YOU ARE AN ILEOSTOMATE

ILEOSTOMATE PATIENT GUIDE

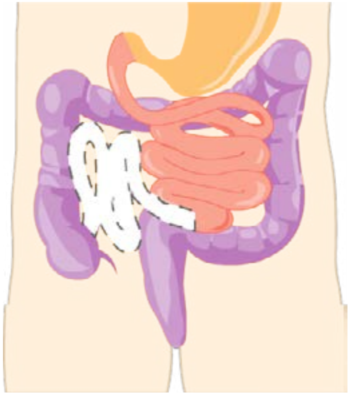
An ileostomy is a surgically created opening into the small intestine through the abdomen. It takes the role of eliminating waste when a number of situations make it necessary to bypass the rectum or colon. An ileostomy is constructed from the ileum. This type of stoma can be temporary or permanent.

Why might you have a stoma?

There are different reasons that can lead to someone needing a stoma, the main reasons are:

- cancer
- inflammatory bowel disease
- familial polyposis syndrome
- trauma
- congenital defects

In the case of an ileostomy the stools are fluid and/or semi-formed with digestive enzymes which are more agressive on the skin.



Ileostomy

Permanent Ileostomy

The rectum and anus (back passage) is usually removed in this operation.

This type of stoma usually protrudes a little from the skin and produces a soft to fluid output. The consistency of the motion can change over the course of each day. This is quite normal and is related to what, and how much, you are eating.

Temporary Ileostomy

This type of stoma is usually done to allow the operation on your bowel to heal. The stoma is usually reversed (put back into your abdomen) three to six months after the first operation. Occasionally this can be left for longer. Your surgeon can give you more details about this. This stoma has two openings in it. The 'spout' of the stoma is where the bowel motion comes from, and the other opening which is flat on the skin surface, is still connected to the rest of your bowel.

Managing your ileostomy

If you are an ileostomate,

There are lots of different types of appliances available to help you manage your ileostomy, an E.T. nurse will explain them to you.

In most cases, after your surgery you will be given a clear drainable pouch in order to help you position your pouch correctly. As you learn how to manage the stoma you will be shown opaque pouches which most people choose to use at home for more discretion.

To manage your ileostomy you will use a drainable pouch. For this type of pouch, the bottom of the bag is open, which allows the bag to be emptied regularly. It is sealed using a clip which is usually built into the bag.

Peristomal skin / Wound Care

During the first months after your operation it's important that you take care of your abdominal wound, if you have one. The E.T. nurse may visit if the wound takes longer to heal. Your physiotherapist will have shown you how to protect the muscles around the wound when you cough.

They are weakened by the surgery and need time to heal. It is essential that you do not put strain on these muscles from vacuuming, lifting heavy objects, moving furniture or ironing for example. Seek advice from your hospital as to how long you should wait before resuming these activities.

If your rectum has been removed you will have a wound at your bottom. This will be checked by an E.T. nurse at home, and your consultant will check this at your first clinic appointment.

FAQ

Theme 1: Taking care of your stoma and pouch handling

1) Can I change the appliance on my own?

Yes! You will need a little bit of training at first but changing it on your own will allow you to remain completely independent. This will also help you if you are faced with a small leakage problem; you'll know what to do (clean with water and soap) in that situation without asking for help.

2) Do I need specific equipment?

5 minutes is all you need to prepare your equipment and to change your appliance.

Get into the habit of always taking the few items required to wash with you, a spare pouch and, at the beginning, some spare clothes as this will avoid any accidents or discomfort. Your stoma is not a wound, it is a mucous membrane, therefore the daily care is a simple clean up that is done with naked hands using water and soap. To be as independent as possible at home, it is recommended to perform the change of appliance yourself.

Suggested Bathroom Wash Kit Contents

1. a good pair of quality surgical scissors, preferably with rounded edges
2. a razor *(not necessary if there is no hair growth around your stoma)*
3. a pen to draw the stoma template onto your new pouch or flange
4. a small mirror to check the positioning of the appliance on the underside of stoma
5. a supply of disposal bags
6. cleaning wipes
7. if you are using a 1 piece system; a new pouch
8. if you are using a 2 piece system; a new pouch and/or a new base plate
9. all your pastes and creams *(if used)*
10. a clothespin to hold your up your clothes when changing pouch

3)How to remove the used pouch, clean the stoma and place the new appliance?

To properly remove your used pouch please refer to the instructions for use provided with the pouch, but here are the basic steps:

- unstick the pouch starting from the top by delicately pressing on the skin above to avoid stretching the pouch too much.
- fold the pouch onto itself before throwing it away (reduces odors).
- wipe the largest part of the stool with a dry or slightly damp gauze, or an absorbent paper (which you throw away in the trash bag).
- thoroughly clean the area around the stoma with warm water abundantly and meticulously, especially if you are using soap as it tends to make the appliance non-waterproof. Avoid using any disinfectant (either alcohol, antiseptic or colorants) as this could damage the skin and prevent proper adhesion of the pouch. Avoid using ointments as they will prevent the skin protector from sticking to your skin. In case of gum residues do not hesitate to use B Braun's Adhesive Remover.

- dry completely by dabbing (the fitting of your new base plate must be done on dry skin) and place your new pouch.

If there are any traces of adhesive left from the removed appliance, do not worry, it will adhere to the new one and be removed with it.

To properly place your new pouch and/or base plate please refer to the instructions for use provided with the pouch. However, here are the basic steps:

If using a cut to fit pouch, cut the skin protector so it fits the size of your stoma, taking good care to respect the cutting guide (do not cut beyond the limit). Ensure you leave 1 to 2 mm around the stoma.

To place a one-piece pouch, start by removing the protective paper from the new appliance and stick the appliance gently starting from the bottom by folding the skin protector of the pouch upwards (filter upwards). Massage the skin protector around the stoma, starting from the stoma to the outside of the skin protector/ base plate in order to check that the pouch is properly stuck and that there are no folds. Ensure you leave 1 to 2mm around the stoma.

To place a 2-piece system, start by removing the protective paper from the base plate and stick the skin protector from the bottom upwards. Massage the skin protector around the stoma, starting from the stoma on the outside of the skin protector / base plate. Then place the pouch onto the base plate.

Tip: Having hair around your stoma can reduce the adhesion of your pouch and cause pain when you remove it. You can shave it very carefully using a razor.

4) When do I have to change a pouch or a base plate ?

It is up to you to decide, eventually everyone finds their own routine and is able to do it alone. The process usually becomes regular a month after surgery. Usually the base plate in a 2-piece system is changed every 3 days and the pouch (both for 1-piece and 2piece systems) is disposed of once filled.

5) Can I customize my pouch?

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

Just be careful if you use airtight materials always make sure the filter is still in case with the air.

6) How can I prevent irritation and redness of the skin surrounding the stoma?

Following a few steps can prevent redness and irritation of the skin surrounding your stoma:

1.Clean your stoma with water and soap (neutral pH, perfume free soap). Do not use disinfectants or alcohol.

2. You can also use skin protective products such as B Braun's Askina Barrier film.

Note: If you experience redness or itching contact an E.T nurse.

7) Where can I order appliances?

Before you leave the hospital the stoma care nurses will give you at least a weeks supply of stoma products. They will give you specific advice about obtaining further supplies at home, as each nurse's practice may be slightly different regarding this. Once your doctor has a note of what is required, you can get a repeat prescription when needed. Order new supplies when you start your last box, this way you will never run short. But don't accumulate supplies, they can be damaged by moisture and temperature changes. If you have difficulty getting your supplies, inform your E.T. nurse You can get your supplies from the local chemist, from delivery services or directly from the manufacturing companies.

Note: You can obtain samples of stoma appliances to try out. Your E.T. nurse can give you the freephone numbers of the manufacturers (or by email through their website). Tell them what kind of stoma you have and they will send you samples. If you try various pouches, keep a written note of the ones you like and those you don't. If you choose to use any new appliance, just give your E.T. nurse a phone call if you require the ordering information.

Theme 2: Food and drinks

In the first month after you operation your appetite may be quite poor, you may experience a loss of appetite. Your taste buds may also make food taste strange. As a result some people cannot eat or drink what that they have always enjoyed. No worries, this won't last. An ET nurse or food advisor can give you specific advice to help you.

If you are feeling this way, following some simple guidelines can help:

✓ Drink! Maintain a good fluid intake
✓ Eat smaller meals more often
✓ Introduce new fruits and vegetables one at a time to see the effect they have
✓ Try fruit without the skins to begin with.
✓ If a food upsets you, don't try it again for a month or so.
✓ If it still upsets you but you want to be able to eat it, then you should try preparing it in a different way. (cooked, boiled, steamed)

You should be able to get back to enjoying most, if not all of the foods you enjoyed before the operation. Some people, may even be able to enjoy foods that they have had to deny themselves for several years!

TIP: It's important to keep in mind that those foods which may have caused wind before the operation will have the same effect after the operation also.

1) What can I eat?

No need to follow a special diet, the important thing is to eat healthy meals. However, it is important to remember that every individual is different. Here are a few easy guidelines in order to have a daily healthy well-balanced diet.

✓ start with small portions then ease into bigger amounts until eating normally
✓ eating every 3 hours (for example) can be easier then eating 3 large meals.
✓ when eating relax, sit upright, eat slowly and chew food well keeping your mouth closed. Also avoid talking when eating to reduce wind.
✓ include fibres in your diet (wholemeal bread, bananas...)
✓ drink! drink (for example water, tea...) at least 1,5 L of fluid daily. (If you are constipated make sure you increase your fluid

intake)

✓ certain ingredients or foods can help reduce/control odors these include: yoghurt, peppermint, water, parsley.

× avoid certain foods that may cause diarrhea such as highly spicy food, fatty foods, under-cooked vegetables…

× avoid certain foods and beverages/drinks that may cause wind such as beer, cider, beans, dairy products

× avoid certain foods that may cause odors or bloating such as beans, broccoli, cabbage…

Tips: If you are passing a hard constipated stool you may find it beneficial to increase your fluids and/or increase your fruits and vegetable intake.

If you are suffering from diarrhea caused by e.g. Antibiotic Therapy, Stress, Enteritis, food Poisoning, Chemotherapy, or Radiotherapy, you may find it beneficial to decrease your fruit and vegetable intake.

If constipation or diarrhea persists, consult your doctor and/or E.T. Nurse.

2) Should I drink a lot?

Yes! Due to your ileolostomy you have to drink more water since your colon is not absorbing as much water as it should. To compensate for this loss you should drink on average at least 2.5 liters of water per day. The amount of water you will have to drink will depend on the type of ileostomy you have. (between 1.5 to 2 L per day)

Note: Consider increasing the amount of water you drink when the temperature rises.

3) What should I do if I have diarrhea, constipation or bloating?

If you experience diarrhea:

✓ Keep your body hydrated! Drink one glass of water per hour
✓ Avoid dairy products for 24hours
✓ If the diarrhea subsides eat dry bland food such as crackers and toasts
✓ Slowly introduce food such as white rice
✓ Use a drainable pouch and eat food with low fiber content.

If you experience constipation:

✓ Drink at least 2 liters per day
(Tip: have a glass of ice water while fasting to accelerate bowel movement, drink pure fruit juice: iced grape, orange, apple and prune juice, in the morning on an empty stomach).

✓ Eliminate rice and cooked carrots

✓ Avoid tea and coffee because it contains caffeine which can cause dehydration and constipation.

✓ Eating citrus fruits such as kiwis, oranges… may help you empty your bowels.

✓ Do physical exercise.

× Do **NOT** take any laxatives without telling your doctor or an E.T. nurse.

If you feel bloated:

✓ Avoid foods that cause fermentation such as dried vegetables, beans, chickpeas, peas, whole wheat bread…

✓ Have your meals in peace and quiet, at regular hours. Chew properly, drink plenty (preferably between meals) and avoid soft drinks. (Tip: If you want to drink a soft drink stir your drink with a spoon to remove the bubbles before drinking.)

Tip: To remove a bad smell in the toilet or bathroom, light a match. The sulfur will remove the odors.

If either of these symptoms persist it is important to contact your doctor or an E.T. nurse who may prescribe the appropriate medication.

Theme 3: Every day life/ Coming home

1) The recovering phase

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

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

2) Driving

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

If you are concerned about this please consult your doctor.

3) Showering and bathing

As the equipment is fully waterproof you can shower or bath. Keep in mind that the heat of the water can have an impact on the adhesive power of the skin protector (1-piece system) or the base plate (2-piece system). Also if you decide to keep your pouch remember to close the filter to maintain its effectiveness. Be aware that if you decide to shower or bath without your pouch, possible uncontrollable stool output can occur.

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

4) Swimming

In the same way that you can shower or bath yourself with your pouch you can just as easily

go swimming either in a pool or in the sea without fear of leaks.

5) Psychological adjustments

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

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

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

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

6) Phantom rectum

Phantom rectum is similar to the"phantom limb" experienced by amputees, where they feel like the amputated limb is still present. If you feel like moving your bowels in the way you did prior to surgery, that is normal. This may even occur for years post-surgery. If the rectum was not removed, you may experience this sensation and may also pass mucus when you're on the toilet. Some people who had their rectum removed have reported that the feeling is greatly alleviated by just sitting on the toilet and acting as though a bowel movement was taking place.

7) Sport and active life style

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

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

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

8) Travelling

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

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

- check that you have adequate insurance, which covers pre-existing illnesses.
- ensure you have adequate toilet facilities within your accommodation.
- plan your best opportunity to empty or change your appliance.
- for longer breaks, send appliances in advance to your destination or have them delivered to you while you are there.
- take a couple of drainable pouches in case you have diarrhea.
- mini pouches are available for swimming and sun bathing. Most standard pouches have a mini version that will suit you. See your E.T. nurse for further advice.
- split supplies between hand luggage and your suitcase, in case of loss.
- avoid alcohol and fizzy drinks on the plane and drink plenty of water.
- to avoid over production of wind before flying eat yoghurt daily and avoid yeasty foods.
- if the local water should not be drunk avoid salads and ice in drinks.

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

9) Can I wear all kinds of clothes?

Yes! However right after the operation you may at first feel more comfortable in loose fitting clothes as your abdomen will be swollen and you will still be feeling a bit sore. This will gradually settle during the first couple of months, but after that you will then be able to start wearing the type of clothes you want as the pouch will be perfectly hidden under your clothes. You might feel a little self-conscious about the pouch the first few times you go out, but no worries this is perfectly normal! With time and as you go back to your usual lifestyle this feeling will gradually disappear.. You can be fitted for a girdle which will be made-to-measure. You should be able to wear tight fitting clothes and swimwear. Ask your E.T. nurse to advise you about the best mini pouch for you.

Don't be afraid to discuss any clothes preferences or any clothes related questions with your E.T. nurse before the operation (see pre-operative consultation). If your operation was done in emergency or if the location of your stoma was not marked before the operation some slight adjustments to the waistline may be needed. Again ask your E.T. nurse for advice.

10) Is it possible to go back to work?

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

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

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

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

The quality of the appliance is such that it does not reveal anything, there are no risks of odors with the filters and there are no risks of leaks, the sealing of the pouch is safe. To be on the safe side you can avoid foods that generate gas, if you are a ileostomate and are using irrigation then you can use a stoma cap. Always plan spare equipment such as an extra pouch, gauze or a tissue, and a plastic bag.

Theme 4: Kids/children and relatives

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

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

Theme 5: Sexuality

Don't forget that you have had major surgery it is therefore only normal for you to be anxious in regards to your partner's response to your stoma. It will take time for both of you to adjust to the changes and for your body to recover. Physically you may not be able to relax and enjoy an intimate relationship for a period of time. This will vary according to how long you were ill before surgery, the extent of the surgery itself, and the need for other treatments after the operation. Although this is perfectly normal a diminished libido can lead to anxiety for both partners, so it is vital that you talk to each other, so that there are no misunderstandings.

A lot of support can be gained from your loved ones. If the presence of the pouch is a problem to you, discuss this with an E.T. nurse who can suggest various options, one of which may help you. You can also consider modifying the exterior aspect of the pouch by creating a customized pouch.

You must be prepared to discuss with an E.T. nurse the details of any problems you have so that she can help you. Her advice can take several forms. She may advise a practical solution, such as changing sexual position, or using lubrication if dryness or discomfort is the problem. There are also several other specialists she is able to refer you to if she feels that you would benefit from their advice. You can also refer yourself to clinics such as the psychosexual counselor at the local family planning clinic.

If you have a partner of the same sex, you can discuss any anxieties with an E.T. nurse who may recommend you contact the dedicated person in your country. You can also refer yourself directly to these agencies.

If you don't have a partner at present, but are concerned about how to introduce having a stoma to a future partner, you should discuss this with your E.T. nurse or a fellow member of your support group. This can be a worrying time, and while we cannot give you specific advice in this website, your E.T. nurse is always available to discuss this in more detail.

1) Can I sleep with my partner?

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

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

2) Contraception, pregnancy and childbirth

Regarding contraception you may need to change the type of contraception you were using prior to the surgery as in the case of oral contraceptives for example, you may no longer be able to absorb the full dosage of medication. You should ask your E.T. nurse about contraception following surgery.

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

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