



Urostomy

patient information

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Urostomy

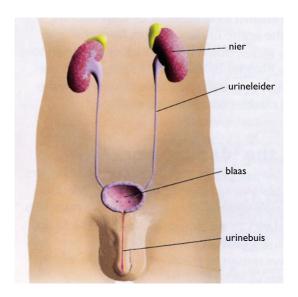
You will soon be admitted to hospital for a urostomy. This is a technique that involves making an artificial opening in the abdominal wall to let urine drain out of your body. The urologist will have explained the reasons for this operation to you.

This brochure provides information on your stay in hospital and the daily routine with a urostomy. Based on a number of photographs we want to provide a clear picture of a stoma. You will also learn how to look after a stoma and get tips to make everyday life as comfortable as possible.

If you have more questions, please discuss them with the (stoma) nurse, the urologist or the social worker. They can also help you find solutions for specific problems.

The nursing and medical team of the urology department

NORMAL FUNCTIONING OF THE URINARY SYSTEM



From the kidneys, urine runs through the two ureters to the bladder. The urethra carries urine from the bladder to outside your body.

The following organs play an important role in the production of urine.

KIDNEYS

The kidneys are two bean-shaped organs, located on either side of the spine.

They ensure that harmful waste products are removed from the blood and that excess water and salts are eliminated from the body. Those waste products and excess water make up urine.

URETERS

From the renal pelvis, urine passes through two fine tubes (ureters) to the bladder.

BLADDER

The bladder acts as a reservoir for urine. This organ is flat when empty and when very full can extend into the abdominal cavity. As soon as the bladder is full, your brains send a signal to urinate. When urinating, the sphincter muscle opens and the muscles of the bladder wall contract. This is how urine is removed from the bladder.

URETHRA

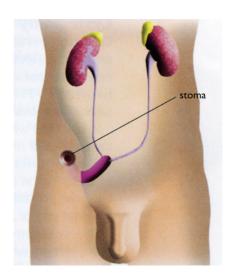
The urethra carries urine from the bladder to outside your body. In women, the urethra is just in front of the vagina, in men in the penis. From the kidneys, urine runs through the two ureters to the bladder. The urethra carries urine from the bladder to outside your body.

SURGICAL TECHNIQUES

Disease , as well as cancer, can affect the bladder. In some cases, surgery, whereby the bladder is removed (cystectomy), is the only possible treatment. After surgery to remove your bladder, you need another way to collect and pass your urine.

This new opening is referred to as a urostomy.

The most common surgery is the Bricker diversion or incontinent urinary diversion, whereby the bladder is removed and an artificial, new opening (urostomy) is made to let urine drain out of your body.



Urostomy: a piece of the small intestine is used to make an artificial opening or stoma to let urine leave your body. The stoma is usually on the right-hand side of the lower abdomen.

Urostomy

During the procedure, along with the bladder, other organs are also removed because of the shared blood supply and for oncological reasons. In men, the prostate (located directly under the bladder and around the urethra) and seminal vesicles are also removed. In women (if it's a bladder tumour), the uterus and the top part of the vagina are also removed.

Once the bladder is removed, urine can no longer leave the body naturally. Using a 10-15 cm piece of small intestine, a new, artificial opening (urostomy) is made on the abdominal wall (see drawing on the previous page).

The two remaining ends of the intestine are stitched back together. The isolated piece of intestine (the Bricker's loop) is closed on one side and remains open on the other. The ureters are implanted into the Bricker's loop. The open end of the loop is brought to the skin on the right of the abdominal wall to form the stoma. The two ureters provide a continuous discharge of urine through the stoma. The urine is thus directly discharged out of your body. Around the urostomy, a stoma flange and pouch are attached on the abdomen, in which the urine is collected. The urine now runs from the kidneys via the ureters and the stoma into the collection pouch.

The procedure can be carried out in two ways:

- 1. Robot-assisted cystectomy with Bricker diversion
- 2. Open cystectomy with Bricker diversion

Your doctor will discuss the most suitable technique with you.

ROBOT-ASSISTED CYSTECTOMY WITH BRICKER DIVERSION

Robot surgery is a form of keyhole surgery (or laparoscopy). Six small incisions are made under general anaesthetic in the abdominal wall, through which a 3D camera and state-of-the art robotic instruments are inserted into the abdomen whilst it is inflated with CO_2 gas.

The Da Vinci Xi robot, which is used in our centre, is not an independently operating machine. It is controlled entirely by the surgeon. The Da Vinci Xi system gives the surgeon a three dimensional, 10 times magnified, high definition view of the operating site. The use of special robotic instruments facilitates highly accurate operations. These instruments are much more flexible and accurate than the instruments traditionally used for keyhole surgery.

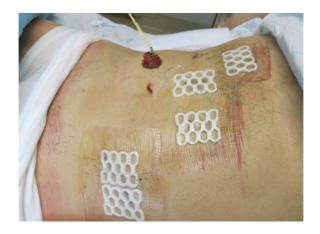






Da Vinci Xi operation robot

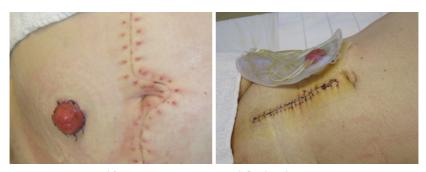
The procedure with the robot is a more recent technique than the classic procedure with an incision in the lower abdomen.



Robot-assisted cystectomy with Bricker diversion

OPEN CYSTECTOMY WITH BRICKER DIVERSION

In open surgery, the surgeon makes an incision in the lower abdomen, from the navel to the pubic bone.



After an open cystectomy with Bricker diversion

Both operations require a number of preparations.

BEFORE THE OPERATION

CONSULTATIONS AND EXAMINATIONS

A number of ambulant consultations and examinations are carried out before the operation

- ✓ Consultation with the urologist
 - 1. Doctor, urologist
 - 2. Nurse
 - ERP (Enhanced recovery programme):
 see next page for more information
 - Stoma nurse for education
 - → Different materials
 - → Positioning
 - → Basic stoma care
 - → Photographs
- ✓ A consultation with the anaesthetist, the doctor who will manage the anaesthetic

The anaesthesia consultation will cover the following:

- Screening for the hospital superbug
- Completion of a questionnaire concerning your medical prehistory, medication, allergies
- Discussion of the anaesthetic and post-operative pain therapy
- A heart examination: ECG (electrocardiogram)
- Lung X-rays if necessary
- A blood sample if necessary
- ✓ A urine test

Additional examinations may take place such as a CT scan or a PET-CT scan.

ERP consultation with a nurse

ERP stands for Enhanced Recovery Programmes: different programmes to ensure that you recover more quickly and more effectively.

This is a quality programme that aims to minimise the stress caused by the procedure and hospitalisation. From diagnosis to discharge, it's all about you, the patient, and you'll be in control of your own recovery process. A whole team will help you during this process.

The preparation, operation and recovery programme are organised according to the better-out-of-bed principle. This principle is aimed at a smooth return to your fixed diet and movement patterns. It will result in a better recovery and a lower risk of complications, which means you will spend less time in hospital. You can read how exactly in the ERP brochure.



The ERP nurses Ann Sterckx and Annelies De Vadder

The doctor and the nurse responsible for you will provide additional information.

HOME MEDICATION

Most home medication will have to be continued as before. Please bring this medication with you in the original packaging when you are admitted to hospital.



Please note! Some medication taken to thin the blood may increase the risk of bleeding during the operation. You may well have to stop taking this medication a few days before the operation. Discuss this with your GP and urologist, and bring the medication with you when you are admitted.

Please ensure that the urologist, nursing staff and anaesthetist know about any medication you take at home.

BOWEL PREPARATION

Low-fibre food facilitates bowel cleansing. It leaves little residue, resulting in almost no stool being formed. This is why low-fibre food is recommended before the operation.

Low-fibre food implies:

- From one week before the procedure, replace brown bread by white bread. You limit eating raw fruit and vegetables.
 Do not eat grapes, tomatoes or kiwis.
- Two days before the operation, it is best to follow a low-fibre diet.
 No raw vegetables, no potatoes, no fruit and no brown bread.
 Make sure you drink enough. You can drink coffee, tea and water without restriction.
- Make sure you eat enough before the procedure (enough calories).

FERTILITY AND SEXUAL ACTIVITY

Women who wish to conceive should definitely discuss this with the treating urologist.

Men are infertile after the procedure because ejaculation is no longer possible. Any desire to have children is best discussed with the doctor before the operation.

In both sexes, the operation has an impact on sexuality.. Men will find it more difficult to achieve or maintain an erection and will no longer be able to ejaculate (although they will still experience an orgasmic sensation). Medication for erectile dysfunction exists. Nerve-sparing surgery can also improve erection retention, especially in young men. Women may experience problems with genital circulation and lubrication, and the vagina may change shape because part of the vaginal anterior wall is stuck to the bladder and will often also be removed. Sensory disturbances may also

occur, which may cause you to orgasm less easily. Vaginal sparing procedures are possible in certain cases. The doctor will discuss this with you if it is an option for you.

PSYCHOLOGICAL IMPACT

You will probably suffer from stress and tension in the period before the operation. For instance, you've been having problems with your health or have just been diagnosed with a serious illness such as cancer. In the case of long-term problems, you've often already reached your limits and can't take much more. This may coincide with lethargy, irritability, fear, worry, sleeplessness and a lack of appetite.

If you're suddenly confronted with sudden, serious diagnoses and a mutilating operation, this may lead to a situation in which you no longer take your life and health for granted.

Asking for information, support from other people, distraction, talking, relaxing activities can all help you through this difficult period. However, if these problems continue for a long time and start to affect your quality of life, it may be advisable to seek help. Talk to your doctor or nurse.

You can contact a social worker, psychologist or the pastoral services on the ward to ask for support. If necessary, they can also refer you for professional support within your own environment.

ADMISSION TO HOSPITAL

The date of your operation will be set during the consultation. The admission's desk will call you one day before your admission. Please report to the check-in desk at the hospital before being admitted.

Up to six hours before the procedure only clear liquids, such as water, tea, coffee without milk, apple juice and energy drinks are allowed.

Before the procedure you'll be given a special drink (Nutricia preOp).

Fasting also means that you must not smoke after midnight.

ANAESTHETIST

The anaesthetist manages your anaesthesia. You have already seen this doctor after the urology consultation to discuss your home medication, among other things. If your home medication is changed after this consultation, please notify the nurse or doctor accordingly when you are admitted to hospital.

You can also consult the anaesthesia brochure before the operation. It is available on the nursing ward, together with the information card of the PAZA (post-anaesthesia care unit).

This is the intensive care unit where you may stay for a while after surgery.

HAEMODILUTION (BLOOD THINNING)

A potential complication associated with the operation is deep vein thrombosis: the formation of blood cloths in the veins of the lower limbs and pelvis.

To prevent this type of complication you will be given injections with an anticoagulant (Clexane[®], Innohep[®] of Fraxiparine[®]) starting on the evening after the operation). You will need this injection daily up to 30 days after the operation.

Until you are sufficiently mobile you will also have to wear special compression stockings (day and night) for one week to prevent thrombosis in the lower limbs.

PRE-OPERATIVE HAIR REMOVAL

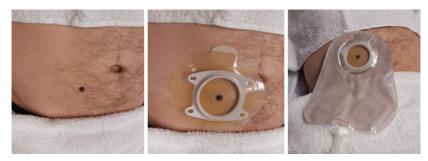
All hair is carefully removed from the costal arch to the pubic bone using a special razor.

POSITIONING OF THE STOMA

The urostomy is almost always located on the right side of the abdomen in the place that is most comfortable for you. This avoids any problems with the care or application of the collection material.

When determining the positioning of the urostomy, at the ERP consultation or the day before the procedure, a piece of intact skin measuring about 10×10 cm is chosen in a place that is inconspicuous to the outside world. The location of the stoma should be clearly visible to you making it easy to care for it. The

collection material should not be a hindrance when you are sitting down, bending over or wearing a belt.



Positioning of the urostomy

During the ERP consultation, the nurse may already apply a stoma flange and pouch and show you some photographs.

THE MORNING OF THE PROCEDURE

The nurse on the ward will give you an operation gown and antithrombosis stockings.

You'll still be able to take certain medications the morning of the operation in accordance with the anaesthetist's instructions. The nurse will check with you which medication you can still take, with a sip of water.

If you feel the need, you can be given a sedative in anticipation of the anaesthetic. Please notify the anaesthetist during the initial consultation to ensure that it is included in the planning.

Spectacles, lenses, jewellery, hearing aids and dental prostheses must be left in a locker in your room. The nurse will look after your key. You will then be taken to the operating theatre.

PROCEDURE AFTER THE OPERATION

Immediately after the operation you will remain in the recovery room for a few hours. You will then be transferred to the ward. The nursing staff will ensure that you are not in pain. You should tell the nurse if you are still in pain.

It is important to breathe in and out deeply several times per hour to properly ventilate the lungs.

- Limited movement exercises in bed (e.g. pulling up your feet and moving your legs) and briefly walking around your room are hugely important to boost the circulation in your legs and prevent phlebitis and blood clot formation in the lower limbs.
 You'll also find these exercises in the ERP brochure.
- You will receive visits from the physiotherapist to support you in performing these important exercises.

PAIN THERAPY

In case of open surgery

For pain management after the surgery, the anaesthetist has suggested a PCA pump to you. PCA is the abbreviation of Patient-Controlled Analgesia which means the patient can control the pain relief.

Urostomy

The advantage of a pain pump is that you can control your pain management yourself rather than having to call a nurse, which means that you can control the pain more quickly and more accurately. . However, visitors should not operate this pump.





How do you work the pump?

The pump is connected to a control button, which you press briefly when you feel too much pain. Pressing the button administers a painkiller. How much is administered and how many times you can press the button per hour is preset. As each person is different, the settings of the pump can be adjusted individually It takes about 5 to 15 minutes for the medication to take effect once you have pressed the button.

It is advisable, therefore, not to wait until the pain becomes too intense before you press the button.

The PCA pump and the control button that allows you to administer pain relief yourself (only for open surgery)

The pump can be used for three days. After removing the pain pump, other pain medication can be administered via the blood, in the arm or via a syringe under the skin, if necessary.

In case of keyhole surgery

Your nurse will give you regular pain medication via the blood, in the arm or under the skin.

OTHER LINES AND TUBES

In addition to the pain pump, various other lines and tubes are connected to you. They may be a nuisance but they are necessary for your recovery and will only be temporary.

Venous catheter (drip)

This is inserted into a vein in the neck or arm and supplies fluids and medication until you can drink again.

You can only switch to normal food when your intestines are working normally again. The switch follows an adapted schedule.

Stomach tube

This is a tube that goes through the nose and into the stomach. The



stomach contents are drained through this tube and is removed as soon as possible so that you can start drinking and eating again. This is done according to a specific food schedule.

Urostomy 2

Blake drain

In some cases a Blake drain will be inserted to remove excess fluid from the abdomen.

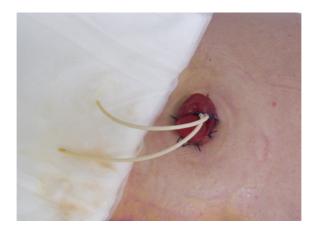
When the excess fluid reduces (after a few days), the drain is removed, always following the doctor's advice.

Ureter catheters left and right

The ureter catheters make sure that both kidneys are drained into the stoma.

The flow of these catheters is checked daily. You may go home with these tubes and their care and flushing (if they are clogged or flow badly) may have to be done by the home care nurse.

Removal by the nurse following the doctor's advice is painless.



Ureter catheters

Urine collection bag (night time pouch)

The urine collection bag is connected to the urostomy pouch and can hold more than 2 litres of urine. The bag is attached to the bottom of your bed. Your urine production over 24 hours is accurately measured. When you return home, we advise using the urine collection bag only at night.

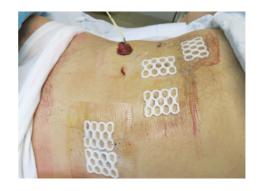






WOUND CARE

1 In robot-assisted surgery transparent dressings are put on the incisions. These dressings don't allow fluid to pass through and you can shower with them. They are removed at the consultation.



② In case of open surgery, a transparent dressing is applied as soon as possible, with which you can also shower. The (metal) stitches are removed by the (home care) nurse.



Wound care after open surgery, sterile (left) and not sterile (right)

STOMA CARE

At first, the nurse will take care of your stoma. Gradually, you and possibly your partner will be involved.

The importance of self-care cannot be underlined enough because this is how you maintain your independence.

If you are not yet fully able to care for your stoma yourself, you can always call on a home care nurse. They can help you care for the stoma or provide more information.

COLLECTION SYSTEMS

The nurse will give you the opportunity to test the two-piece systems from different companies The nurse will help you choose the most appropriate collection system for you. Information brochures about the different collection systems are available on the nursing ward.

1 One-piece system

The unit consists of a flange (part that sticks to your skin) and a collection pouch. The flange is attached to the skin. The collection pouch is attached to the flange. When due for replacement the entire system needs to be replaced.

One-piece system of three different companies



2 Two-piece adhesive or click system

The flange and collection pouch are two separate components. The collection pouch can be clicked or stuck onto the flange. The advantage is that, if necessary, only the pouch can be replaced and the flange can be left in place.

Two-piece system of three different companies



Urostomy pouch

Following surgery, a two-piece click system is always used. A one-piece system or a two-piece adhesive system can be used at a later time.

The urostomy pouch can be emptied (as often as required) via the tap at the bottom.

Stoma care should take into account a number of factors:

- Is the flange coming loose?
- Does the flange remain intact and flat?
- Where are the skin folds?
- · Is the flange clearly visible to you?
- Is the flange bothering you?
- · Are the flange and pouch easy to get to for you?

CARE AT THE HOSPITAL

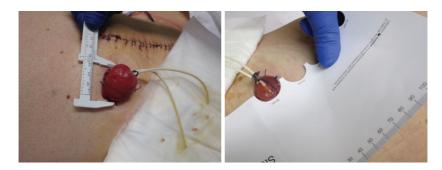




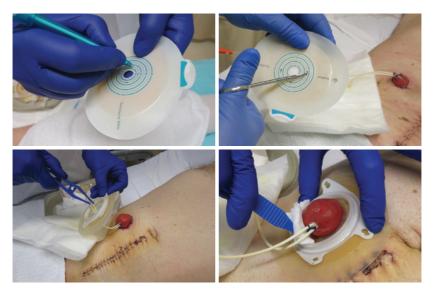
Removal of the flange



Cleaning the stoma



Getting the right size of the stoma



Cut out the correct flange diameter and attach the new flange



Attach the pouch and connect to the night time pouch

The nurse will look after your stoma at the hospital. Caring for a stoma is quite intensive. However, you'll gradually be involved in the care, and the nurse will explain step-by-step how to do it.

During the operation two ureter catheters were placed. These catheters are in the kidneys, come out via the ureters along the stoma and stay in place for at least 10 days.

Caring for a stoma has to be done in the most sterile possible way (to prevent urinary tract infections). The nurse wears gloves and uses sterile material: compresses, tweezers and scissors

Initially, the stoma is still swollen and may also bleed slightly. This is normal. The intestinal loop produces mucus, which sticks between the ureter catheters.

All this explains why care takes a little longer the first few days.

HOME CARE

In this section we provide practical information about daily care at home and the materials you need. Through practice you will find the best care method for you.

The importance of self-care cannot be underlined enough because this is how you maintain your independence. The best time to replace the flange is in the morning before eating or drinking. There is little urine production which means it stays 'dry' and there's less risk of leaks. Standing upright is usually the best position.

Necessary care supplies:

- plastic bag
- toilet paper or tissues
- wash cloths
- lukewarm water
- medical adhesive remover spray if necessary
- neutral pH soap if necessary
- scissors
- stoma measuring guide
- new collection system

Take care of your stoma as follows:

- Remove the previous material (flange and pouch)
- Cleanse the skin and stoma.
- 6 Check the stoma and skin around the stoma
- Measure the diameter of the stoma
- 6 Cut out the correct diameter from the flange
- 6 Attach the new flange
- Attach the pouch to the flange (if you are using a two-piece system)
- Ossibly attach a leg pouch or urine collection bag to the urine pouch (at night)

Remove the previous material

- Bend forward before removing the stoma flange. This squeezes as much urine as possible out of the stoma, thus reduce urine leakage during care.
 Make sure the stoma pouch is empty and disconnected from the urine collection bag.
- → To remove the flange from the skin, gently ease off the upper edges of the flange. Do not tear off the flange, gently press your other hand against your skin. Use a medical adhesive remover spray if necessary.
- → Pouch and flange can be removed simultaneously.
- → Fold the pouch and seal with the adhesive edges of the flange. Insert it in a hygienic or plastic bag before disposing in a bin bag. Never flush it down the toilet!



Removing the flange

- 2 Cleanse the skin and stoma.
- → If there's mucus on the stoma, it is best to first remove it with soft toilet paper or paper tissues.





Removal of the mucus

Cleansing the stoma

→ Use a flannel with lukewarm water and possibly neutral soap (type Eubos) to wash the stoma and skin. Do not use ether, alcohol or perfumed soaps. Pat the skin and the stoma dry. Rubbing may damage the stoma and injure the skin

3 Check the stoma and skin around the stoma

- → Always inspect the stoma and the skin around it to detect any changes early.
- → The skin around the stoma must be unblemished. During the first few days after the operation the stoma may be slightly swollen and bleed a little during the care process.
- → The stoma is attached to the skin with absorbable sutures, which degrade naturally.



Stoma cleaned

- 4 Size (diameter) of the stoma
- → Every company has its own measuring instrument.
- → Always measure the size at the base of the stoma, against the skin.
- → The round opening in the flange must fit exactly around the stoma. The nurse will teach you how to do this.
- → Retain the backing paper as a template to cut out the correct diameter when next replacing the pouch. It's important to check the diameter at regular intervals as the stoma diameter will reduce in size in the first few weeks/ months following the operation.
- → After a couple of months the diameter of your stoma will not change.



Getting the right size of the stoma

5 Cut out the correct diameter from the flange

- → On the back of the flange you can draw the size of the stoma, possibly using the measuring instrument.
- → The flange must fit closely around the stoma. Make sure the opening is not too big or too small (to provide maximum protection for the skin).
- → To cut, it is best to use scissors with curved tips. These scissors are available on the ward and you can take a pair home with you.
- → Sharp edges can be smoothed with your fingers afterwards.





Drawing the diameter on the flange

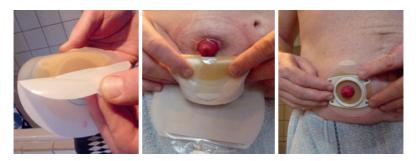
Cutting the flange

6 Attaching the new flange

First remove the backing paper without touching the adhesive edges. Attach the flange with the opening centrally above the stoma. Lean back slightly so that the skin is slightly stretched. Always start from the bottom.

Press the flange firmly everywhere, first under and around the stoma as leakage may occur there.

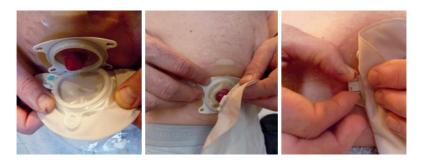
If you wear a belt, make sure that you stick the flange so that the attachment points on the stoma flange are horizontal.



Attaching a new flange

Attaching the pouch to the flange

You can then attach the collection bag (two-piece system) by clicking it on the flange. Make sure the collection bag is well attached by gently pulling it.



Attaching and securing the pouch

Sealing the stoma pouch or connecting the urine collection bag to the stoma pouch (always use a piece in between)





Connecting to the night time pouch

Sealing the stoma pouch

The nurse will gradually involve you in the care of your stoma until you can perform all the operations yourself.

GENERAL POINTS TO REMEMBER WHEN CARING FOR YOUR STOMA

- Always wash your hands before and stoma care.
- Take time to look after your stoma.
- It is best to empty the pouch when it's half-filled with urine, because if it becomes too heavy, the flange may come off. It can be emptied in a collection cup or directly into the toilet.

- Never leave your flange in place for longer than three days. Make a habit of replacing the flange as soon as the inside starts to dissolve.
- It's advisable to adopt an upright standing or sitting
 position whilst dealing with your stoma so that you don't
 have to bend over and to avoid folds developing in the
 skin.
- Use lukewarm water (or soap with a neutral pH) to cleanse your skin. The care procedure doesn't require a sterile environment.
- Wet wipes without alcohol and oil can also be used.
- Don't use bubble bath to prevent skin irritation or bath oil because that would interfere with the adhesion of the flange.
- Taking a bath or shower, with or without the collection pouch, is absolutely fine. You can always attach a new collection pouch if the non-transparent material is still wet afterwards. When bathing it's best to leave the stoma material in place.
- Rinse your skin well and pat it dry. Don't be perturbed by minor bleeding. Pressing lightly can stop any bleeding. Notify the doctor if it does not stop bleeding.
- Remove any hair around the stoma. The flange will adhere better to (almost) hairless skin, but avoid injuring your skin.

- Never use ether or alcohol to cleanse the skin as they
 have a drying effect. The use of disinfectants will increase
 the adhesion of the flange and risk injuring the skin when
 you try to remove it. Eosin must not be used either.
- In case of skin problems (redness and irritation) it is best to make an appointment at the stoma consultation as soon as possible.
- Pre-warm the flange by placing it on your upper body underneath your clothing as this increases adhesion.
 Never place the flange directly onto a heat source!
- Regularly check your stock and make sure you always have spares.

The following material should be in your emergency kit:

- ✓ two pre-cut flanges and one pouch
- one flannel and one hand towel
- ✓ Soap
- Wet wipes for once-only use are handy when travelling. Make sure they don't contain any oil or alcohol.
- Underpants
- A throw-away bag
- ✓ Personal items such as paste, powder, etc.

Don't forget to place a new order when you open the last box.

Sleeping: some tips

- Sleeping on your left side is recommended (the side opposite the stoma).
- ✓ To avoid having to get up at night, connect the stoma pouch to a larger urine bag (2 litres).
- Use a mattress cover. Mattress covers are available in regular stores.
- If you like to sleep on your stomach, you can continue to do so. Slide a pillow under your hip on the side of the stoma to avoid direct pressure on the stoma.

Your weight

Check your weight regularly. Gaining weight can cause difficulties in caring for your stoma, because it will be located deeper in your skin.

Drink enough

You need to drink enough, at least 1.5 litres a day which is sufficient for normal urine production.

Drinking enough also helps prevent urinary infections. The presence of flakes in your urine is normal because the stoma consists of intestinal tissue, which produces intestinal mucus.

LIVING WITH A STOMA

General tips

- ✓ Always make sure you have enough material in stock.
- ✓ It is advisable to store the pouches and flanges in a cool, dry place, but not in the refrigerator.
- During the first few months following the operation it is advisable to put your hand on the stoma to absorb some of the pressure when coughing or sneezing.

FOOD

The presence of the stoma in itself has little impact on your eating habits. Make sure you have a healthy diet with enough variety. Some foods, such as fish, eggs, asparagus, citrus fruits, tea and also antibiotics may cause your urine to smell strongly. However, this does not mean you should eliminate them from you diet, as they also contain valuable nutrients.

Some medication may change the colour of your urine. Plenty of fluids, at least 1.5 litres of water a day, help prevent urinary infections.

PSYCHOLOGICAL IMPACT

You will need some time to recover after a stoma operation and this will often require a considerable adjustment, both physically and psychologically. After all, you'll be confronted with a significant sense of loss in terms of your health and perception of your body. For instance, you may find it hard to look at your wound and stoma at first. However, it is important you gradually start doing so, at your own pace. Some people try to continue as before, but then the consequences of the operation take their toll later on. It is normal, however, that you should take your time to come to terms with the operation and the disease, and living with a stoma.

Stoma care often involves stress and insecurity. Will I be able to do it? What if the flange comes loose? Whom can I go to? Sometimes people tend to focus solely on the problems associated with their stoma, or become isolated because of a fear of urine loss, or that others might notice or perceive an unpleasant odour, or they might become depressed, etc. It is important, therefore, that you should try to venture out. Start by meeting the people you feel at home with, who might be aware of the fact that you have had an operation, in places where you feel 'safe'.

Seek support from your partner, good friends and family members. If you feel you cannot cope, psychological support may offer a solution. Ask your GP or nurse for assistance.

You and your next of kin can contact a social worker, psychologist or the pastoral services at the hospital. A consultation with the social worker or the pastoral services is free. Consultations with an onco-psychologist are also free.

And once you're at home, you can make contact for an appointment with the psychologist. The Stichting tegen Kanker (Cancer foundation) (www.kanker.be) also offers short-term psychological support (maximum six sessions) by telephone. Both patients and next of kin can use this service. You can also contact a Centrum voor Geestelijke Gezondheidzorg (Psychological Healthcare Centre) in your area through your GP.

RELATIONSHIP WITH CHILDREN AND FRIENDS

When you are ready to do so, you can talk about your operation with immediate family or friends. Tell them the facts in a neutral way without too many details. Truthful and straightforward information will prevent those around you from coming up with all kinds of unnecessary questions or from becoming overly concerned.

SEXUALITY AND PARTNER RELATIONSHIP

A stoma can lead to problems with intimacy and sex. These problems may arise because the normal functioning of the sexual organs has been disrupted by the procedure and/or because your sexual experience has changed.

The procedure may have damaged the nerve pathways responsible for sexual functioning, altering the functioning of the sexual organs.

In men, this may result in erection, ejaculation and/or orgasm problems.

In women, it can affect vaginal wetness or the experience of orgasm. When the uterus and a piece of the cervix are removed, it can result in a shortened vagina.

The severity and nature of the impact on sexual functioning depend on the location and extent of the procedure. If you want more information about your personal situation, it is best to speak to your surgeon about it. Depending on your medical situation, the surgeon may refer you for further assistance (urologist, andrologist, gynaecologist, sex therapist, psychologist), for tips, advice, supportive medication or tools for a satisfactory sex life.

Sexual experience can also be affected by a number of psychological factors. You may well have to come to terms with a profound sense of loss during the period following the stoma operation (see 'psychological impact' above). Moreover, people often feel as though they have been physically scarred and are sexually less attractive. With serious diseases such as cancer, survival becomes paramount, as a result of which sexuality sometimes becomes (temporarily) less important. Furthermore, the erogenous zone may well be associated with less stimulating aspects such as wound care and pain. Fear of rejection by the partner, or fear of pain, may also reduce sexual desire. All these factors may lead to a reduced interest in sex.

If, as a result of sickness or an operation, you have not had sex for a long time, you should take into account that more time for preparation will be required. It is not dissimilar to the beginning of a new relationship when partners often need to discover each other step by step and get to know what they do and don't like. Some couples tend to focus more on other kinds of intimacy. However, these changes in sexual behaviour can sometimes lead to

tension and misunderstanding. Open communication about what you think and feel, what you are afraid of, etc. is essential to avoid misunderstandings in a relationship. Take time to talk to each other and don't hesitate to explain to your partner what you feel ready to try and what not.

If you and/or your partner want to discuss relationship or sexual issues with a care worker you can contact a doctor or nurse of the care team at any time. They can provide information concerning your physical problems and, where necessary, refer you to a psychologist, sex therapist, urologist, gynaecologist or andrologist More tips and information are also available in the brochure on Sexual functioning and experience following stoma surgery (in Dutch). (www.uzleuven.be/nl/brochure/123545). Ask your nurse.

- → Psychologist and sex therapist on the urology unit:
 - psychologist-sex therapist tel. 016 34 15 99
 - psychologist tel 016 34 76 84
- → Multidisciplinary consultation female sexuality: tel. 016 34 47 50
- → Urologist or andrologist specialised in male sex: consultation urology tel 016 34 66 85
- → Context CeKKS, Centrum voor klinische seksuologie en sekstherapie (Centre for clinical sexology and sex therapy): Telephone 016 34 80 01

HYGIENE

You can shower or bathe with a stoma. You can shower with or without the collection material, but it is best to take a bath with stoma material.

Water and non-irritating soaps are not harmful to the stoma. Be careful not to point the full jet of water on the stoma.

CLOTHING

There is no reason to dress differently because of the stoma. The most important thing is that you feel comfortable and that the free flow of urine in the collection pouch is not impeded.

There are plenty of companies that sell special lingerie and underwear.





OCCUPATION

If you were working before the operation, there is no reason why you should not return to work afterwards.

If you, your employer or your insurer doubt whether you will be able to continue working, you should discuss this with your doctor or nurse.

HOUSEWORK AND GARDENING

You can garden and do housework, but at a 'steady pace'. Let others do the heavy work, e.g. digging and lifting.

SPORT

You can engage in recreational sports such as cycling and swimming.

However, because the prostate is also removed, men should not cycle during the first six weeks.

Sports with a lot of physical contact such as wrestling and judo are not recommended, as are strength sports such as weightlifting.

Swimming with a stoma is possible. Many urostomy patients wear a normal swimming costume or swimming trunks (boxer shorts) over their collection pouch. You can wear close-fitting bottoms under the swimwear for better protection of the collection pouch.



TRAVEL

Travelling is not a problem. Take a health insurance card with you. For travel assistance, contact your health insurance and, if necessary, take out travel assistance insurance with an insurance agency (if you are travelling outside Europe).

Be sure to bring enough material for the holiday period as your stoma material is not available everywhere. If you are staying in a foreign country for an extended period, find out from the company whether you can buy their products in this country and where you can do so.

If you are travelling by plane, make sure you take the stoma material in your hand luggage as your main luggage may get lost or arrive late. This will ensure that you have it on arrival.

Make sure the flanges are kept in a cool place. This is particularly important when travelling to warmer countries. You can ask the nurse for a list of common keywords in different languages (she can find it on the UZ Leuven intranet, urology sub-site, 'practical information').

PROBLEMS WITH THE STOMA

LEAKS

Convex flanges

If the stoma is a little too deep under the skin, you can apply a special convex flange. The somewhat convex shape prevents urine from seeping under the flange. Together with the flange, you can use a belt that keeps it all in place.



Convex flange Convatec



Convex flange Hollister

Belt



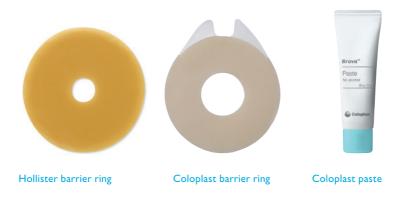
Coloplast belt



Convatec belt

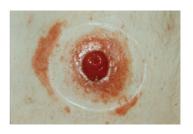
Paste

To prevent leakage, possible cavities or folds around the stoma are filled with a paste. This can be done before or after applying the flange.



SKIN IRRITATION

Skin irritation may occur due to leakage, frequent removal of the flange and also if the flange is cut out too big or too small.



This is why you should gently push the flange away from the skin in an even motion and with both hands rather than pulling.

Remover spray

Using remover spray reduces the risk of skin damage.



Powder

You can spread the powder on the moist and irritated skin around the stoma. Blow or wipe away the excess powder and then attach the flange.

You can insert a rolled-up compress or rolled-up piece of toilet paper into the stoma to avoid dripping urine.



Protective powders



Applying powder around the stoma

Skin protection spray

A (barrier) spray, which you also get on doctor's prescription, is very suitable to protect or treat the skin in case of mild irritation.



Skin protection spray



Important

You need to drink enough, at least 1.5 litres a day which is sufficient for normal urine production.

GENERAL POINTS TO REMEMBER

Contact your GP or the specialist in the following cases:

- ✓ You have an unexplained fever that lasts for several days.
- ✓ You are constantly tired.
- ✓ You are losing weight without explanation.
- ✓ If your urine is cloudy even though you are drinking enough.
- ✓ You notice blood in your urine several times.
- If the amount of urine decreases significantly even though you are drinking enough.
- ✓ You feel persistent pain in your loins.
- ✓ Your urostomy is painful.
- ✓ You suddenly notice a bulge around the stoma.
- ✓ You have skin problems such as persistent redness and irritation.
- You have continuous bad-smelling urine even though you are drinking enough.
- ✓ If the stoma flange is already affected by urine after only one day.

Contact the stoma nurse if you have problems with the material.

REIMBURSEMENT OF STOMA MATERIAL

WHEN ARE YOU ELIGIBLE FOR REIMBURSEMENT?

If you have health insurance cover for major and minor risks.

HOW DO PURCHASE AND REIMBURSEMENT WORK?

Upon discharge from the hospital, you will be given a package of material for a number of days.

You can also get the material:

- from a surgical material supplier: you need to order and pick it up yourself
- from medical companies, affiliated with a surgical material supplier, that deliver material to your house. The company comes to your home within two days, after telephone contact

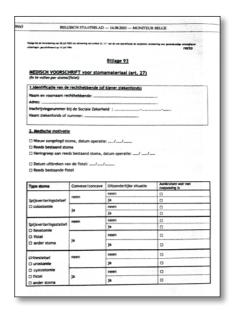
WHICH PRODUCTS ARE REIMBURSED?

✓ flanges (flat and convex)
✓ open pouches with tap
✓ urocaps
 one-piece collection systems (flange and bags attached to each other)
✓ night time pouches
✓ leg pouches
✓ barrier rings
✓ convex rings
✓ protective paste
✓ protective film
✓ protective powder
✓ belt

REIMBURSEMENT PROCEDURE

The doctor's prescription, annex 93, opens a 'virtual portfolio' for you: you are entitled to a certain amount, but this is not paid in cash Without a prescription, you cannot order materials. You also need a new prescription when the old one expires.

This budget can be used to buy stoma material and appliances that are on the restrictive lists of the RIZIV (National Institute of Health and Disability Insurance).



You do not have to make any payment, as long as you stay within budget.

The surgical material supplier arranges the payment directly with the health insurance.

There are two phases:

- Learning phase = the first three months following surgery.
 - In this phase, more budget is freed up to give you more time to find the right material
- Follow-up phase = from the fourth month

What do you need to order material?

- ✓ Annex 93
- ✓ A prescription with the reference numbers of the stoma material and appliances
- Your stoma folder which you receive upon discharge from hospital.

The surgical material supplier delivers material to cover a maximum of three months to your home. You also receive a certificate of delivery that you need to keep in the stoma folder

Urostomy

GUIDELINES FOLLOWING DISCHARGE FROM HOSPITAL

When you are discharged from hospital, you need a period of adjustment to 'normal' life. Don't forget you have to take it easy for several months. Recovery from such an operation takes time and is boosted by a personal positive attitude and of those around you.

MEDICATION

You should continue taking any medication you normally take at home. If you need to take other medication, it will be discussed with you and you will be given the necessary prescriptions.

If you were taking anticoagulants at home, they will have to be restarted in consultation with the urologist or your GP.

Subcutaneous injections of Clexane®, Innohep® or Fraxiparine® must also be continued for a few weeks at home to prevent blood clots. When you are discharged from hospital you will be given a prescription for medication and, where necessary, a prescription for home care. The prescription will be for three boxes of Clexane®, Innohep® or Fraxiparine®, which must all be used.

You can learn how to inject yourself if you wish. The nurse will teach you how to do this.

Administering injections yourself

(Photographs www.thrombosiscare.be)

Where?



- The recommended injection location is in the lower abdominal fat.
- This means at least five centimetres away from your navel towards the outside and on either side.
- Choose a different place in the lower abdomen for each injection, alternating between the left and the right hand sides.

Preparation



- Sit or lie down in a comfortable position and clean the selected injection area with an alcohol wipe.
- Take the syringe and remove the protective cover.
- There should be an air bubble at the top against the plunger. Do not remove this air bubble from the syringe.
- If there is a drop at the tip of the needle it can be removed by tapping the syringe, with the needle pointing downwards.

Injection



 Pinch a skin fold between your thumb and index finger.



- Insert the needle fully and level into the thickest part of the fold.
- Carefully push the plunger on the syringe; the injection should be done slowly.
- Keep hold of the skin fold until the injection has been completed.
- Do not massage or press on the skin after the injection.

Urostomy

PRESCRIPTIONS AND CERTIFICATES

When you are discharged from hospital you will be given all necessary prescriptions and certificates for medication, care and insurance.

- Medication started at the hospital:
 - Clexane[®], Innohep[®] or Fraxiparine[®]
 - Antibiotics if necessary
- ✓ Home care: subcutaneous injections of Clexane[®], Innohep[®]
 or Fraxiparine[®] (if necessary)
- ✓ Home care: stoma care
- ✓ Stoma material: prescription
- WC pass. You can apply for a toilet facilities pass to StomaVlaanderen, at a cost of five euros. You will have to ask the doctor in charge of your treatment to complete a certificate and then forward this together with a passport photograph. The certificate is included in the stoma followup folder you received upon discharge from hospital. Upon presentation of your WC pass, catering establishments must give you free access to their toilet facilities, without having to buy any food and/or drink.

✓ Certificates:

- Hospitalisation cover
- Health insurance
- Incapacity for work

FOLLOW-UP FOLDER

You will receive a lot of information, documents and brochures related to the care of your stoma. Collect everything in a follow-up folder. Bring this folder with you to every consultation or when you are admitted. It allows all care providers to support your healthcare process.

DISCHARGE PACK

To bridge the first few days, you will be given a discharge pack to take home, containing a number of flanges and pouches, protective spray, remover wipes and information brochures.

APPOINTMENTS AFTER YOUR DISCHARGE FROM HOSPITAL

• Your first appointment after the procedure will be with the stoma nurse. Blood will be taken and the stitches removed.

We will also go over the full stoma care with you.

Your next appointment is with the urologist (urology consultation unit), approximately six weeks after surgery.

The dates for these two appointments will be notified on the day of your discharge.

Always bring your follow-up folder.

CONTACT

In the event of problems please contact:

- ✓ Erp.urologie@uzleuven.be
- ✓ The urology consultation unit on Friday (business hours): tel. 016 34 66 85
- ✓ In the event of problems during the evening, at night and/ or during weekends, please contact the nursing units on the following telephone numbers:
 - E 661: Telephone 016 34 66 10
 - Accident & Emergency: Telephone 016 34 39 00.
 Always ask for the urologist on call.

EXTRA SUPPORT

Do you need extra support?

You will find the contact information of different self-help groups in your follow-up folder.

You will also find information here:

- www.stomavlaanderen.be
- for the Antwerp area: www.stoma.be
- www.allesoverkanker.be/lotgenotengroepen#voor-stomadragers (it lists all the stoma associations)

Urostomy 6.

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Duplication of this text and these illustrations shall always be subject to prior approval of the UZ Leuven Communications Department.

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