



ONKOLOŠKI INŠTITUT
INSTITUTE OF ONCOLOGY
LJUBLJANA

HANDBOOK FOR PEOPLE LIVING WITH AN EXCRETORY STOMA



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INTRODUCTION

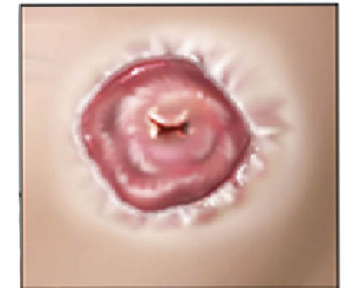
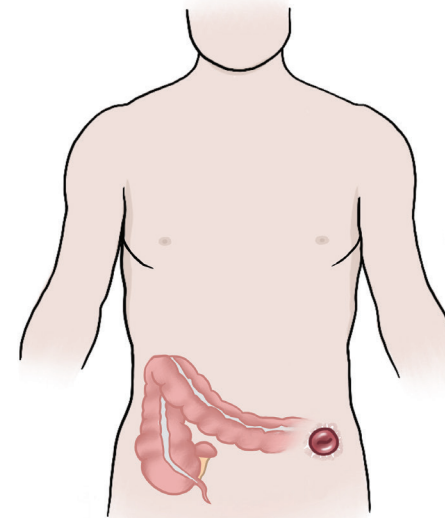
Dear Patient,

Treatment of malignancies on the intestines or urinary system often requires surgery, due to which a person can no longer excrete faeces or urine the natural way. A surgeon pulls a part of the bowel or urethras through an opening made on the abdomen and connects it to the surface of the skin, thus forming what is known as a stoma. Through this opening, waste is then discharged from the body into a pouch. The composition of the output depends on the part of the bowel where the stoma was created.

Adapting to life with an excretory stoma is not easy. The aim of the present booklet is to help you better understand how to care for the various types of excretory stomas. Proper rehabilitation enables patients with a stoma to enjoy the same quality of life as before their ostomy.

WHAT IS AN EXCRETORY STOMA?

A stoma is a surgically made opening in the abdomen that allows an internal organ (bowel or urinary system) to be connected to the surface of the skin.



Stoma

Based on the type of surgery, a stoma can be:

- **Temporary**, in which case the surgeon retracts it into the abdominal cavity after a certain period of time or
- **Permanent**, meaning that it remains there for ever.

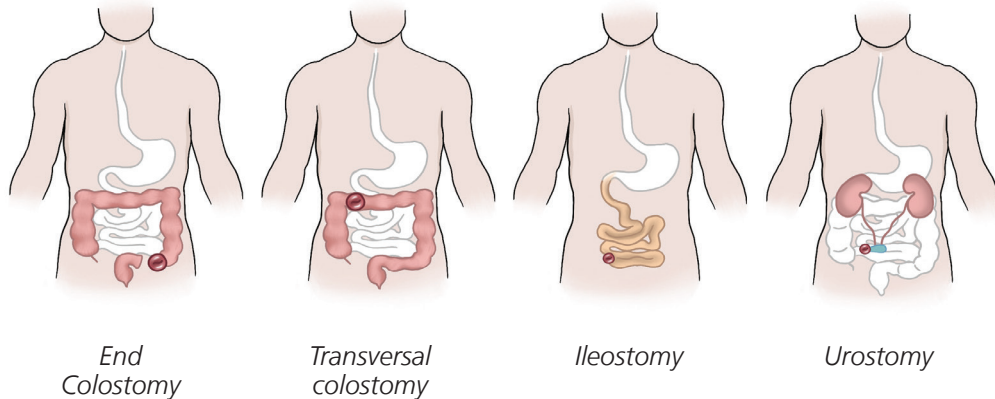
A stoma is pinkish red, warm, moist and prone to bleeding. As it has no nerve endings, you can touch it without feeling any pain. It functions independently of your will. Formed above the level of the skin, it may be round or oval in shape.

After surgery, a stoma will be swollen at first and then it will shrink slowly, reaching its final shape and size in about six weeks.



Stoma appearance (source: Flickr.com)

Excretory stomas are named after the part of the bowel or urinary system that is connected to the surface of the abdomen.



End colostomy

A colostomy is the connection of the large bowel through the abdominal wall to its surface. In most cases the stoma is placed in the lower left part of the abdomen. The contents of the bowel start to be excreted between the third and the seventh day after surgery. The large bowel absorbs water and forms stool. Therefore, the output of the stoma is a stool of normal density, which is discharged once or twice per day. The daily amount of the output is about 700 millilitres and gasses present are also present.

Transverse colostomy

A transverse colostomy is the passage of the transverse part of the large bowel through the abdominal wall. Most commonly, it is a bipolar stoma which lies on the right or left side of the upper abdomen. The contents of the bowel start to be excreted between the second and the fifth day after surgery. The excreted content is pulpy. Daily, 500 to 800 millilitres of stool is discharged.

A transverse colostomy is usually temporary, intended to unburden the bowel.

Ileostomy

An ileostomy is the passage of the small bowel through the abdominal wall, usually after the removal of the large bowel and rectum. In most cases, the stoma lies in the right lower part of the abdomen. The contents of the bowel start to be excreted between the second and the fifth day after surgery. The discharged contents are liquid to pulpy, as the small bowel still contains a lot of water and salts dissolved in it as well as digestive enzymes. The stoma discharges 600 to 1000 millilitres of stool daily.

Urostomy

A urostomy is the surgically diverted discharge of urine where the urethras from the kidneys are connected to an isolated part of the small bowel used as a pouch to collect urine. Commonly, it is located in the right lower part of the abdomen. Urine starts draining immediately after the stoma is created and drains continuously. The stoma discharges 1000 to 1500 millilitres of urine per day.

It is important to remember that excretory stomas have no muscles, so it is not possible to control the excretion of stool or urine.

PATIENT EDUCATION BEFORE AND AFTER OSTOMY SURGERY

Patient education before surgery can start in an outpatient clinic or in the ward when you are admitted to hospital. You will be cared for by a multidisciplinary team of doctors, nurses, an enterostomal therapist, dietitian, physiotherapist and psychologist. When in hospital, you will be visited by an enterostomal therapist – a nurse specialised in the care of stomas. Depending on the planned surgery, they will work with you to decide on and mark a suitable site for the stoma. They will also give you information on how to care for your stoma and the surrounding skin, on the devices used to care for your stoma, how to monitor the odour and gasses, and on how to live with a stoma (diet, clothing, physical activity, identification of potential complications and their management, sex, sports and returning to work).



Marking of a stoma site

CARING FOR YOUR STOMA

After the surgery, you will be transferred to the intensive care unit for a few days and nurses will take care of your stoma. After returning to the surgical unit, you will be visited by the enterostomal therapist again. With their help, you will gradually become actively involved in the care of your stoma. They will show you the correct way to empty and change the pouch and to take care of the skin around your stoma.

The skin must be kept clean and dry and the appliance must attach properly to the skin. The wafer on the appliance protects and heals the skin, so the opening must be the right size. The use of a measuring template is recommended. If the opening is not right and the wafer does not fit properly, the output may leak under the wafer and cause the skin to become inflamed. Use warm water and washcloths to clean the skin around the stoma. You can shower without wearing your pouch and use a mild, pH-neutral soap which you must wash off thoroughly. Do not use disinfectants (or disinfecting wipes) or petrol for cleaning, as they may damage the skin around the stoma. Regularly remove any hairs from around the stoma, using a disposable razor blade. Do not apply creams, as they reduce the adhesiveness of the wafer.

Empty your pouch when it is one-third full, or half full at most. Use pouches with filters to release gas in order to prevent the pouch from ballooning.

The best time to change the appliance device is in the morning before breakfast. Before you start, prepare all the items you will need. Gently press the wafer to the skin to bring it up to body temperature, which will make it fit the skin more snugly. Change the appliances routinely; do not wait for them to loosen and potentially leave you in a predicament. How frequently you replace the appliance depends on the system you use (a one-piece or two-piece solution) and your activities, but you should never wear the same appliance for more than four days.

Keep the appliances in a dark, cool place, preferably in a cupboard. When you leave home, make sure you always take a set of accessories for cleaning and changing the pouch with you in case something unforeseen should happen.

In case of any problems with the stoma or skin irritation and inflammation, turn to an enterostomal therapist for help.



Specifics of colostomy care

Closed pouch systems are used for colostomy care, as it would be difficult to empty the formed stool through a drainable pouch. The pouch needs to be changed when it is approximately half full. It is recommended to use pouches with a carbon filter that neutralises the odour of gasses passing through it. Gasses need to be released on a regular basis.

This type of stoma also allows for irrigation. This is the process of washing out the bowel contents through a stoma; as a consequence, the stoma does not excrete for the next 24 to 48 hours. Before you decide for to perform irrigation, you must consult a surgeon who will tell you whether this method is suitable for your type of colostomy.

An enterostomal therapist or a nurse who is familiar with irrigation will teach you how to do this. Learning begins six to eight weeks after surgery. The procedure is carried out at the same time every day to improve its efficiency and better modulate the functioning of the bowel that gradually adapts to the rhythm of bowel movements. The ostomy patient chooses the time for irrigation based around the daily tasks and routine they had before the surgery. Irrigation is recommended after having consumed warm liquids or an hour after a meal, as this is when the bowel is full and the procedure is more effective.

The procedure is not recommended for temporary stoma, in case of stoma complications, heart and kidney disease, during chemotherapy treatment or radiation, for diarrhoea and bowel diseases. The patient's age and concomitant illnesses must also be taken into consideration.



Specifics of transverse colostomy care

Drainable pouch systems are used for transverse colostomies where the stool is liquid to pulpy. Gasses and odours are present, so the use of pouches with charcoal filters is recommended. However, the bar that supports the stoma during the first days after surgery makes it difficult to change the appliances. This means that the change is performed by an enterostomal therapist, who also removes the bar on the sixth day after the surgery. Your active learning of stoma care begins after the removal of the bar.



Specifics of ileostomy care

In ileostomy care, the choice of appliances is very important. They must be sealed well to keep the skin around the stoma intact. Therefore, it is necessary to use a drainable pouch and empty it regularly.



Specifics of urostomy care

Urine drains constantly, therefore it is necessary to use a pouch with an anti-reflux valve that prevents backflow of urine towards the stoma. The pouch is drained through the outlet at the bottom. The skin wafer needs to be changed regularly, as urine will dissolve it. If the wafer is not changed regularly, the skin around the stoma may get severely damaged due to exposure to urine and mucus. It is recommended that a person with a urostomy occasionally drinks cranberry juice or fruit tea, or takes a vitamin C tablet to acidify the urine. This reduces the possibility of infections and improves the durability of the wafer.

After surgery, two tiny tubes pass through the stoma enabling urine to drain from the kidneys. They have to remain in place for at least 14 days, so be careful not to pull them out while changing the appliance.

It is recommended to drink at least two litres of liquid daily, and it is important to empty the pouch regularly. It is possible to attach an additional pouch overnight to collect urine so you don't have to get up out of bed.

OSTOMY CARE ACCESSORIES

There are two different systems of stoma appliances:

- One-piece system (the wafer and the pouch are joined together)
- Two-piece system (the wafer and the pouch are separate)



Two-piece system (drainable pouch and wafer)

one-piece system (closed pouch with a wafer attached)

There are two types of pouches:

- Drainable pouches
- Closed pouches.

Washcloths

Warm running water (you can also use a pH-neutral soap)

Measuring template for cutting the wafer

Felt tip pen

Disposable bag

Scissors (curved)



Curved scissors and measuring template

CHOOSING THE RIGHT APPLIANCE

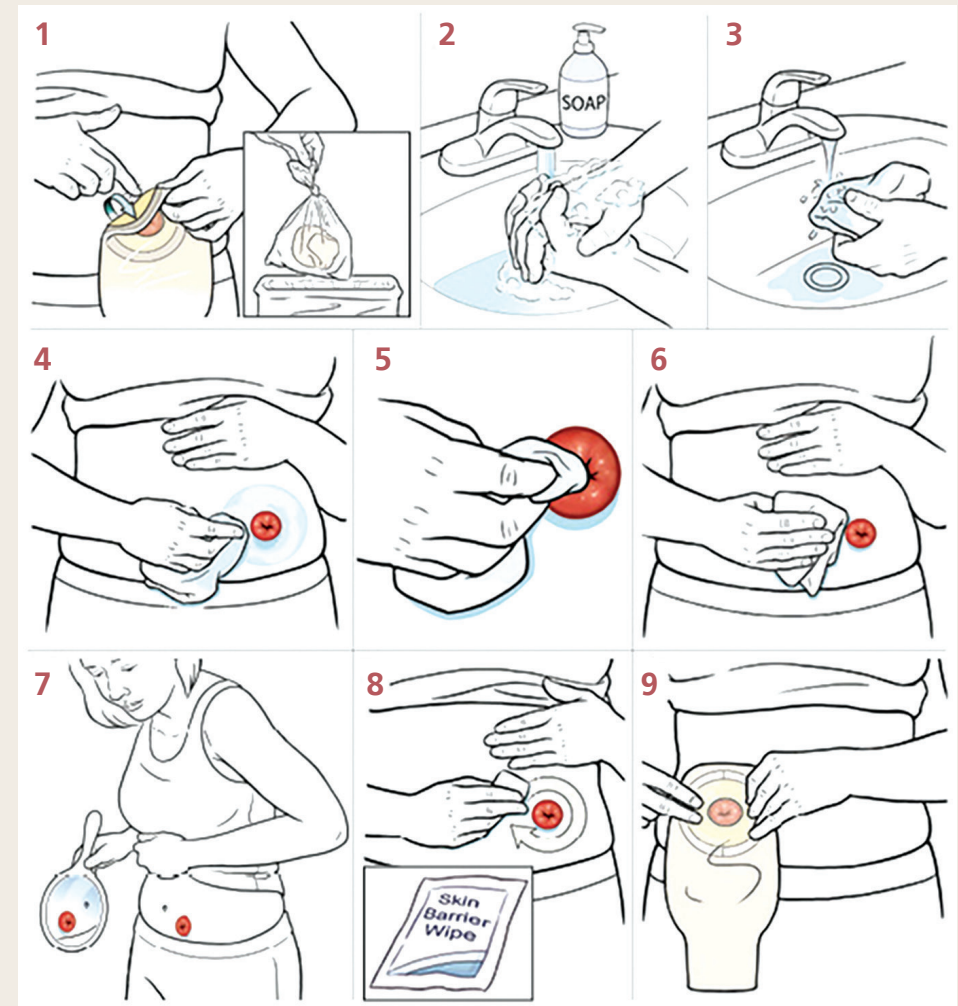
The care of an appliance must be individually adapted to the type of stoma and the output.

- For a **colostomy**, use closed pouches
- For a **transverse colostomy** and **ileostomy**, use drainable pouches (with hook-and-loop fasteners)
- For a **urostomy** use a pouch with an outlet at the bottom (with a plug)

Your enterostomal therapist will advise you on the selection of your appliance.

THE PROCEDURE OF CHANGING THE APPLIANCE

- Empty the pouch (if it is drainable).
- Wash your hands.
- Carefully remove the old wafer with the pouch, starting from the top.
- Put the removed appliance in a disposable bag (never in the toilet).
- Start by cleaning the skin around the stoma with wipes that you have wet with warm water. Start from the outer area and move inwards towards the stoma with circular movements. Clean the edges of the stoma and finally the stoma itself.
- Dry the surrounding skin with dry wipes.
- Remove the protective foil from the wafer.
- Place your wafer (previously cut accurately to fit your stoma) on the skin below the stoma, press it against the skin and then continue adjusting it upwards.
- Make sure the wafer is stuck down properly.
- If you use a two-piece appliance, attach the pouch to the wafer.
- If you use a drainable pouch, do not forget to close it.
- Wash your hands.



*The procedure of changing the appliance
(Source: The StayWell Company, Yardley)*

GETTING THE APPLIANCES AND SUPPORT OF A DISTRICT NURSE

When you are discharged from hospital you will receive a purchase order for a month's supply of appliances. The next purchase order will be issued by your personal doctor (after a month). You can get the appliances in a medical equipment shop. No payment is required, because your health insurance covers the costs.

When you return home, a district nurse will visit you. She will help you with the initial procedure of caring for your stoma and getting supplies. Later she will advise you on the evaluation of your physical impairment, retraining for less strenuous jobs and other matters regarding living with a stoma.

COMPLICATIONS WITH THE STOMA AND THE SURROUNDING SKIN

Some complications with the stoma or the surrounding skin can occur.

The correct choice and good fitting of the appliance as well as the right diet are important for solving problems such as stoma leaks, loosening of the appliance, a retracted stoma or inflammation of the surrounding skin.

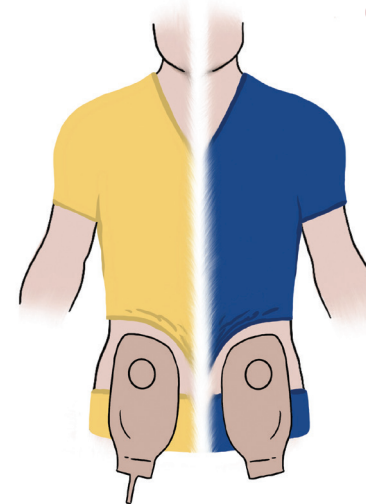
With good care it is possible to prevent any changes of the stoma or detect them in time. If you have problems with your stoma or the surrounding skin is irritated, contact your enterostomal therapist who will help you solve the problem.

What problems and complications can you expect with an excretory stoma?

Complications are divided into two groups: early complications (stoma bleeding, necrosis, retraction, abscess of subcutaneous tissue around the stoma) and later complications (parastomal

hernia, stoma prolapse, granulomas, fistulas, ulcerations, bleeding, narrowing of the stoma).

If you start to bleed heavily, feel nauseous and vomit, your stoma is swollen or you have abdominal cramps, you should immediately see a doctor who may also refer you to a surgeon.



Do you empty your pouch before it is half full?



Do you remove the wafer gently?
▶ It is recommended to use an adhesive remover spray.



Do you clean your skin with warm water?



Have you recently checked the size of your stoma?
▶ It is recommended to use a measuring template.



Are there any folds or scars around the stoma?
▶ Use a stoma ring to fill in folds or scars.



Is the skin around the stoma clean and dry before you put on a new appliance?



Is the skin damaged and moist?
▶ It is recommended to use baby powder.

Check list for detecting problems in stoma care.

DIET

Before your surgery you will attend consultations regarding your need to go on clinical diet. A clinical dietician (diet expert) will assess your current diet and prepare a pre-surgery diet plan for you. You will be advised about your diet and you will receive a brochure on the topic.

During first few days after the surgery, the surgeon, clinical dietician and nurse will inform you about the type and amount of food you will be able to consume. As a rule, you will receive solid food (such as rusks) from the first day after the surgery, as chewing is important for the functioning of the digestive system, the secretion of digestive juices and decomposition of food. It is important to chew your food well and slowly, mixing it with saliva in your mouth, and consume liquids in sips, especially after meals. It is recommended to eat your main course before eating soup.

After being discharged from hospital, patients with a **colostomy** or **transversal colostomy** can gradually start eating the food they were used to before the surgery. A clinical dietitian will also provide you with dietary recommendations before you leave hospital. Over time, you will find out which foods suit you or cause you problems such as wind, bloating, cramps, diarrhoea or constipation.

It is recommended that patients with an **ileostomy** monitor their weight regularly, which means weighing themselves at least three times a week in the morning before breakfast. You should also monitor the quantity and colour of your urine; if there is only little urine and it is darker in colour, you are probably dehydrated. If you experience weight loss, you should make an appointment for an examination and consultation with a clinical dietitian. Food rich in non-soluble fibres, e.g. cellulose, often causes loss of nutrients, water and salt through the ileostomy. Cellulose is found in the peels, pits and seeds of fruits and vegetables, legumes, all wholemeal flour products and hard leafy vegetables, so these foods should be eliminated from your diet. Loss of nutrients, water and salt can also be caused by excessive intake of liquids such as plain

water, carbonated liquids, unsweetened tea or coffee, which do not contain salt or electrolytes.

Bigger losses of liquid can also be experienced by patients with a urostomy. Therefore, it is important to have an adequate intake of liquid, i.e. 1.5 to 2 litres a day. Monitor the quantity and colour of the discharged urine regularly.

Even later on, a few weeks after surgery, it is important to eat a balanced diet, to have regular meals, to eat slowly and chew your food well, and to be physically active on a regular basis. This can make an important contribution to maintaining your body weight and muscle mass, maintaining physical strength and fitness, and preventing problems such as bloating, cramps, wind, nausea, constipation or diarrhoea.

Patients with an intestinal stoma may also develop functional problems, such as diarrhoea (excessive output of stool through the stoma) or constipation, later on and for various reasons. **If those problems cannot be resolved with diet, you must consult a doctor!**

CLOTHING

You do not need special clothes. The stoma pouch is invisible beneath clothes. However, it is recommended to empty it regularly. You can wear it under your underwear or over it. Avoid very tight clothes and clothes that are too tight in the waist or rub over the stoma.

PHYSICAL ACTIVITY AND RETURN TO WORK

It is recommended to resume an active lifestyle as soon as possible. While you are in hospital, a physiotherapist will teach

you how to get up correctly (to avoid parastomal hernia) and how to walk. After returning to your home environment, start to carry out easy tasks and take walks as soon as possible, as this will help you recover faster. Avoid lifting heavy loads and doing contact sports, such as karate and boxing, to prevent stressing the abdominal wall and damaging the stoma. Recommended forms of exercising include yoga, dancing, cycling, hiking and swimming. You can swim in a pool or in the sea when wearing a stoma pouch. You can gradually resume other activities as well, such as skydiving, cycling and group aerobic workouts.

You can go back to work when you feel up to it and when your doctor gives their approval.

SEX

When you feel strong enough, you can start getting back to having sex and family planning. A stoma is not an obstacle for having sex or pregnancy, as it is completely independent from the uterus. It is important that you and your partner understand that the pouch cannot be damaged and that it will not leak or emit odour. A non-transparent pouch can hide its content. If you experience any psychological stress due to having a stoma or your new physical appearance, please consult your doctor.

TRAVELLING

There are no limitations to travelling. However, take care of your personal hygiene; hand hygiene is of paramount importance. You will probably try food you are not used to and this can cause changes in bowel movements (diarrhoea or constipation). Always have enough ostomy care accessories at hand. If you travel by air, it is important to have your stoma card and basic ostomy care accessories in your hand luggage. Fasten your seatbelt above or beneath the stoma.

STOMA REVERSAL (TEMPORARY OSTOMY)

If you have temporary ostomy, you will be operated on again in a few weeks or months. The surgeon recesses the stoma into the abdomen (closes the stoma) and waste passes through the normal way. At first, there will be some problems with constipation, as the bowel was not active for quite a while. Stoma reversal is a rather simple surgery, but it takes some time for your bowel movements to get back into a normal rhythm.

JOINING AN OSTOMY PATIENT ASSOCIATION

Associations in Slovenia:

- The ILCO Slovenia Association which patients with stoma and their relatives can join. The association comprises six societies from Slovenia. Members offer advice and active help to each other. They also organise lectures by doctors, enterostomal therapists, psychologists and social workers.

Link: <https://www.zveza-ilco.si/>

- The EuropaColon Slovenia Association offers psychological help and support to patients with cancer and/or their relatives. Help is free of charge and accessible without a doctor's referral or a health card. Prior notification by phone is required.

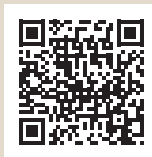
Link: <http://www.europacoloni.si/>



VIDEO OF THE WORKSHOP AT THE INSTITUTE OF ONCOLOGY LJUBLJANA

Link:

<https://www.youtube.com/watch?v=zRH5BBVsJSQ>



IMPORTANT PHONE NUMBERS

Enterostomal Therapy Consultation Office

(8 am to 3 pm): 01 5879372 or 015879462.

Clinical Diet Consultation Office

(8 to 9 am and 2 to 3 pm): 01 5879234.

SOURCES AND LITERATURE

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