

lleostomy Hints & Tips



Introduction



This Hints & Tips booklet has been designed for those with an ileostomy. Its purpose is to guide you from your operation, through the first months and beyond, and help you adapt to life with a stoma.

This book is a compilation of hints and tips from the 'university of life': those living with a stoma and health care professionals' experience within stoma care. Some of the hints and tips included may seem different or unusual; however they have made life easier for many people with a ileostomy.

We realise that there are probably more hints and tips throughout the world than those included in this book and we are always happy to receive any input for future editions.

We hope that the contents of this book will aid and ease your daily life with your stoma and add quality to your life.

Pat Black Nurse Consultant Stoma and Colorectal Services The Hillingdon Hospital UK

Part Black

Chris Hyde Colorectal Specialist Nurse Stoma and Colorectal Services The Hillingdon Hospital UK

Vigdis Hannestad Global Clinical Manager Dansac A/S

Contents

Introduction
Contents3
Now you have had your surgery
Care of your stoma
• Ileostomy skin care
• Hints and tips
• Changing the bag9
Hair removal around the stoma
Disposal of products10
Going home11
• First weeks
Food management12
• Food guide
• Loose watery output14
• Odour/Smell
• Gas/Wind/Flatus16
Ileostomy obstruction/blockage
Clothing18
• Hints and tips for men
• Hints and tips for women
Sex and relationships19
Hints and tips
Hints and tips for men 20
Hints and tips for women
• General hints and tips

Contents

• General hints and tips for making love21
Contraception, pregnancy and child birth
Training and exercise
• Hints and tips
3 months and beyond
Phantom rectum
Going back to work
• Hints and tips
Medication
Travel 27
• Travel insurance
Ostomy travel certificate
• When travelling
Travel by air, hints and tips
Travel by sea, hints and tips
Travel by rail, hints and tips
Travel by road, hints and tips
Food and drink 29
• Swimming30
Chemotherapy and Radiotherapy
• Chemotherapy31
• Radiotherapy31
• Hints and tips
Temporary ileostomy (loop ileostomy)
• Hints and tips

Contents

lleo anal pouch	33
Hints and tips	33
Appendix	
• Kits	
Support organisations	3
Notes	

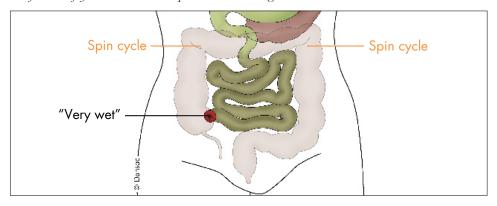
Now you have had your surgery



Learning to take care of your stoma is not as difficult as learning to walk, learning to drive a car or wearing contact lenses – but it will take time to adapt.

The function of your large bowel can be compared to the spin cycle of a washing machine. When the stool enters the large bowel, it is quite similar to when your washing enters the final spin cycle of the washing machine. The stool, like your washing, is very wet at this stage - this means that when your large bowel has been removed, it can be compared to missing the spin cycle in your washing machine, making the stool wet and loose.

The function of your bowel can be compared with a washing machine:



At first, it will take time for you to adjust and learn to care for your stoma. While you are recovering from your surgery, it will seem as if you will be unable to cope with this new situation. But as you recover and gain more strength, you will find it easier and become quicker and more efficient with your stoma care. Going home is a challenge and recovery will take time.



Keep a notebook or a patient diary to put all your queries and questions in. This way you will not forget to ask the important questions when in contact with your stoma care nurse/ doctor/health care professional.



Care of your stoma

There are three different types of stomas: colostomy, ileostomy and urostomy. Because the output and consistency is different with each stoma, it is important for you to know which one you have. This book relates to your particular stoma - an ileostomy.

Your stoma care nurse will give you the appropriate instructions and guide you as to the products you may use.

There are many reasons why people have an ileostomy, but the questions and concerns are usually the same. The output, volume and consistency vary in each individual case, depending on the exact location of the stoma in the small bowel. The stoma is red and moist, there are no nerve endings in the stoma and therefore no sensation.

The output from an ileostomy is normally between 400-800 ml in 24 hours and is usually of a porridge-like consistency, however this can change throughout the day depending on how much food and fluid is consumed. The ileostomy appliance will need to be emptied several times a day and sometimes at night. A person with an ileostomy is not able to control the output.

It is important to drink larger amounts of fluid/water. Ensure you have plenty of salt in your diet because you loose more salt than other people through your ileostomy output. If, prior to your ileostomy surgery, you were on a restricted intake of fluid and/or salt, please check with your doctor before increasing your fluid/salt intake.

lleostomy skin care

The area around your ileostomy, where your stoma bag is attached, is called the peristomal area. The sticky area of your stoma bag/flange/wafer, called the skin barrier, is designed to protect the peristomal skin whilst allowing it to breathe.

It is important that this area is kept clean and protected from stoma output.

Remember your stoma is unique to you.





If your bag leaks, change it!

It is important to be prepared and have all the equipment you require at hand before starting your stoma care.

When trying any new cream/gel/wipe under your flange/wafer test it on a small segment of the peristomal skin - if you have a reaction it will not cause the whole area to be involved.

It is the ileostomy output that may cause soreness of the peristomal skin and not the continuous use and removal of the skin barrier. If the peristomal skin becomes uncomfortable, itchy and painful, your stoma bag needs to be taken off, the area washed, rinsed and dried and a new stoma bag re-applied.

Hints and tips

- Many stomas are not round, therefore make sure the skin barrier fits as snuggly as possible.
- The easiest way to measure your stoma is by using the backing paper of the skin barrier as a pattern. You may want to stand in front of the mirror to do this.
- During the first 3 months you may want to check the size of your stoma on a weekly basis, as your stoma may change in size.
- If your skin is damp you may find it useful to dry the peristomal skin with a hair dryer on a low setting before you apply the new skin barrier.
- To aid adhesion of your flange/wafer/stoma bag, you may find it helps to place your new clean flange/wafer/stoma bag in a warm place (e.g. sit on it, put it under your arm or on top of a radiator) prior to application.
- Excessive sweating may reduce the skin barrier's ability to stick to the skin. The use of a non-perfumed antiperspirant underneath the skin barrier helps solve the problem.
- Care must be taken when applying peristomal skin creams. They are often greasy and may prevent the skin barrier from sticking to your skin. The amount needed is no more than the size of a match head and should be well rubbed in before applying the new skin barrier.
- A bulge around the stoma may indicate a hernia, contact your stoma care nurse for advice.
- · A prolapse is an increased protrusion/lengthening of the stoma.
- If you think you have a prolapse or a hernia, providing your stoma is still functioning
 properly and you are not experiencing any problems with the performance of your
 stoma bag, there is no urgent need to see your stoma care nurse or surgeon. Your next
 routine appointment will do.
- Do not worry if your stoma bleeds when washed this is normal, because it has the same delicate texture as the inside of your mouth.

Try to get into a routine when changing your stoma bag.

You will need

- Disposal bag
- Non-woven wipes for washing/drying
- · Warm water for washing
- Fragrance free mild soap (if required)
- · New pouch and/or flange
- · Scissors for cutting flange/wafer (if required)
- Any accessories you may use

Changing the bag

- · Secure clothing out of the way (pegs and safety pins may help to hold clothes out of the way).
- · Empty your stoma bag.
- Dampen a few non-woven wipes to help release the adhesive barrier.
- Remove the used stoma bag carefully, from top to bottom supporting the skin with the dampened non-woven wipes.
- · Clean any stools on the stoma and skin with toilet paper.
- Wash the stoma and surrounding skin with your dampened non-woven wipes/paper kitchen towels.
- Dry skin thoroughly.
- Do not apply anything to the skin unless recommended by your stoma care nurse or health care professional.
- Remember to remove the backing paper before applying the new stoma bag/flange/wafer.
- Do not forget to carry your spare kit with you when leaving home (see page 36).

Hair removal around the stoma

Some people find it necessary to remove hair from the skin around the stoma. The best way to do this is either by shaving or cutting long hairs with scissors. Dry shaving is uncomfortable, so it is preferable to wet shave the area with a clean disposable safety razor each time. Shave gently and carefully in the direction of hair growth once a week. Do not use or share family razors. It is not advisable to use hair removing creams or gels.



When washing the peristomal area, it is not advisable to use baby wipes/wet wipes, disinfectants or antiseptic fluids – they may cause skin reactions around the stoma.

Always carry your spare kit when leaving home.

If you need to shave the stoma area: use the cylinder from an empty toilet roll to protect your stoma and shave safely around the stoma.





Disposal of products



Nappy sacks make good disposal bags for used stoma bags. All stoma bags should be emptied before disposal. If possible, the stoma bag should also be rinsed through. The empty stoma bag should be placed in a disposal bag and sealed before disposing of in a rubbish bin.

When away from home you may wish to double wrap the used stoma bag before placing in the appropriate bin.

Disposal of used appliance

- Empty pouch contents into the toilet.
- Do not dispose/flush the stoma bag down the toilet.
- Place used stoma bag and wipes in disposal bag and tie a knot before placing it in household waste.





Going home

First weeks

The first 2 weeks after returning to your home, your daily routine will be slower to begin with. When you become confident with your stoma care, you will get into a routine and the changing of the bag should only add a few minutes to your normal bathroom routine. In the beginning you may feel that the stoma will be controlling you, but you will soon be in control of the stoma.

Remember to renew your spare kit regularly.

Accept all offers of help (the offer may

only come once).

Sleep, eat and drink regularly.

Your tummy may still be distended after surgery, so you may wish to keep your clothing loose for the first couple of weeks. Try moving around your house or garden every 2 hours, as this will help your general blood circulation and reduce the feeling of distension and discomfort in your pelvic area and lower limbs.

To avoid undue abdominal discomfort and the risk of developing a hernia around the stoma, it is advisable to avoid the following activities in the early weeks after surgery:

- Mowing or cutting the grass
- Using the vacuum cleaner
- Pushing a pram, pushchair, supermarket trolleys or wheelchair
- Digging the garden
- Lifting anything heavy (such as a full kettle)
- Moving furniture
- Cleaning the windows
- Ironing

It is also recommended not to drive a car during the early weeks following surgery because the side effects of medication and anaesthetic slow your reaction time and reduce concentration.

Your progress will go up and down, one day forward, two days back in the beginning. You may be tearful, irritable and snappy. Make sure your family and friends understand, as this is a normal reaction following surgery and during recovery.

You will be best in the morning, tired in the afternoon and exhausted in the evening.



Food management



Remember that eating should be a pleasure! Our bodies need a whole range of different food types for recovery and health – the secret is to know what you're eating and strike the right balance.

It is important to

- Eat at regular times.
- Enjoy your meals in a relaxed atmosphere.
- · Do nothing else while eating.
- Sit down to eat, preferably at a table.
- Not to drink and eat at the same time, as this may cause wind.
- If you wear dentures, make sure they fit properly.

Food management after surgery

- Enjoy small meals, taken often.
- · Proteins (meat, fish and dairy products) are good for healing.
- Chew food thoroughly to aid digestion.
- Use the fork-test: if cooked food can be cut with the side of a fork it is tender and can be digested easily.
- If you have lost your appetite, simply eat food that you enjoy.
- Listen to your body and your cravings (Mother Nature knows best!).

Day-to-day food management

- Enjoy 3 4 regular meals a day.
- Add extra salt to your food.
- Balance your food intake, try to eat a bit of everything from the food circle.
- Eat fruit and vegetables each day.
- Drink plenty of fluids, especially water, each day.
- A glass of wine, sherry or a beer with your meal is OK.

Always remember to drink plenty of fluid each day. Approximately 2½ litres of water and other fluids are needed to hydrate your body. An easy way to remember is to re-fill an empty 2-litre bottle with water each day and have this emptied by evening.



Remember to eat a balanced diet, chew well and eat your food slowly.

Food guide



Remember to increase your fluid and salt intake.

Loose watery output

If you think your diarrhoea (loose, watery stools) is caused by illness, tummy upset/food poisoning, or it continues for more than 24 hours you should consult a doctor.

If you believe it is due to change in food/water/daily routine these are some of the things that may help you.

A very good emergency remedy is a Coca Cola (not diet) and a bag of salted crisps.

Hints and tips

- Under ripe bananas
- Marshmallows (approx. 30 a day)
- Jelly babies (approx. 200 grams)
- · Smooth peanut butter
- Apple sauce (cooked apples)
- White rice
- Pretzels
- Yoghurt (natural, you could flavour it with honey)
- · Noodles/pasta
- Buttermilk
- · Gravy granules to be used in sauces etc.
- Arrowroot

Odour/Smell

Hints and tips

- If the stoma bag is correctly applied there should not be any smell.
- When you have finished your stoma bag change and everything is cleared away and the
 toilet is flushed, strike a match and blow it out straight away. The sulphur tip of the
 match will reduce/eliminate the smell.
- There are some foods that may increase smell, like onions, garlic, cauliflower and cabbage.
 You may want to avoid the ones that affect you.
- A few drops of vanilla essence or proprietary ostomy deodorizer in the stoma bag may help with odour.
- Proprietary odour absorbers to spray towards the bathroom ceiling.
- Buttermilk to drink.

When changing the stoma bag in the toilet/bathroom there will be a smell different to before your stoma surgery. The difference is due to the bypassing of the large bowel.

Odour may also indicate leakage. This can be leakage from the pouch sealing or underneath the skin barrier. It is important that you change your stoma bag immediately - both to eliminate the odour but more importantly to clean and protect the skin around the stoma.

Gas/Wind/Flatus

Some people produce more wind than others. If you experienced problems with wind before the surgery this will not change after surgery.

Wind can result from swallowing air and after drinking fizzy/gassy drinks, talking when eating, smoking, chewing gums and some foods.

Foods that may cause wind are

(Add these foods to your diet gradually and see how they suit you.)

- Green beans, baked beans
- · Cauliflower, broccoli, winter root crop vegetables
- · Onions, garlic
- · Sweetcorn, peas
- Apricot, bananas
- · Cabbage, spinach
- Cucumbers
- Mushrooms
- Eggs
- Beer
- Lactose/wheat intolerance
- Pretzels

Hints and tips to avoid wind

- · Charcoal tablets to be chewed
- · Peppermint oil in hot water to drink
- Peppermint tea
- Cinnamon, to eat or drink (not if you are pregnant)
- Fennel, to eat or drink
- Angelica
- · Sage, to eat or drink
- · Yoghurt or yoghurt drinks

Ileostomy obstruction/blockage

If your ileostomy stops working either by blockage from adhesions (bands of fibrous scar tissue joining together two surfaces which normally should be separate) or undigested food, you may experience abdominal pain, distension, nausea and vomiting. There will be minimal watery or no output from the stoma. Things that may help include drinking clear fluids only and massaging your tummy while relaxing. A food blockage will in most cases resolve spontaneously, but if symptoms persist you may need admission to hospital for observation.

Foods that may cause blockage are

- Nuts
- Dried fruit
- Coconut
- Dried vegetables
- High fibre vegetables
- Asparagus
- Mushrooms
- Celery
- The white pith on citrus fruits (tinned fruit is fine)
- Some Chinese meals (with nuts in)
- Onions and peppers
- Pineapple, melon
- Bean sprouts
- Bamboo shoots
- Lettuce
- Popcorn
- Tomato/fruit skin

Clothing



You may wish to keep your clothing loose for the first couple of weeks because your tummy may feel uncomfortable. In a few weeks you will be able to wear your usual clothes. Wearing tight-fitting clothes will not affect your stoma. If the operation was an emergency and your stoma was not sited, it may be necessary to adjust the waistline on your clothes slightly.

Hints and tips for men

- You should be able to wear the same type of clothes you wore before your surgery.
- Trousers with waistband pleats will give more room across the stoma bag area and can be bought from most stores.
- Tight-fitting clothes can still be worn.
- A belt can sometimes cause a problem if it goes across the stoma braces are better.
- Some companies design specific clothing for men with a stoma, such as swimwear, underwear and high-waisted trousers.

Hints and tips for women

- You should be able to wear the same type of clothes you wore before your surgery.
- · Panties/underwear should go either under or completely over the stoma bag.
- You can still wear a support girdle after stoma surgery.
- Some companies design specific clothing for women with a stoma, such as swimwear, underwear, nightwear and high-waisted tights.
- · Patterned swimwear is more flattering.
- Tight-fitting clothes can still be worn.

Sex and relationships

Even though your stoma surgery may have brought an end to years of illness and discomfort, or been done to cure a life threatening disease, it still represents a change to a natural body function. Some of the emotions you may experience will be a result of this change and may affect the way you see yourself.

Most changes in the way we see ourselves take place gradually over a period of time, as in ageing. Surgery resulting in the formation of a stoma means a sudden major change in your body and in the way you see yourself. It will take time to get used to this change. It is natural to experience sadness and grief while you adapt to the new, but not really so different, you. Sexual activity is one of our normal functions and having a stoma should not prevent this activity.



Hints and tips

- Share your thoughts and needs with your partner.
- Your sleeping arrangements should stay the same.
- Show that you appreciate a warm and loving relationship.
- · Remain intimate and discuss issues openly.
- Touching, caressing, warmth and affection are all important.

If you don't have a partner at present but are concerned about how to tell a new partner that you have a stoma, there is no right or best time to tell. You need to use your own judgement. However it may be better to tell them early in the relationship, prior to a first intimacy. This may make things easier and help you relax.

People with stomas have relationships, marry, have children, and lead normal lives. Relationships involving a person with a stoma are just as stable as relationships in general.



Men may experience difficulty with erection and ejaculation, because the nerves and blood supply involved in sexual function lie close together and may be bruised during any pelvic surgery where the anus and rectum have been removed. If you are unable to have or maintain an erection, talk to your surgeon or stoma care nurse for advice.

Pain during intercourse and lack of sexual interest may also occur. This is not unusual and in most cases temporary, but the experience can be worrying and you may think that your sexual desire and arousal have disappeared.

It is important that you and your partner understand these difficulties, so that you will both keep calm and not be unduly worried.

Hints and tips for men

- It has been said that sex is 95 percent mental and 5 percent physical.
- Consider psychological factors that may stop you having an erection.

There are a number of different ways to help erectile problems:

- Medication such as Viagra
- Penile injections
- · Penile implants
- Mechanical erectile appliances, e.g. vacuum pumps

Hints and tips for women

Women who have had their rectum removed during surgery may feel a different sensation in their vagina when having sexual intercourse. There may be pain, vaginal tenderness, dryness or vaginal discharge for some months. It is important that you and your partner understand these difficulties, so that you will both keep calm and not be unduly worried.

- Try using water-soluble lubricant.
- Treatment with a hormone replacement.
- Oestrogen cream.
- · Change of position during intercourse.

Contact your stoma care nurse for further advice.

General hints and tips

Several things may make sex more difficult in the immediate postoperative period. For example:

- Anxiety or fear about your ability to perform sexually.
- · How you feel about your body.
- The worry of odour and that the stoma bag might leak.
- The worry that the stoma bag might come off.
- Attempting intercourse before your strength and confidence have returned after the operation.
- Depressed mood, which many people experience following major surgery.
- Medication such as blood pressure medication, anti-depressants, etc.
- Alcohol.
- Chemotherapy and/or radiotherapy.

Understanding, communication and warmth between you and your partner are vital. We cannot read each other's thoughts so it is important to ask questions and talk about needs and desires when it comes to what you like best sexually.

Hints and tips for making love

- Empty/change the appliance before sexual activity.
- You may like to wear a cover over your appliance to prevent the plastic clinging to your skin.
- Covers can be made in many styles and materials from cotton to sensual satin.
- Sexual activity will not harm the stoma.
- As long as your appliance is secure, whatever positions you choose should not affect the stoma bag, the cover or dislodge the appliance.
- A normal size appliance can be folded and taped into a smaller shape (see picture).
- Do not mistake your partner's concern for rejection.
- Any position that is comfortable for both of you is suitable for sexual activity.
- If you have a partner of the same sex, the surgical removal/closing of the anus may cause a problem in a sexual relationship. Intercourse via the stoma can be dangerous and is not advisable.
- Your stoma care nurse can refer you to an appropriate counsellor or appropriate stoma organization.









Surgery and the type of stoma you have may change the reliability of your birth control pills. Choice of birth control should be discussed with your surgeon, gynaecologist or stoma care nurse.

Having a stoma does not prevent pregnancy and giving birth. Most doctors recommend a waiting period of approximately one to two years following stoma surgery before becoming pregnant so that everything can settle down. Generally, there is no reason why you cannot have a baby, but it is important to talk with people who can advise you – your doctor, your gynaecologist, and your stoma care nurse.

Having a stoma will not prevent you from having a normal pregnancy, including morning sickness and backache! The stoma may swell and protrude more than usual in mid pregnancy and you may have to consult your stoma care nurse for advice. The stoma tends to return to its previous size after delivery.



Training and exercise

Having a stoma should not prevent you from exercising or from being as physically active as you were before your operation. Talk to your doctor/stoma care nurse about contact sports or very heavy lifting; apart from that you should be able to enjoy the same type of physical activities you enjoyed before your surgery.

Ask a friend to join you in exercising.

Ŷ

Remember, even light exercise is good exercise - for your heart, your joints, your muscles, your lungs, and for your general sense of well-being.

You will need to allow some recovery time - and walking is a great place to start. Post-operatively, just walking around the house or to the end of your garden is fine. One thing to bear in mind is that there is more to getting back in shape than running a mile or playing a set of tennis. Thirty minutes of walking every day is very good for you.

The benefits of regular exercising are well known – but it is a good idea to talk to your doctor or stoma care nurse before starting an exercise programme, especially if you're out of practice, or if you have other medical conditions.

There are lots of easy ways of making yourself stronger each day; you must find the one that is right for you.

Hints and tips

- Don't overdo it and remember to listen to what your body is telling you (do not try to do too much).
- Most important is to take one day at a time and pat yourself on the back for every accomplishment - no matter how little it might seem!



3 months and beyond



At this stage you will find that you have made a lot of progress in your recovery. You will most likely be confident with the care of your ileostomy, have resumed your social activities and perhaps started working - you may even have taken a short holiday away from home. In other words you may be back to your normal way of life.



For those undergoing further treatment these activities may take longer to resume.

If you feel that things aren't going as well as you had hoped, or if you have any type of problem, do not hesitate to contact your stoma care nurse or health care professional for advice.

Phantom rectum

It is not uncommon to experience the sensation of wanting to open your bowel in the normal way when your anus has been closed. This is a normal sensation, which may happen occasionally. Sometimes it helps just to sit on the toilet for this sensation to pass.



Going back to work

You should be able to resume your previous work within 8 to 12 weeks after surgery. No one at work needs to know about your stoma if you don't want them to. If you wish to tell some of your colleagues about your surgery, plan whom you wish to tell and how much you want them to know.

Before returning to work you may want to discuss with your employer about the possibility of starting work on a part-time basis for the first 2-4 weeks. Most employers are happy to help if they can. Having a stoma should not restrict you in the type or choice of work you do.

Hints and tips

- · Take extra fluid to work to drink during the day.
- Eat regularly during the day at work.
- · If you are involved in heavy lifting at work, remember to wear a support belt while lifting.
- If you work on a building site you may want to wear a protecting shield over your stoma (ask your stoma care nurse/health care professional).



Remember to take your spare kit with you to work, as you may need to use this during the day.



Medication

ALWAYS

remind your doctor/
pharmacist that you
have a stoma when
being prescribed new
medication or buying
non-prescription
medication.

Do not insert anything into an ileostomy at any time.

Anyone with a stoma may experience problems when taking medication.

Any medication taken by mouth is absorbed primarily through the beginning of the small bowel. Many factors influence the absorption of drugs into the body, depending on the type of drug, dosage and the way it is taken. Having a stoma may interfere with this process.

Remember

- Sugar-coated tablets should never be crushed.
- Sugar-coated tablets are not absorbed easily, an alternative may need to be taken.
- Chewable/dissolvable tablets are easier to absorb.
- Some tablets will change the colour and odour of stoma output.
- Antibiotics may give you diarrhoea.
- Seek advice from your pharmacist or stoma care nurse.

Example of some drugs that colour urine/stools		
Antacids (indigestion medication)	Colostomy/ileostomy output grey	
Senna	Urine to go brown or yellow	
Warfarin	Urine orange	
Some anti-depressants	Urine blue-green	
Iron, charcoal, some blood pressure pills	Stools black	
Antibiotics	Stools green or urine reddish-brown	

Certain medications may not be absorbed, such as large tablets, sugar-coated tablets, time release capsules and birth control pills.

Never take any laxative or bowel preparations before investigations unless you have discussed this with your stoma care nurse or doctor.

Some peppermint sweets, some cakes and drinks are sweetened with Sorbitol, which is a laxative, and should therefore be avoided.

Travel

Having a stoma will not prevent you from travelling, whether it is for pleasure or business, home or abroad.

Travel insurance

Travel insurance is a must when travelling away from home. There are many insurance companies offering travel insurance - remember to declare pre-existing diseases and illness and the fact that you have a stoma. This ensures that you are covered for all eventualities.

Within the EU (European Union) reciprocal agreements are in place to provide you with free emergency health treatment if you become ill. For the most up-to-date information and obtaining the necessary documentation, consult your stoma care nurse or local stoma association.

Ostomy travel certificate

This travel certificate is available from your stoma care nurse or local stoma association. The certificate will assist you when going through customs/airport security, if there is a need to explain about your stoma appliances. It has been translated into several European languages, but does not replace European Union reciprocal agreements or private travel insurance.

When travelling

Always take with you the size, name, order number and the manufacturer's name of your stoma equipment in case of need of replacement. It is also useful to have the telephone number of your stoma equipment supplier with you. Remove your stoma equipment from its boxes and put in clean plastic bags for easier packing.

If you are away for an extended period of time discuss with your stoma care nurse or stoma association how to contact a local stoma care nurse/local agent/how to get help if needed.



Every successful holiday takes planning!



Remember personal travel insurance is essential.





Always remember your travel kit!

Do not forget to have your travel kit readily available at all times (see page 36). Wear clothes that are comfortable and easy to remove when travelling.



Travel by air, hints and tips

- Always keep your ostomy products with you in your hand luggage, not in your checked in luggage.
- Remember to cut and prepare your stoma bags/flange/wafer before packing, because scissors must only go in the checked-in luggage.
- Pack twice as much stoma equipment as you would normally use.
- Prior and during travelling do not miss meals. Remember to drink plenty of fluids, be careful with alcohol and avoid fizzy drinks.
- It is useful to book an aisle seat.
- Think ahead, a meal trolley can make it difficult to get to the toilet.
- Security/seat belts must be used when told to. Try to position the belt below or above your stoma.

Travel by sea, hints and tips

- Toilet facilities are usually good on ferries. When the sea is rough the toilets can be very busy.
- On cruise liners the facilities usually include medical staff that may be able to help you in an emergency.

Travel by rail, hints and tips

- Most trains have toilets, you can check first if in doubt.
- Not all trains have buffet facilities so make sure you have plenty of fluid to drink and something to eat with you.

Travel by road, hints and tips

- There are usually toilets in service areas/petrol stations and most coaches have toilets.
- Do not leave your supplies in the car in hot weather, as the adhesive may start to melt.
- An insulated bag can be useful for carrying your stoma equipment during summer time/hot weather.

Attachments to adjust the tension of your seat belt are available (pregnancy seat belts)



Food and drink when travelling

A change in water, either in your own country or abroad, can cause a change in bowel habit. Only bottled water should be drunk outside your own country. Check that the bottle seal has not been tampered with by holding the bottle upside down to check for leaks.

To avoid travellers-diarrhoea be aware of what you are eating and drinking.

The following may cause problems

- Tap water and ice in drinks.
- Cleaning your teeth with tap water.
- Previously opened bottled drinks.
- Raw vegetables and fruits that you haven't peeled yourself.
- Salads.
- Shellfish.
- Cream, ice cream and mayonnaise.
- Buffet food, which has been left out for extended periods of time.
- Meat and fish, unless freshly cooked and piping hot.
- Be aware of inadequately cooked food at barbeques.

Always take Imodium (Loparamide) with you when travelling. If diarrhoea occurs avoid spicy foods and dairy products. You need to drink lots of fluids and take added salt with your meals. This is the one time that full strength Coca Cola and salted crisps are encouraged. Seek medical help if it continues for more than 24 hours.

Swimming

Many people enjoy swimming and there is no reason why having a stoma should stop you from doing this, in either a pool or the sea.

Swimwear for women comes in a variety of styles, designs and colours. Choose one that is suitable for you. For men, the boxer short style has a higher elasticated waist and comes in a variety of styles, colours and designs.

You may find that wearing a smaller version of your stoma bag is useful when swimming. If you plan to be in the water for a prolonged period of time you may want to apply additional adhesive tape around the flange/wafer for added security.



Chemotherapy and Radiotherapy

If your original surgery was for cancer it may be suggested that you need further treatment, such as chemotherapy or radiotherapy.

Chemotherapy drugs destroy cancer cells throughout the body, whereas surgery and radiotherapy are directed to where the cancer has originated.

Chemotherapy

Chemotherapy works by interfering with cancer cells' ability to grow within the body.

There are different ways of giving chemotherapy, e.g. by drip or mouth. Each course of treatment is specific and will be discussed with you by your oncologist (cancer specialist doctor).

People worry about the side effects of chemotherapy such as nausea and hair loss. There are good treatments for these side effects – you need to discuss this with your cancer specialist doctor.

Radiotherapy

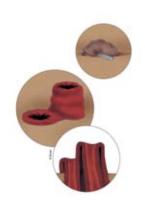
Radiotherapy works by directing radiation to the area where the cancer still is or has been.

Hints and tips during your chemo- and/or radiotherapy treatment

- Smoking may reduce the effect of your treatment.
- Remember to drink enough fluid.
- Refer to your post-operative food management advice and/or discuss with your stoma care nurse.
- Treatment may cause ulcers and soreness in the mouth and on the stoma.
- Your stoma may change in size and shape during your treatment courses.
- Contact your stoma care nurse for any further advice.







The temporary ileostomy has two distinct openings, one end where the stool comes out and the other end which is still connected to your bottom. This construction means that faeces can occasionally flow from one to the other. Therefore you may want to sit on the toilet and have your bowels open in the normal way.

Your surgeon will have explained to you how long you can expect to have a temporary stoma.

Hints and tips

- Your stoma may be oval and not round.
- Larger, oval shaped wafers/flanges may be required.
- You may need to change your stoma bag more often due to mucous from the non-functioning opening breaking down the adhesive quickly.
- Your stoma care nurse will be able to advise you on the appropriate type of stoma bag for your temporary stoma.
- You may find that your stoma appears to be bigger suddenly and this is called a prolapse and is not dangerous.
- A bulge around the stoma may indicate a hernia, contact your stoma care nurse for advice.
- A prolapse is an increased protrusion/lengthening of the stoma.
- If you think you have a prolapse or a hernia, providing your stoma is still functioning
 properly and you are not experiencing any problems with the performance of your
 stoma bag, there is no urgent need to see your stoma care nurse or surgeon.
 Your next routine appointment will do.
- Do not worry if your stoma bleeds when washed this is normal, because it has the same delicate texture as the inside of your mouth.



It is important to check your stoma size regularly as it may increase.

lleo anal pouch

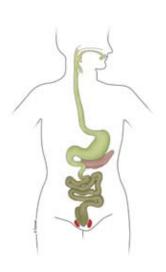
An ileo anal pouch may be an option to an ileostomy, but is not an alternative for everyone. During this procedure the colon and rectum are removed and a reservoir/pouch is constructed. To help healing you may need a temporary loop-ileostomy for a short period of time.

Following pouch construction and closure of the temporary ileostomy, continuity of the bowel function will be restored and you may empty your bowel between 4-8 times in a 24-hour period. This will be more frequent in the initial months until the internal pouch has adapted to its new function. You may need anti diarrhoeal medication to help control output.

Skin irritation and soreness around the anus is common. Cleansing of the anal area is therefore important after each bowel action, even during the night. Skin barrier creams can be applied to prevent skin irritation in this area.

Hints and tips

- · Use good quality white soft toilet paper.
- Dampen the toilet paper for wiping your bottom.
- Wash the area with soap and water, rinse and dry thoroughly.
- Drink plenty of fluid.
- Add salt to your meals.
- Excessive alcohol can cause dehydration.
- Avoid large quantities of caffeine based drinks (causes dehydration).
- Avoid nutty cereals and muesli (this will scratch the delicate lining of the internal pouch).
- Use a skin barrier cream that is designed for peristomal skin on your anal area.



Anal irritation may be caused by

- Spicy food
- Coconut
- Popcorn
- · Citrus fruit
- Nuts
- Apples
- · Coleslaw and celery
- Ground spices such as pepper (use powder spice)

Wind may be caused by

- Hunger
- Anxiety/stress
- Caffeine
- High fibre foods
- Too many carbohydrates
- Excessive intake of sugar
- Excessive intake of dairy products
- Sorbitol (alternative to sugar)
- Eating too fast
- · Talking and drinking while eating

Foods that may cause wind are

- Green beans, baked beans, winter root vegetables
- · Cauliflower, broccoli
- · Onions, garlic
- · Spinach, cabbage
- Sweetcorn, peas
- · Apricot, bananas
- Cucumbers
- Mushrooms
- Eggs
- Beer
- Pretzels

Food that may thicken output

- Marshmallows, jelly babies
- Jello/jelly
- Apple sauce (cooked apples)
- Smooth peanut butter
- Boiled white rice and pasta
- Buttermilk, eggs

Kits



Spare kit

A spare kit contains:

- A clean new stoma bag or stoma bag and flange/wafer (cut and ready for use)
- Bag clip if needed
- Non-woven wipes
- · Disposal bag

Travel kit

A travel kit contains:

- Hook
- Pegs
- · Wet and dry wipes
- · Hand washing
- · Stoma bags
- Wafers/flanges
- Any accessory products you may use

Support organisations

There are many stoma support organisations, ask your stoma care nurse for information and details.

My stoma care nurse is: _		
Hospital:		
Clinic times:		
Contact datails:		

Notes		

Notes			

Notes		

