustments

Depending on the reasons for your operation you may feel that you are on an emotional rollercoaster, being weepy sometimes for no apparent reason especially in the first weeks after the operation. It is important that you talk to someone you feel comfortable with, to help you cope. If you don't find the right person to begin with, don't give up. There are lots of people to help, and remember, you're worth it!

Having a stoma makes your body look and work differently, and there will be times when you find this difficult to cope with. You may find yourself feeling quite angry about having the stoma, and thinking that you will never live a 'normal' life. It seems that during these first weeks all you can think about is having the stoma, and you find yourself thinking 'Is this how it will always be? But through time you will most likely become less conscious of your pouch. It's common to feel disgusted when dealing with the stoma output also. Most people are not used to having such close contact with their bodily functions, and so it can take quite a time to adjust to. Talk to your E.T. nurse or another ostomate who will understand how you feel and may have useful ideas on how to combat these problems.

If you have a partner, they may also feel upset and emotional about all that is happening to you both. Sometimes your partner can be more upset than you are, and might also need some support. The E.T. nurse can arrange to speak to your partner either while you are in hospital, or when you get home.

If you have had emotional problems in the past, you may find yourself struggling to cope with your emotions now so please don't try to do it alone, talk to your doctor or E.T. nurse.

Theme 4 : sports and outdoor life

1) Swimming

In the same way that you can shower or bath yourself with your pouch you can just as easily go swimming either in a pool or in the sea without fear of leaks.

2) Sport and active life style

Exercising and maintaining a healthy lifestyle isn't incompatible with your urostomy, far from it! They are actually the key factor to your recovery and will help you gain back your confidence. However, you must start exercising progressively in order not to strain your stoma too much especially right after your surgery. Avoid any heavy lifting as your abdomen has been made more fragile by the stoma also.

Swimming, cycling, hiking, skiing and horse riding are strongly encouraged. However, avoid any sports that put too much stress on the abdominal muscles such as weight lifting, rowing, fighting sports or rugby as it may injure your stoma. Of course don't forget to do the type of sport that you enjoy, you can even go snorkeling or swimming!

Tip: Wearing a belt or a protection band is sometimes useful.

Being a urostomate shouldn't prevent you from travelling. But you will need a bit of preparation before hand to make sure that everything goes smoothly. When deciding to travel for the first time since your operation remember to be cautious. Start by going away for a weekend or going back to a familiar place where you will be able to relax.

The main aim of this first vacation is to build up your confidence! Following some simple guidelines will help you go on vacation with peace of mind:

- Pack the needed material for the length of your vacation, take a bit more then usually needed to be on the safe side.
- For your comfort, empty your pouch before boarding on a plane or train etc.
- Check that you have adequate insurance, which covers any pre-existing illnesses.
- Ensure you have adequate toilet facilities within your accommodation.
- Plan your best opportunity to empty or change your appliance.
- For longer breaks, send appliances in advance to your destination or have them delivered to you while you are there..
- Divide supplies between hand luggage and your suitcase, in case you lose them.

- For long trips and for more comfort pack a urine leg bag.
- Bring your prescription with you to have the references of your products.

Prepare a pocket-bag:

1. scissors
2. a new pouch *(preferably already cut to your current size)*
3. a disposal bag and a few wipes
4. clothespin
5. a small packet of wet wipes *(in case you have no access to water)*
6. a second skin wipe *(if the first has been used)*

3) Can I wear all kinds of clothes ?

After a urostomy, you can wear the type of clothes you want, however avoid wearing a belt too tight as this can hurt your stoma or wearing right clothes too.

4) Is it possible to go back to work ?

There is no reason why your stoma should prevent you from working (unless your doctor or E.T nurse says otherwise for a specific reason). Before going back to work think about the practical things. For example, think about how you will change or empty your pouch in the toilets at work. Think of the time you will need, the equipment you will need and look to see if there is a specific toilet that would be best to use (one that may be larger, or that has a hook on the door, a shelf, a window, or simply one that is less used). If the trip from your home to your work is a long one look to see if there are available toilets that you could use to empty your pouch if necessary. By doing that you won't feel rushed or worried so your level of anxiety should be low. Also, think about who you will tell and how much you want them to know. Remember no-one except your employer needs to know unless you want to tell them. The decision is yours.

If you are worried about going back to work, ask you employer if you can start by working part time. Start by working only in the morning, or only in the afternoon or on certain days of the week... Talk with your employer to find out what works best for you both. Most people are able to resume their previous employment within 3 months depending on their surgery and work.

Before going back to work, check with the person in charge in your company to make sure that your job is compatible with your stoma (physical efforts needed, place of work...)

5) I am invited to a dinner, a meeting, a party. What can I do ?

Most venues have a bathroom, allowing you to empty your pouch when needed. With the right equipment you will be able to fully enjoy the event you have been invited to. In order for you to not have to empty your pouch too often, avoid drinking too much. If needed, you can also wear a leg pouch.

6) Do I have to tell my kids and relatives about my urostomy?

Children need a climate of trust, you have to speak to them and explain the situation in a simple way. They must not have the feeling that something is being hidden from them in this case what they are imagining is often far worse than the reality.

Saying that you have a stoma does not mean one have to show it! Regarding relatives, it is up to you to judge whether you find it necessary to talk about it. You are the one living with the stoma, you have the choice to talk about it or not. It will seem natural to you with some people, and less with others. Speak about your urostomy with your partner in a calm and open manner to get rid of any fear he or she may have.

Theme 5 : Sexuality

1) Can I sleep with my partner?

Of course! Just check the sealing of your pouch beforehand and, depending on the situation, remember to change it before going to bed.

Initially you will most probably be worried: how to lie? On which side? Gradually you will gain confidence in yourself and bedtime will no longer be synonymous with fear and apprehension, but will be a moment of intimacy.

2) Contraception, pregnancy and childbirth

Regarding contraception you will most likely be able to keep the same as before. For more information do not hesitate to ask your doctor for advice.

Having a urostomy doesn't prevent a woman from becoming pregnant or giving birth. Many women have had successful, uncomplicated pregnancies after their surgery. Indeed in many cases they have had several children following stoma formation. However it is usually advisable to wait for about a year after your operation to have a family, this gives you time to heal after the surgery, and allows you to recover psychologically from the operation.

If you have any concerns ask an E.T. nurse

Urinary tract infection

Symptoms "fever and kidney pain"

A urinary tract infection manifests with an unexplained fever, actual kidney pain, shivering, and malodorous urine. In case of these symptoms, consult your treating physician immediately.

Urine sampling

Under no circumstances should you take urine from the bag (even if it is clean!) because it is not sterile.
✓ Empty the equipment completely
✓ Proceed with care as usual

The most reliable sampling technique is to have a competent person insert a catheter directly at the base of the stoma.

If you do the sampling yourself:
✓ Let the urine flow directly into the bottle, which should be positioned at the base of the stoma.
✓ For more ease of use, we recommend bending over beforehand, or coughing lightly (the abdominal contractions permit more rapid flow of urine into the bottle).
✓ A few drops of urine are enough; it isn't necessary to fill the bottle
✓ Take the sample quickly to the analysis laboratory or place it into your refrigerator. Be sure to specify that you have a urinary bypass.

Controlling the pH level of your urine

pH is a measurement that indicates whether the urine is acid, neutral, or alkaline. If the pH in the urine is too high, there is a major risk of infection.

The pH is normally around 7. This number varies according to diet and the quantity of liquids absorbed.

You can monitor this pH yourself using test strips.
This test does not need any particular conditions; it is simply a strip of reactive paper with a color scale that varies depending on pH:

- Below 7, the urine is acidic
- Above 7, the urine is alkaline
- If your pH is between 8 and 9, you are not drinking enough.

Urine has a strong odor, is cloudy and concentrated, and the risk of infection is high *(a germ often found in this case: Proteus mirabilis).*

The actions to be taken to remedy this are simple:

✓ Increase the amount of water you drink *(especially if the weather is very hot)* during meals
✓ Also drink prune juice, blueberry juice, cranberry juice and, if the pH stays above 7, and if your doctor recommends it, 1g of vitamin C
✓ Eat high-protein foods with acid residue *(meat, eggs, fish, cauliflower, etc.)*
✓ Limit foods that alkalinize *(oranges, lemons, pears, pineapple: daily authorized ration of 4 fruits)*
To maintain your pH:
✓ Drink 2 L of low-mineral water every 24 hours *(excluding coffee, tea, herbal teas, wine, etc.).*

Questions & Answers

1) Cutaneous ureterostomy (with catheter)

How to position the urostomy pouch with a catheter:

In the case of a urostomy the urine flow is practically permanent, especially after drinking. In order to change your appliance the easiest way possible, avoid eating or drinking two hours prior to the installation of your appliance. When possible place your appliance in the morning.

✓ Wash your hands
✓ Place the following material on a towel:
- a new base plate and a new pouch if you are using a 2-piece system or a new pouch if you are using a 1-piece pouch and a bar of soap.
- a few wet compress (use water from the tap)
- a few dry compress
- a piece of thread (about 30 cm) (cotton tapestry style)
- a garbage bag
- microporous adhesive

✓ Remove the used pouch from top to bottom while keeping your catheter in one hand to avoid it leaking. Follow the same procedure when removing your base plate (after having first removed the used pouch) in the case of a 2-piece system.

✓ Hold the catheter by the thread or aim it and fasten it to your abdomen with the microporous adhesives so that it cannot come off.

✓ If there are long hairs around the stoma, cut it with clippers *(avoid scissors and depilatory creams)*

✓ Hold the catheter with one hand, and with the other one apply soap to the skin around the stoma, then rinse thoroughly. After, carefully dry the skin (do not use a hairdryer; as it can cause burns).

✓ It is possible to change the thread if it is wet or dirty. To do this, pull out the old thread and fasten the new thread as closely as possible to the skin, exactly in the same place, and make a knot (tie it tightly to avoid it sliding away, but be sure not to pinch the catheter!)

✓ Place the thread against the skin so that it doesn't go over the dressing, which could detach the equipment.

✓ Quickly pass the catheter into the support opening or the bag (don't cut it, because the size of the ureter corresponds to the precut opening)

✓ Stretch the skin well (be sure there are no folds) before applying the support or bag on the thread.

✓ The catheter can never pass into the anti-reflux system; it must stay in the upper part of the bag.

How to clean the catheter:

The exterior of the catheter can easily be cleaned with soap and water, but keep an eye on its fastening.

- What do I do if my catheter is blocked?

This can happen if you don't drink enough; in this case your urine is salty, concentrated, has debris in it, and there can be hematuria (blood in the urine). You will see reduced flow and start to feel pain in your kidneys.

It is necessary to rinse with sterile water, which only qualified personnel are able to do.

- What do I do if my urine catheter falls out?

Don't panic, but follow your normal routine and have it replaced without delay during an appointment with your urologist. Avoid drinking too much, because if urine is no longer collected your kidneys will dilate and become painful.

- How often should the catheter be changed and who is in charge of it?

The catheter is changed at the urologist application by a surgeon, a doctor (stomatherapist), or a trained nurse.

How frequently it is replaced depends on the type of material, but in general it should be every 4 to 6 weeks or even more. In any case, these changes are scheduled and you will be given an appointment.

- Is there any risk of contamination by the catheter?

If it does not pass through the anti-reflux system of the bag: no. That is, if it is placed in the upper part, the urine cannot flow back up into the kidney. On the other hand, if the catheter goes into the collected urine, there is nothing to prevent the urine from flowing into the kidney, leading to a kidney infection!

Note that it is very important not to inject anything at all into the catheter, especially non-sterile material. ! ! Your role will simply be to clean and change the equipment; everything to do with the catheter will be handled by qualified personnel.

The Bricker

1) Maturation of the stoma

When you return home, your stoma will look like a "greenhouse" strawberry because there is edema around it, but as the weeks pass (usually around two months), it

will shrink in size, reaching its final size and shape (similar to a "wild" strawberry). You will need to adjust the collection based on the new dimensions (2 to 3 mm around the stoma).

Be careful not to confuse it with stenosis.

Stenosis of the stoma is an abnormal shrinking of its size (the skin starts to uncover the intestine and you can only see just a single point and the urine always emerges under pressure, etc.). In this case you must immediately see a doctor because this is rare (for example, it may be due to the appearance of crystals in the urine).

2) Crystals

These are complications specific to bladder bypass.

The peristomal zone changes (a reddened, swollen, blemished appearance).

These are hard, painful encrustations that close the stoma and can cause stenosis.

Often due to insufficient drinking, the urine becomes infected, the pH is alkaline (above 7), and there is a strong odor.

Treatment is as follows:
- General (see urinary pH and dietary rules)
- Local: by bandaging with soaked compresses (1/2 white vinegar and 1/2 water), for 5 or 10 minutes several times a day
- Covering wounds (verify collection, add peristomal paste)
- Reviewing care and equipment (2 parts, more frequent changes, etc.)
- Consulting a doctor or stomatherapist.

3) Mucus

It is present in large quantities when you first have the Bricker procedure, giving the urine a "snowy" appearance with deposits like egg white and a particular odor.

This is normal; the intestinal segment is alive and continues to secrete mucus, which contains intestinal germs that are not entirely harmful and should only be treated if there is a high fever and change in the person's condition.

The mucus will decrease and sometimes disappear over a few months, but it can stay present, whether or not it is visible to the naked eye.

4) Prolapse

This is the total or partial external projection of the intestinal segment. It can be due to an accidental strain or happen spontaneously.

Although unusual in appearance, it is not dangerous, but you must be careful not to injure the intestine during care or with the equipment, and you should consult a urologist to proceed to a surgical correction.

5) Eventration

Around the stoma there sometimes appears a more or less pronounced projection that causes discomfort in the system (leakage) or aesthetic problems (visible under the clothing).

This is an "eventration", which can be corrected by wearing a special "stoma belt" or may require surgical correction.

Miscellaneous

– What should I do in case of leakage?

Try to find the cause:

- Is your support or pouch properly centered?
- Has the protective paper of your support or bag completely come off?
- Is the collector properly adapted to the size and shape of your stoma? (+3 mm)
- Did you properly dry your skin when you attached the support?
- Are you feeling discomfort due to too much peristomal hair?
- Could you have let a drop of urine fall between the skin and the equipment?
- Could you have placed your fingers on the skin protector?
- Are the supports or the pouch damaged from poor storage?
- Pay attention to changes in temperature (they must be preserved in their original box, in a room at 18 °C that is not humid).
- Has care been performed with the product that could cause irritation or dryness of the skin and preventing good adhesion of the equipment?
- Has the support been in place for too long, or is it used?
- Is your urine too alkaline or too acidic right now (check the pH) (see the question on urinary tract infections) and could it be destroying the support too quickly?
- Is your stoma located in a fold or on an irregular surface?

TIP:
If one or more of this criteria is not met, you will have to readjust your care activities.
If the leaks persist, don't hesitate to consult your stomatherapist, who can provide advice and, if necessary, change the equipment.

– I have cloudy urine, should I worry?

No, because cloudy urine doesn't necessarily indicate infected urine.
The urine coming from a Bricker bypass is often cloudy due to the presence of mucus secreted by the intestinal tract. This produces a cottony, white deposit in suspension in the urine. A simple excess of mucus is enough to make the urine cloudy. However, urine can sometimes be "salty", concentrated and malodorous.

This can be due to:

- Insufficient hydration (you are not drinking enough)
- A possible infection, which can usually be avoided by good preventive care

- Urinary tract infection:
The contamination of the urine is more frequent, because the catheter is a way for germs to enter. Regularly changing the catheter reduces this risk.

Please note: The presence of a catheter in the ureter can under certain circumstances cause a violet color of the pouch.

– My urine has a strong odor. What should I do?

The simplest solution is to drink a glass of water regularly, so that you are drinking about 1.5 to 2 liters each day in addition to the water drank at meals.

These quantities must be increased in case of sweating or diarrhea.
Alkaline urine can often be recognized due to its strong odor. To acidify it, you can drink prune or cranberry juice.

To reduce odors, consider changing the pouch regularly, every 1 or 2 days.

Always make sure you don't have a urinary tract infection. In the case of a Bricker bypass, mucus can also be responsible for odors

– There is blood in my urine. Why? What can I do?

The emission of blood in the urine (hematuria) is a relatively frequent event that generally causes a lot of fear. Bleeding can be due to different causes, it is important to identify the cause in order to adopt the most effective treatment:

- Local origin: the most frequent, and the simplest. This is bleeding of the stoma itself, due to the fragility of the mucus membrane, a wound, an ulceration, or crystal deposits. In this case:

-Increase the amount you drink,
- Avoid trauma during cleaning and placing new equipment
- Verify the diameter of the stoma and be sure that the collector of the pouch or support is at least 3 mm larger than the size of the stoma.

- Renal origin: kidney stone, infection, or a polyp can be the origin of blood in the urine.

The ureterostomy catheter can also occasionally cause microtrauma to the renal papillae if it is inserted too far.

- Medical or food origins:
Certain medicines or foods (such as beets) can color the urine.

- Anticoagulants can cause bleeding, which is why you must regularly check your coagulation level so that your doctor can adapt and calibrate your treatment.

In any case, don't panic, but don't hesitate to contact your stomatherapist or doctor, who will guide you and help you find the cause and take charge of the problem.

– I have skin problems. What can I do?

The adhesive part of the pouch is often a skin protector. Its role is to keep the pouch in place, but also to protect your skin. So changing it daily doesn't constitute a risk of irritation.

Wounds are often due to leaks or improper care, the most common reasons are:

- Use of irritating or drying products
- Incorrect hygiene (too seldom or too often)
- Shaving of hair or using a depilatory cream.
- A collector diameter that is too large can also be the cause of irritation and urine collecting on the skin.
- Equipment not appropriate to your case

So don't hesitate to consult your stomatherapist if there are persistent symptoms ; they are used to answering question of this nature.