Living with an ileostomy

Patient information

FUNCTIONING OF THE INTESTINE

Introduction

Welcome to our ward. You have been admitted to hospital for an ileostomy procedure to create an artificial opening to collect stools from the small intestine (ileum).

Your physician will have discussed the reasons for this intervention with you. This brochure aims to guide you through your stay in hospital and provides further information on how to temporarily (or permanently) manage an ileostomy.

Please do not hesitate to contact the consultants, nursing staff, social worker or your GP if you have any further questions.

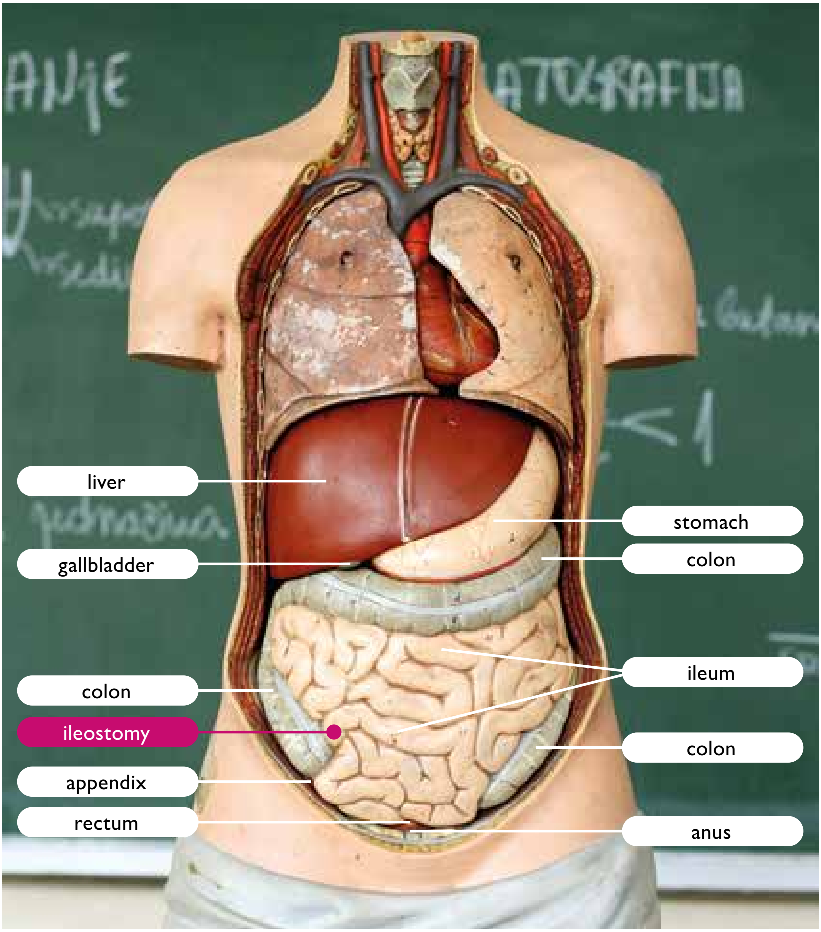
We hope you have a comfortable stay in hospital and wish you a speedy recovery.

The medical and nursing team of the stoma care work group.

FUNCTIONING OF THE INTESTINE

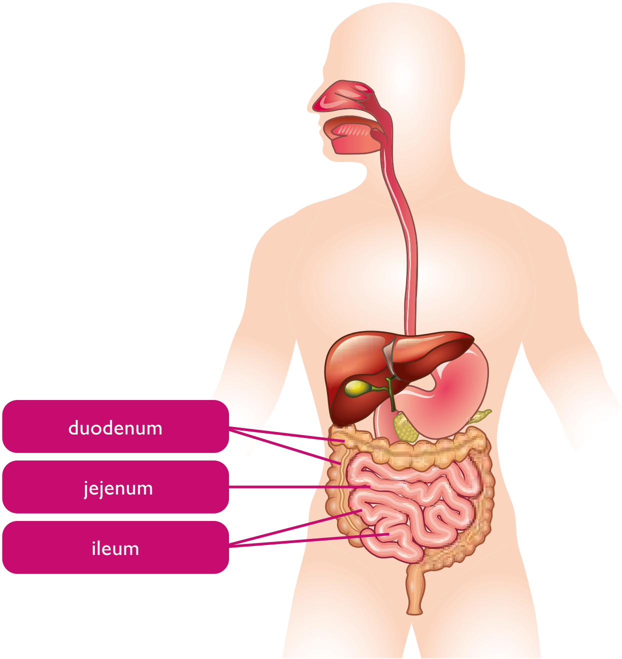
The intestine ensures that waste is removed from the body once the digestion process is complete.

The long and winding intestinal tract (7 to 8 m) is made up of two main components: the small intestine and the large intestine.



FUNCTIONS OF THE SMALL INTESTINE (ILEUM)

- **Digestion:** intestinal secretions, bile and pancreatic juice help to digest ingested food.
- **Absorption:** the small intestine plays a vital role in the absorption of digested products such as sugars, fats, proteins, amino acids and electrolytes.
- **Mechanical function:** food and undigested residue is propelled by peristaltic movements.



FUNCTIONS OF THE LARGE INTESTINE (COLON)

- **Absorption:** excess water and salt are absorbed in the intestine to thicken the stools.
- **Mechanical function:** stools are propelled by peristaltic waves to the rectum (the final part of the colon) where they accumulate until a defecation reflex occurs.

WHAT IS AN ILEOSTOMY?

It may be necessary to create an artificial opening (which is referred to as a stoma) for passing stools as a result of an intestinal disorder. During the operation one end of the small intestine is brought out through the abdominal wall and attached to the skin. This procedure is referred to as an ileostomy.
An ileostomy is usually performed on the right of the abdomen, below the navel.

Because the excretion of stools cannot be controlled via this opening, a collection system needs to be created for the stools.

TYPES OF STOMA

A stoma may be permanent or temporary, depending on why it is necessary.

Permanent stoma

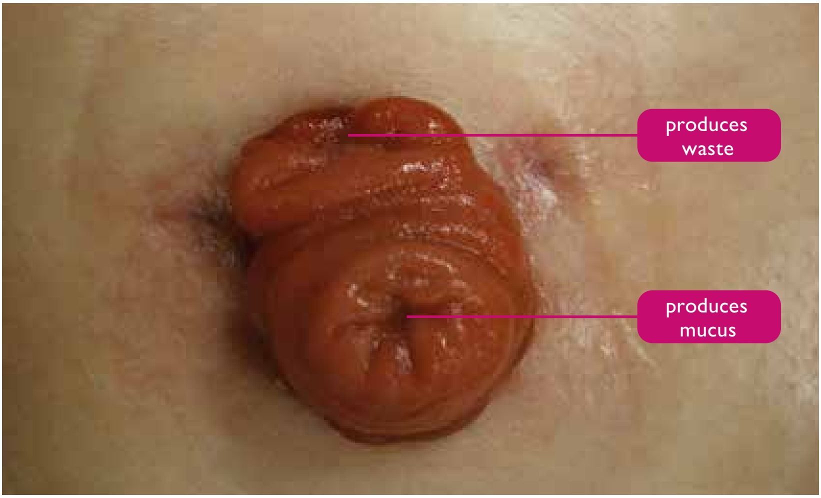
With a permanent stoma the operation has been so invasive that the natural exit, the anus, can never be used again. A permanent stoma often has a single opening, also referred to as an end stoma. An end ileostomy is performed when the entire large intestine needs to be removed.

Temporary stoma

A temporary stoma is created with a view to removing it again at some point in the future. This procedure is sometimes used to give a particular section of the intestine the opportunity to heal, e.g. following an operation or chronic inflammation.
A temporary stoma will not always be reversed, e.g. due to the severity of the disease or if the patient opts to retain the stoma.

A temporary stoma may have a single opening, also referred to as an end stoma.

A temporary stoma with two openings is referred to as a double loop stoma. One opening produces waste, the other opening only mucus.



With a temporary stoma mucus can still be excreted via the natural route, i.e. the anus.

BEFORE THE OPERATION

EXAMINATIONS

Your operation will be preceded by several examinations:

- a blood test;
- an electrocardiogram: a test which measures the electrical activity of your heart;
- a lung X-ray;
- a colon X-ray;
- an ileum X-ray;
- a colonoscopy: a thin hollow tube is inserted via the anus into the colon to examine it;
- a CT scan of the abdomen: a diagnostic imaging test to produce an image of the organs within the abdominal wall;
- a manometry test: a test to evaluate the functioning of the anal sphincter muscles;
- an MRI scan: an examination that produces detailed images of the body.

It may not be necessary to conduct all of the above examinations. Your physician will determine which ones are required.

PREPARATION

Preoperative anaesthesia consultation

The anaesthetist is the doctor who administers and monitors anaesthesia during an operation.

A dedicated appointment will be made with the doctor/anaesthetist well before the planned operation date.

The doctor/anaesthetist will ask you a number of questions, examine you and set up a specific dossier in order to get to know you better, gather details about, and assess, your health/condition (also refer to our 'anaesthesia' brochure).

The preoperative anaesthesia examination is vital to be able to assess any risks associated with the operation. It will also give you the opportunity to ask questions and discuss potential side effects with the doctor/anaesthetist.

Patients who have already been admitted to hospital are visited by the doctor/anaesthetist the night before the operation. A good night's sleep before the operation is essential.

The doctor/anaesthetist may prescribe premedication in consultation with the surgeon, which you will have to take on the morning of the operation.

After the operation you will remain in the recovery room at the post-anaesthesia care unit (PAZA) for a number of hours or overnight. Every effort will be made after the operation to ensure that pain is kept to a minimum. The anaesthetist will discuss the various pain relief treatment options with you during the preoperative anaesthesia consultation. If you would like more detailed information the nurse and/or anaesthetist will take you through the anaesthesia information brochure.

Preoperative ERP surgery consultation

The ERP nurse will run through the specific colorectal care programme with you before the operation. This care programme aims to ensure that you recover more quickly and more effectively from the operation with a lower risk of complications and without an unnecessarily long stay in hospital (also refer to the 'abdominal surgery: colorectal operation' brochure).

During the preoperative consultation the ERP nurse will check and complete your dossier using a questionnaire. A number of practical aspects will also be discussed: matters you have to arrange before the operation, the duration of your stay in hospital, the progress of the admission and preparations for your discharge from hospital. If you require more information the ERP nurse will run through the 'abdominal surgery: colorectal operation' information brochure with you.

Preoperative consultation concerning stoma care and location

The stoma nurse will use a power point presentation to explain the stoma care programme. The preoperative consultation aims to introduce you to the concept of stoma care. You will receive information concerning the type of stoma, care instructions, the material, nutrition, health insurance reimbursement and material purchases.

The position of the ileostomy will be decided by the stoma nurse during the preoperative consultation whilst you are lying down, sitting up and standing up. The most appropriate location will be indicated using a marker pen, photographed in three positions and stored in digital format in your electronic dossier. An ileostomy is usually located on the right hand side of the abdomen. If you wish, a collection system can be attached so that you can experience what it feels like.

It is important that the stoma should be positioned in the most appropriate location for you in order to avoid problems during the care procedure or when attaching the collection material. The collection material should not be a hindrance when you are sitting down, bending over or wearing a belt. The location of the stoma should be clearly visible to you making it easy to care for it.

The location of the stoma may have to be changed slightly during the operation for surgical or technical reasons.

Patients who have already been admitted to hospital are visited by the stoma nurse the night before the operation.

Whilst you are in hospital the stoma nurse will contact you just after the operation and before you are discharged. Nurses on the ward will provide stoma related care and instructions whilst you are in hospital.

A check-up appointment will be arranged with the stoma nurse after your discharge from hospital. During this initial postoperative consultation the stoma nurse will ask about your progress following your discharge from hospital, potential care related problems, your intake of food and drink, your weight, material supplies and home care.
The stoma nurse will also treat the stoma during the consultation to ensure that potential skin or stoma problems are identified early and your care programme can be adapted where necessary. If necessary a follow-up appointment will be arranged.

Remember not to replace the collection material at home before a stoma consultation appointment!

Bowel preparation

In most cases there's no need for a complete bowel preparation. The doctor will decide the type of bowel preparation needed. Specific bowel preparation arrangements will be made before the operation upon instruction from the doctor. The nurse will provide the necessary explanation.

Fasting

For safety's sake we ask that you do not ingest any solid food from 24.00 hrs (midnight) before the operation. You can drink water up to three hours before the operation. In hospital you will be given a preoperative drink three hours before the operation. After that you have to fast completely and should definitely not smoke.

AFTER THE OPERATION

Various tubes/lines will be inserted during the operation. They are necessary to ensure optimum recovery:

- ✓ **Venous catheter:** a line into a vein to regulate the administration of fluids and medication.
- ✓ **Drainage gastrostomy tube:** a tube inserted via the nose into the stomach to drain excess fluid from the stomach and prevent nausea.
- ✓ **Drain(s):** hose(s) to drain excess wound secretions (blood, lymph fluid etc.) from the abdomen.

- ✔ **Petzer:** a drainage system inserted in or via the anus.
- ✔ **Bladder catheter:** a catheter inserted into the bladder via the urethra to discharge urine.
- ✔ **Epidural catheter/intravenous analgesia:** please refer to the ‘anaesthesia’ brochure for more information.

These lines will be removed upon instruction from your physician.

COLLECTION SYSTEMS

Two types of collection system are used, irrespective of which material brand you choose: a one piece and a two piece system.

The stoma nurse will help you choose the most appropriate collection system for you.

ILEOSTOMY POUCH

An ileostomy pouch is an open bag, which is fitted with an activated carbon filter and has to be emptied. The filter neutralises intestinal gas and odours. You can choose between a transparent pouch or a pouch made of a discrete, non transparent grey or skin colour material.

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. It is advisable to replace the complete system once a day.

TWO PART SYSTEM

The flange and collection pouch are two separate components. The pouch can be clicked or stuck onto the flange. The pouch must be replaced once a day. The protective flange can be left in place for several days, but it is advisable to replace it every two days.

ILEOSTOMY CARE

You will be shown step by step how to care for your ileostomy to ensure that you are able to apply the stoma material yourself once discharged from hospital. We recommend that a member of your family also attends a care session.

You will also be able to call upon home care services when you are discharged from hospital.

CARE PROCEDURE FOR A ONE PIECE SYSTEM

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 one piece system

Removing the material

- Gently ease off the upper edges of the flange, using a medical adhesive remover spray if necessary.
- Remove the one piece pouch and flange system from the skin. Fold and seal the pouch using the adhesive edges on the flange.
- Insert it in a hygienic or plastic bag before disposing in a bin bag. Never flush it down the toilet!

Applying new material

- ✔ First wipe the stoma with toilet paper or tissues. a
- ✔ Cleanse the skin and stoma with clean water. (Tip: use a wet and a dry face cloth.) If using soap, always use soap with a neutral pH. Oil based soap will affect the adhesion of the flange. b
- ✔ Pat the skin and the stoma dry. Rubbing may damage the stoma and injure the skin. c
- ✔ Cut out the correct diameter from the flange. The flange must fit closely around the stoma to provide maximum protection for the skin. (Tip: test whether the opening is the right size by briefly sliding it over the stoma.) d
- ✔ Retain the backing paper as a template to cut out the correct diameter when next replacing the system. It is important to check the diameter at regular intervals as the stoma diameter will reduce in size in the first weeks/months following the operation.
- ✔ Remove the backing paper from the back of the flange. e

✓ Attach the flange to the skin, always starting from the bottom of the stoma.

✓ Check that the collection system is securely attached to the skin. Gently pull on the collection pouch to check that the collection system doesn't come away from the skin.

CARE PROCEDURE FOR A TWO PIECE SYSTEM

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 flange
- new collection pouch

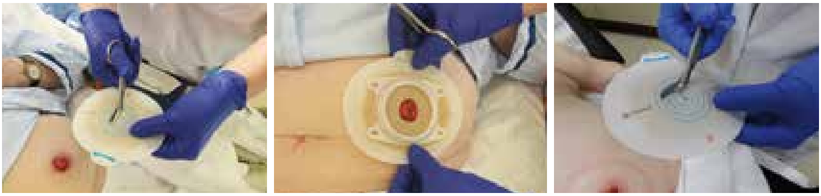
Removing the material

- Gently ease off the upper edges of the flange, using a medical adhesive remover spray if necessary.
- Remove the collection pouch and flange from the skin. Fold and seal the pouch using the adhesive edges on the flange.
- Insert it in a hygienic or plastic bag before disposing in a bin bag. Never flush it down the toilet!

Applying new material

- First wipe the stoma with toilet paper. a
- Cleanse the skin and stoma with clean water. (Tip: use a wet and a dry face cloth.) If using soap, always use soap with a neutral pH. Oil based soap will affect the adhesion of the flange. b

- Pat the skin and the stoma dry. Rubbing may damage the stoma and injure the skin. C



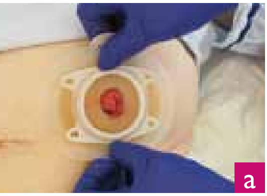
- Cut out the correct diameter from the flange. The flange must fit closely around the stoma to provide maximum protection for the skin. (Tip: test whether the opening is the right size by briefly sliding it over the stoma.)

- Retain the backing paper as a template to cut out the correct diameter when next replacing the system. It is important to check the diameter at regular intervals as the stoma diameter will reduce in size in the first weeks/months following the operation.

- Smooth any sharp edges on the flange with your finger.

- It is advisable to warm up the flange of the new collection system before attaching it to the skin, by placing the flange between both hands or putting it underneath your clothing.

- Remove the backing paper from the back of the flange.


a


b


c


d

- Attach the flange to the skin, always starting from the bottom and pressing it down properly around the stoma using your fingers. a
- Start pressing on the flange ring at the bottom of the pouch ring and work your way up until the pouch is fully attached and secure. b Click the closing system into position. c
- Check that the collection system is securely attached to the skin. Gently pull on the collection pouch to check that the collection system doesn't come away from the skin. d


attaching the flange
pouch


attaching the flexible pouch


attaching the collection

If you are using an adhesive system, position the pouch at the bottom of the flange and ensure that the pouch is positioned in one flowing movement from the bottom up onto the flange.

Emptying the ileostomy pouch

These photographs were taken when the patient was lying down in bed. We recommend that you empty the pouch into the toilet. To do so sit down on the toilet and allow the pouch to drop between your legs. It is advisable to empty the pouch when it is one third full.

- Undo the Velcro fastenings, keeping the pouch upright to prevent the faeces from leaking.

- Open the collection pouch.

- Create an opening to allow the faeces to discharge into the toilet.

- Wipe the edge of the pouch with toilet paper.

- To close the pouch: roll it up until the seal is visible.

- Close the (Velcro) seal.

- Check the seal.

- Conceal the seal by placing it underneath the grey/beige material.

Other instructions on how to seal the collection material may apply, depending on the type of material you are using.

General points to remember when caring for your stoma

- Always wash your hands before and after stoma care.
- Take time to look after your stoma.
- It is 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.
- Stand in front of a large mirror to monitor your activities.
- Use lukewarm water (or soap with a neutral pH) to cleanse your skin. The care procedure doesn't require a sterile environment.
- Don't use bath/shower gel/foam 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. Most stoma pouches have a mositure resistant outer layer, which means that they don't always have to be replaced.
- Rinse your skin well and pat it dry. Don't be perturbed by minor bleeding.
- Remove any hair around the stoma. The flange will adhere better to (almost) hairless skin, but avoid injuring your skin. (Tip: use an old electric razor.)
- 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.

- Don’t use moist tissues to cleanse the skin as they may contain oil and affect the adhesion of the flange. There is also a risk of an allergic reaction to the preservatives used in moist tissues.
- 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. You need to place a repeat order when opening the last box.

SKIN PROBLEMS

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 (oedematous) and bleed a little during the care process. The stoma is attached to the skin with absorbable sutures, which degrade naturally.

If you notice dry irritated skin (skin around the stoma is bright red, itchy and painful), moist irritated skin (surrounding skin is bright red, itchy, moist and painful and may be blistered), uneven skin (due to skin folds) it is advisable to contact a stoma nurse or doctor.

The information brochure you received upon discharge from hospital also provides further information concerning skin problems. Try to find out what is causing it and adapt your care routine if necessary.

LIVING WITH A STOMA

GENERAL TIPS

- ✓ 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.
- ✓ You can reduce the sound somewhat by placing and keeping your hand on the pouch.

A stoma is often perceived as a kind of mutilation and associated with a sense of anxiety and insecurity. Learning to live with a stoma takes time. It is important to talk about these feelings rather than suppress them. Don't hesitate to seek support from your care providers.

Social contact

Having undergone stoma surgery, you will start to perceive your body differently. Try to maintain social contacts whenever possible. Those around you won't know about your stoma should you decide to keep it to yourself.
However, if you feel the need you should talk to your children, family and close friends about your stoma. Try to approach it from a neutral angle without putting too much emphasis on the situation.

Try to respond to spontaneous questions as honestly as possible. 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 fertility

If you require further information on sexuality and fertility you should visit the Stomazorg Vlaanderen website for information brochures such as ‘Sexual function and experience following stoma surgery’, STOMA and sexual drive?!’ and ‘Sexuality and relationships’. Visit www.stomavlaanderen.be/brochures to access these brochures.

Work

Most occupations can be continued as normal. If your job involves considerable physical effort it may be necessary to adapt your tasks or find another acceptable solution.

Sport

Most sports can be pursued again following a period of recuperation. Sports involving a lot of physical contact, e.g. wrestling, judo or karate, are not recommended.
To swim you can use your usual material and wear it underneath a swimsuit or high-waisted swimming trunks/shorts.

Travel

Travel is not a problem at all. Just make sure that you take sufficient material with you or find out where you can buy it abroad. The manufacturer of your stoma material will be able to assist with this. Don't leave stoma material in the car for too long as the flange may distort and become less adhesive when exposed to fluctuating ambient temperatures.

When travelling by plane it is advisable to take sufficient material in your hand luggage. Bear in mind that you can't take scissors on a plane, so remember to take ready cut flanges. Also remember to distribute your material between different cases to ensure that you don't lose everything should a case go missing.

It is definitely advisable to take extra material when travelling to warm, tropical destinations and to store your material in a cool place once there.

Clothing

There is no need to dress differently with a stoma. It is not advisable, however, to wear tight clothing in the stoma area. The main thing is that your clothing should be comfortable. The internet provides lots of information on special stoma accessories, e.g. stoma covers, support belts, swimwear, etc.

Nutrition/medication

Please refer to the information brochure entitled ‘Enjoying your food’. Please do not hesitate to consult the nursing staff or dietician, who will be happy to provide further information.

Medical advice

If you develop any of the following symptoms you should contact a doctor and/or stoma nurse:

- if the stoma inexplicably starts bleeding;
- if you inexplicably develop a fever;
- in the event of persistent pain;
- if you are passing significantly fewer or more stools;
- if the stoma develops an unusual bulge.

DISCHARGE FROM HOSPITAL

GENERAL

You will need the following data/documentation when you are discharged from hospital:

- a hospital discharge letter for your GP;
- an appointment for the first medical check-up consultation with the abdominal surgeon;
- a stoma consultation appointment;
- a certificate for the home care nurse (if necessary);
- a prescription for stoma material;
- a stoma material discharge kit;
- where appropriate an application for bin bag compensation payments;
- a certificate to apply for a WC pass;
- a stoma follow-up folder.

The stoma material discharge kit

POSTOPERATIVE FOLLOW-UP AND EXAMINATIONS

Remember whenever you visit the hospital:

- to take extra stoma material (flange and pouch);
- to take a change of clothing;
- to tell the nurse that you have a stoma before the start of the examination;
- to only drink two, rather than three, cups of contrast medium in preparation for a CT scan.

STOMA CONSULTATION

When you are discharged from hospital an appointment will be made for a stoma consultation.
During the stoma consultation a stoma nurse will discuss any questions and comments you might have concerning the stoma care procedure, stoma materials, nutritional advice and any other issues. Sometimes you will also be seen by a doctor, who will address any medical concerns you might have.

The stoma consultation unit nursing team

If you have an urgent question for the stoma nurse whilst you are at home, you can always call them during the week between 09.00 and 16.00 hrs:

- Tel. +32 (0)16 34 37 75 (stoma team)
- Tel. +32 (0)16 34 42 31 (abdominal surgery function measurements)
- Tel. +32 (0)16 34 48 50 (contact centre outpatient care centre)
- Tel. +32 (0)16 34 42 65 (abdominal surgery secretariat)

The stoma nurse will try to solve the problem over the phone or make an appointment aimed at helping you as soon as possible.

For urgent questions during the weekend, it is advisable to contact a nurse on the ward to which you were previously admitted:

- E 444: tel. +32 (0)16 34 44 40
- E 445: tel. +32 (0)16 34 44 50
- E 447: tel. +32 (0)16 34 44 70

Non urgent questions can be submitted via e-mail (stomazorg@uzleuven.be) and the stoma team will respond or call you as soon as possible.

SELF-HELP GROUPS

There are several self-help groups for stoma patients in Belgium. They provide the following services:

- ✓ **Mutual support and advice.** By meeting people in the same situation you will feel less isolated.
- ✓ **Information.** During their meetings information is provided on new equipment, social provisions, medical aspects, etc.
- ✓ **Lobbying.** A group is more powerful when it comes to defending shared interests and pushing for specific decisions at policy making level, e.g. concerning material subsidies/refunds.

The social worker and/or stoma team will be happy to provide further information on this topic.

General address for self-help groups in Flanders

Trefpunt zelfhulpgroep vzw
Information on any existing self-help groups
E. Van Evenstraat 2C
3000 Leuven
Tel. +32 (0)16 23 65 07

Contact the above telephone number to obtain addresses of the Stomailco Clubs in the three provinces. The information brochure you were provided with when admitted to hospital includes the telephone numbers of local self-help group units in Flanders. It also provides the contact data of independent self-help groups.

TOILET FACILITIES OR WC PASS

You can apply for a toilet facilities pass to StomaVlaanderen, at a cost of 5 euro. You will have to ask the physician in charge of your treatment to complete a certificate and then forward this together with a passport photograph. The certificate is included in the appendix to the information brochure you received upon discharge from hospital. Upon presentation of your WC pass, catering establishments that are members of Horeca Vlaanderen will give you free access to their toilet facilities, without you having to buy any food and/or drink.

FINANCIAL ASPECTS

When you are discharged from hospital you will be provided with a discharge kit, containing, amongst other things, the materials necessary to manage the first few days at home. You will also receive the necessary prescriptions from the doctor for your first stoma material purchases. The health insurance fund will subsidise most stoma materials. For further information on these refunds please contact the stoma nursing staff.

The following materials will be/have been refunded since 1 January 2000:

- 90 ileostomy pouches every 3 months (one per day);
- 45 flanges every 3 months (one per 2 days);
- 45 convex flanges every 3 months (one per 2 days);
- 90 one piece systems (one per day);
- if you need to use paste and/or powder, they will also be subsidised:
  - ✓ 120 g paste every 3 months;
  - ✓ 55 g Orahesive powder every 6 months.

Everyone now has to work with a third party payment scheme. Bandagist services or pharmacies that supply the material have to reclaim the cost via the health insurance fund. You will only have to pay the extra for materials that are not covered by the repayment scheme. Some hospitalisation insurance policies provide subsidies for the first three months following the operation, but this varies depending on the insurance provider.

Independent operators, who are only insured for major risks, do not qualify for refunds from the health insurance fund. In such cases you should contact your social worker.

NOTES

If you have any questions or comments please make a note of them here so that you can discuss them later with the doctors, nurses, social worker or your GP.

NOTES

Design and implementation
This text was written by the medical and nursing team of the stoma care work group in cooperation with the communications department.

You can also find this brochure www.uzleuven.be/en/brochure/700672.

Please send comments or suggestions relating to this brochure to communicatie@uzleuven.be.

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