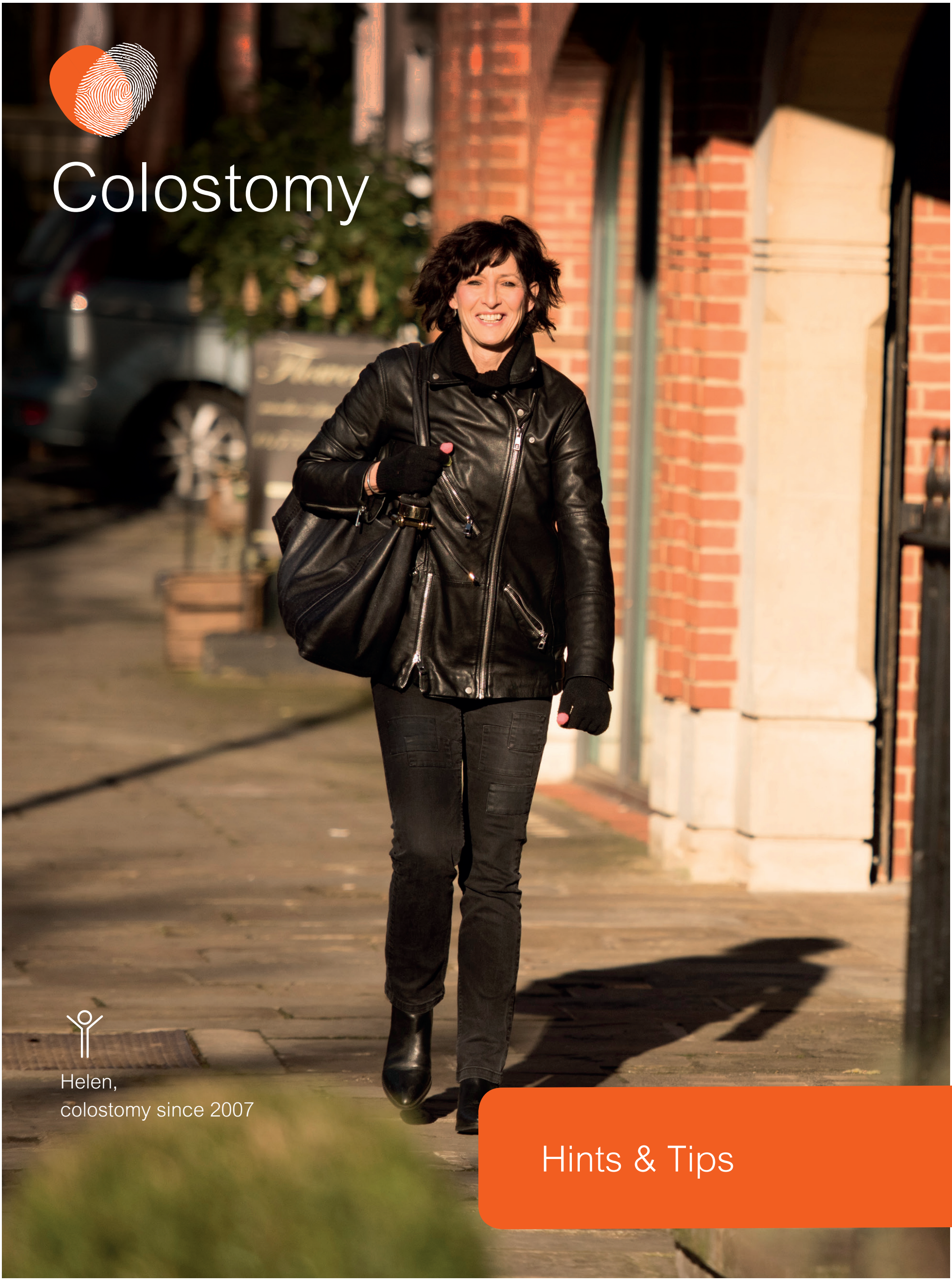
Colostomy



Helen,
colostomy since 2007

Hints & Tips

Dedicated to Stoma Care

dansac

Introduction

The word stoma originates from Greek and means “mouth or opening”.

Stoma surgery can be an overwhelming and emotional experience, and it can be difficult to know exactly what to ask and how to prepare.

With this booklet we hope to address your worries and concerns about having a stoma. We have provided general information and advice about living with a stoma to support your transition from the time before your surgery to going home.

The Hints and Tips booklet will hopefully make life with a colostomy easier for you.

We would like to thank Pat Black and Chris Hyde, Stoma Care Specialists, UK for their work on the original version of this booklet.

Global Clinical Marketing

Dansac A/S

INTRODUCTION

Jamie

”The staff at the hospital told me what a stoma was and how it works. I realised that a stoma could mean that I would avoid the daily problems I‘d been having throughout my life, as having a pouch on my stomach would allow me to control my bowel movements. I was immediately excited about this new idea because it sounded as though it would totally change my life - for the better! A stoma could also stop me from being teased and bullied. I could become a ’normal’ kid – I‘d be able to go out and play, ride a bike, play football – and wear boxer shorts just like all my friends.”

Jamie,
colostomy since 11 years old

CONTENTS

GENERAL INFORMATION
ABOUT YOUR STOMA AND YOUR SURGERY

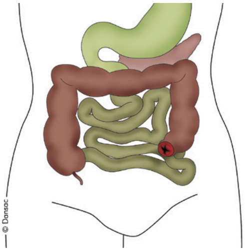
What is a colostomy (stoma)?

The word stoma originates from Greek and means “mouth or opening”. A stoma is the medical term used to describe when the bowel is brought through the abdominal wall, to form an opening on your abdomen where your stool is passed instead of the usual way through your rectum.

Stomas can both be temporary or permanent, depending on the reason for having a stoma.

There are three types of stoma and the type of stoma you will have is called a colostomy. A colostomy is created from the large bowel.

In order to understand how your colostomy looks and functions it may help to understand how our digestive system normally works.

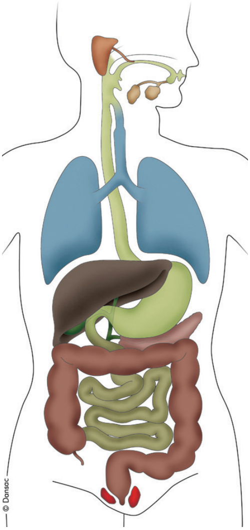


Colostomy

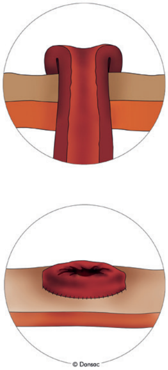
The digestive system

The digestive system – also known as the gastrointestinal tract – is the part of the body that digests food and produces body waste. (The different parts of this system start with the mouth, then the oesophagus, stomach, small and large intestine and finally the rectum. Along the way accessory organs (gall bladder, pancreas, liver) aid the digestion and absorption processes.

The digestive system is vital in maintaining health. Food swallowed through the mouth enters the stomach where it is churned and mixed with gastric juices. It is pushed into the small bowel (ileum) where your body begins to digest and absorb the nutrients it needs. The waste from this process moves forward into the large bowel where moisture is absorbed turning your body waste into a solid stool that you pass from your rectum. So, an ileostomy is a stoma formed from the small bowel and has fluid output because it has not been through the colon (large bowel) where the fluid is absorbed. A stoma in the large bowel (a colostomy) is in the latter stages of absorption and passes a solid stool.



Digestive tract



Stoma

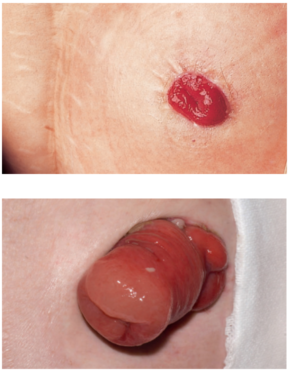
Why are you having a colostomy?

There are a number of different diseases and conditions that result in colostomy surgery. Some of the problems that lead to this type of surgery can be:

- Cancer
- Diverticulitis
- Trauma/Perforation
- Constipation
- Damage after radiation

Your doctor and stoma care nurse will have described and discussed the reason for your surgery, any further treatment you might have and why you need to have a stoma.

You may have questions and queries, so it is a good idea to keep a notebook or a patient diary to note them in. This way you will not forget to ask the important questions when attending appointments with your stoma care nurse/doctor/or other healthcare professional.



Stoma post-op

How is the stoma made?

A colostomy is made from the large bowel. The bowel is brought through the abdominal wall, turned inside out and stitched to the skin.

What will the stoma look and feel like?

The stoma is red and moist, the colour and texture are similar to the inside of your mouth. It may protrude a few centimetres, but stomas can also be flush (flat) with the skin. The stoma may be quite swollen immediately after the operation, but will usually shrink in size over the first 6-8 weeks after your operation. Please note that no two stomas are alike, every stoma is different.

There are no nerve endings in the stoma, so with little or no sensation, your stoma will not be painful to touch, but with a multitude of small blood vessels, it can easily bleed if knocked or rubbed (when washing for example). This is quite normal.

Dansac Personal Trainer Kit

Where will the stoma be?

Stoma siting is about finding the right place on the abdomen for the position of the stoma and marking this so the surgeon can see it during the operation.

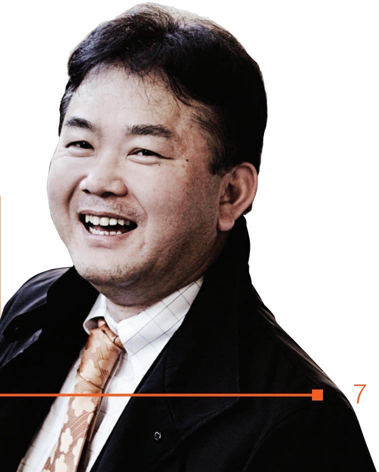
It is very important that the stoma is positioned correctly as it improves the fit of your appliance and comfort, and helps to ensure that you can wear your normal clothes after surgery and resume your normal activities.

Your stoma care nurse will usually do this with you before surgery. The stoma site should be marked in an area without skin creases or scars to improve the pouch fit and reduce the risk of leakage. After checking your abdomen in standing, sitting and lying positions, your stoma care nurse will mark the appropriate site.

It can be a good idea to practice with an artificial stoma and a pouching system before the surgery to check the position and learn how to open, close and change a pouch.

Kanji

”My physician sited three potential locations for my stoma the day before surgery.”



Kanji,
colostomy since 2004

Remember, there are no silly questions.

Keep a notebook!

Waking up with a stoma

When you wake up after surgery, your stoma will be swollen and you will probably be wearing a large clear drainable pouch which enables the medical and nursing staff to inspect your stoma post operatively.

You may also have drains, infusions, a urine catheter as well as an epidural catheter attached to your body.

You will probably feel weak and emotional, but please don't worry about this, it is perfectly normal and it takes a while to get over surgery.

Later, when your stoma is functioning and in preparation for discharge home you will have the opportunity to choose and fit a more appropriate pouch.

How does the stoma work?

A colostomy generally starts to function 2 – 5 days post operatively. The output, volume and consistency vary in each individual case and on the location of the stoma within the colon/large bowel. The average person with a colostomy would change/empty the pouch 2 – 3 times a day.

Care of your stoma and skin

The area around your colostomy, where your stoma pouch/appliance is attached, is called the peristomal area. The sticky area of your appliance is called the skin barrier (also flange or wafer) and 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.

It is the output from the stoma that may cause soreness of the peristomal skin and not the continuous use and removal of the skin barrier/pouch. If the peristomal skin becomes uncomfortable, itchy, red or sore, this may indicate some seepage of the stoma output onto the skin. Your appliance needs to be taken off, the area washed, rinsed and dried and a new appliance applied. You may need to review the fit of your appliance or contact your stoma care nurse if this problem is ongoing.

Remember, your stoma is unique to you.

Hints and tips

- Use kitchen towel to dry the skin
- 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/pouch.
- To aid adhesion of your skin barrier/pouch, you may find it helps to place your new clean skin barrier/pouch 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 roll-on 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 appliance.
- 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; contact your stoma care nurse for advice.
- 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.

- 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.

Changing your appliance

You will need

- Disposal bag
- Toilet paper and non-woven wipes for washing/drying
- Warm water for washing
- Fragrance free mild soap (if required)
- New pouch and/or skin barrier
- Scissors for cutting the skin barrier (if required)
- Any accessories you may use

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.

How to change the pouch

- Secure clothing out of the way (pegs and safety pins may help to hold clothes out of the way).
- Dampen a few non–woven wipes to help release the skin barrier.
- Remove the used stoma pouch 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
- 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 pouch/flange/wafer.
- Do not forget to carry your spare kit with you when leaving home (see page 45).

Always carry your spare kit when leaving home.

Disposal of products

If possible your stoma pouch should be emptied before disposal. The stoma pouch should then 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 pouch before placing in the appropriate bin.

Nappy sacks make good disposal bags for used stoma bags.

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.

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. 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. Do not share razors. Do not use hair removing creams or gels.

First days and weeks after surgery

At first, it will take time for you to adjust and learn to care for your stoma. While you are recovering from your surgery, you may feel as though you will be unable to cope. But as you recover and gain more strength, you will find it easier and become quicker and more efficient with your stoma care.

The first 2-4 weeks after returning 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 pouch 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.

Your tummy may still be swollen after surgery, so you may wish to keep your clothing loose for the first couple of weeks. Try to move every 2 hours, standing up and walking around the house or garden will help your general blood circulation and reduce the feeling of swelling 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
- Pushing a pram, pushchair, supermarket trolleys or wheelchair
- Digging the garden
- Lifting anything heavy (remember a full kettle can be heavy)
- Moving furniture or using the vacuum cleaner

Remember to renew your spare kit regularly.

Accept all offers of help (the offer may only come once).

You should not drive a car during the early weeks following surgery. We recommend you contact your insurance company to check if they have any specific guidance on returning to driving after abdominal surgery. The side effects of medication and anaesthetic can slow your reaction time and reduce concentration. Before returning to driving you need to be pain free so that you can perform an emergency stop.

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

Your progress will go up and down. In the beginning, you may feel that some days you take two steps forward and the next day take one step back. You may feel tearful, irritable and snappy. This is a normal reaction following surgery and during recovery.

Talking to your family and friends so they understand how you feel, can help reduce anxiety and help you to understand your emotions.

Remember to sleep, eat and drink regularly.

You may be at your best in the morning, getting gradually more tired as the day progresses. Remember to allow yourself some rest time each day so that you don't overdo it or you may feel exhausted by the evening.

Listen to your body and pace yourself.

Phantom rectum

It is not uncommon to experience the sensation of wanting to open your bowel in the normal way if 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.

Take an undisturbed afternoon sleep in bed.

Miriam

"I remember initially believing that my life was going to be heavily restricted by having the stoma and that my life, and in particular my social life, would drastically change. But I can honestly say that that has not been the case!"

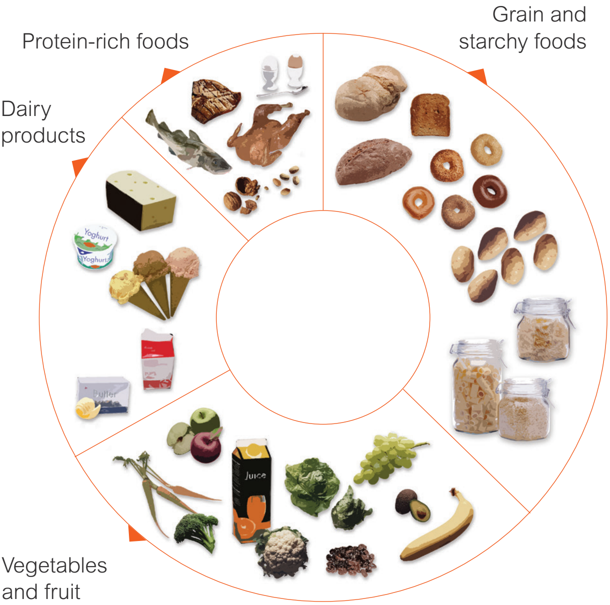
Food management

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. If you suffer with other medical conditions such a renal or cardiac problems or diabetes, you may need some additional dietary advice. Please discuss this with your stoma care nurse.

Drinking and eating at the same time may cause wind.

The Food Circle - for a balanced diet

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



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!).

Helen,
colostomy since 2007

After the first few weeks you should

- Enjoy 3 – 4 regular meals a day.
- 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 2 litres of water and other fluids are needed to hydrate your body. An easy way to remember this is to re-fill an empty 2-litre bottle with water each day and have this emptied by evening.

Hints and tips to avoid smell:

- If the stoma pouch is correctly applied there should not be any smell.
- When you have finished your stoma pouch change and everything is cleared away and the toilet is flushed, strike a match and blow it out straight away. This may help 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 pouch may help with odour.
- Proprietary odour absorbers (air freshener) to spray towards the bathroom ceiling.
- Drink buttermilk.

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
- Eggs
- Beer
- Foods containing lactose/wheat, if you have an intolerance
- Pretzels

Hints and tips to avoid wind:

- Charcoal tablets to be chewed
- Peppermint oil in hot water to drink or peppermint tea
- Fennel, to eat or drink
- Sage, to eat or drink
- Yoghurt or yoghurt drinks

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 should 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.

Simon,
colostomy since 2010

MEN:

Hints and tips:

- Trousers with waistband pleats will give more room across the stoma pouch 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 can be better.
- Some companies design specific clothing for men with a stoma, such as swimwear, underwear and high-waisted trousers.

Mariam,
colostomy since 2006

WOMEN:

Hints and tips:

- 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.
- You can still wear a support girdle after stoma surgery.

Lilljan,
colostomy since 1992

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.

Every successful holiday takes planning!

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.

Remember personal travel insurance is essential.

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 pouches 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.

Do not forget to have your travel kit readily available at all times (see page 45). Wear clothes that are comfortable and allow easy access to your appliance when travelling.

Always remember your travel kit!

Travel by air, hints and tips

- Always have enough ostomy products with you in your hand luggage, in case of emergency.
- Remember to cut and prepare your stoma appliance before packing, because scissors can 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.
- Try to position the seat belt below or above your stoma.

Lilljan,
colostomy since 1992

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.

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

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 skin barrier may start to melt.
- An insulated pouch can be useful for carrying your stoma equipment during summer time/hot weather.

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.

If diarrhoea occurs avoid spicy foods and dairy products.

Lilljan,
colostomy since 1992

Training & 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.

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. Set yourself small exercise goals each week to improve your strength and stamina gradually, such as walking for ten minutes and then fifteen minutes, or measure it by distance. 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!
- Set yourself a target each week to increase the amount of exercise you take.

Hints and tips to avoid wind:

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. A patterned or ruched panel on the front of the costume disguises the stoma well. 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 pouch 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 skin barrier for added security.

Mariam,
colostomy since 2006

Diny,
colostomy since 2007

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.

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

Hints and tips

- Eat and drink regularly during the day at work.
- If you are involved in heavy lifting at work, remember to wear a support belt while lifting (ask your stoma care nurse/health care professional).
- 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).
- Keep a spare change kit/pouches at work.

Emotional aspects of getting a stoma

Having a stoma formed may be as a result of an accident, long term disease, or a newly diagnosed illness needing acute or even emergency treatment. For some, a stoma can be perceived as a relief from severe inflammatory bowel disease and years of pain. Others will think of it as something unexpected and unwanted, which can make it more difficult to accept.

A stoma means a sudden major change in your body and in the way you see yourself and may impact your quality of life. No matter how much support and information you can get from skilled and helpful doctors and nurses, it will take time to adjust to this change and it is natural to experience sadness and grief, even anxiety and stress while you adapt to the new, but not really so different, you.

Sometimes you may struggle with thoughts like: “Why me?” or “What have I done to deserve this?” Thoughts and strong emotions can be difficult to put into words or to speak about. Experience shows that before we come to accept the inevitable and thus are ready to move on, we have to start by acknowledging our difficulties. Once we do, we can find countless examples of people who live full and satisfying lives with a stoma.

Lilljan,
colostomy since 1992

For most people living with a stoma means going through emotions like:

- Loss - in this case the loss of a bodily function, you are not in control of your bowel movements any more
- Low self-esteem
- Shame or embarrassment
- Thoughtfulness
- Anger
- Fear and/or anxiety

Graham

“The cancer tumour was first to be treated with chemotherapy followed by radiation therapy - and then a stoma. My reaction was: “Better a stoma than a coffin”. That’s how I am, I wanted to move on and refused to let fear and grief lead me because I am in no way finished living.”

Graham,
colostomy since 2006

Emotions and body image

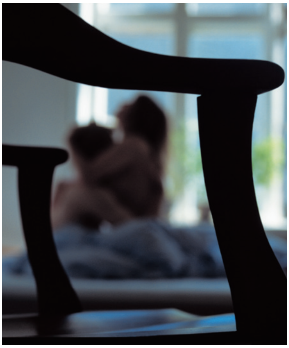
We all have a mental picture of our own body and this picture involves more than just size and shape. It includes the whole emotional and physical experience of the body, and stretches acrossthe range of pleasures and pains of being human. The delights of eating, drinking, sex, laughter, sleep, the distress of exhaustion, anxiety and pain, childbirth, the overwhelming feelings of being in love or in mourning, are all bodily experiences.

Most changes in the way we see ourselves take place gradually over a period of time, as in ageing. Stoma surgery makes both sudden and fundamental changes to your body, changes that will inevitably cause intense feelings and emotional reactions.

During childhood we learned to gain control over our toilet functions, an essential part of being an adult human. Losing control of that function changes your self-perception and can make you feel inadequate and different.

This may make you sensitive to how others will respond to your new stoma. You may feel shocked and surprised by your stoma so it is natural to think that others will feel the same way. Having a stoma does not make you any different when it comes to human relationships. It is important to remember that relationships are not determined by the shape and size of your body.

Remember that it takes time to adjust.



Sexuality & Relationships

No matter whether you are young, old, married or single, and regardless how active or inactive your sexual life is, accepting life with a stoma is of major importance to intimate relationships.

After surgery, it is normal and natural to feel anger, fear, and the need to be left alone. You may be angry at having an illness, and having to have surgery. You may have underlying fears that are hard to express; fear of the unknown, change in body function, loss of your life, your attractiveness and the fear of being unable to engage in sexual behaviour.

Since sexuality is intimately tied up with feelings, it is important to recognize these emotions of fear and anger and deal with them or they may lead to resentment and feelings of rejection. You may remain distant from the very people you care for and need most, and who care for you.

After surgery, while you are recovering and learning to manage your stoma, you may not experience any sexual feelings for days, weeks or even months. You may have feelings of shock and revulsion until you get use to your stoma, how it works and how to manage it. You may feel “different” or abnormal and unacceptable, fearing that your appliance smells, that the stoma is obvious to everyone, or that it makes you less attractive than you were before surgery.

Several things may make sex more difficult in the immediate post-operative period, e.g.:

- Anxiety or fear about your ability to perform sexually, the attractiveness of your body, the possibility of odour, or that the stoma pouch 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 and alcohol

As a result of surgery you are forced into dealing with your body in new ways and into talking about things you have never needed to discuss before. Your sex life is one of these things. Returning home after surgery is a time for healing and recovery, which may take priority over sexual adjustment. Yet there are specific things you can do to help yourself adjust sexually:

Talking about your feelings can be a great help.

Hints and tips

- Share your thoughts and needs with your partner.
- Continue to sleep together. Tell your partner the most comfortable position for you to lie in.
- Allow yourself to be touched and held. Affectionate touching can be very positive and reassuring during recovery.
- Show that you appreciate a warm and loving relationship. By remaining intimate and discussing issues openly, it is often easier for you and your partner to accept life with a stoma.

Mariam,
colostomy since 2006

Most people who undergo stoma surgery are concerned that the stoma may threaten their sexual attractiveness and the opportunity to have a satisfying sex life. You will probably experience a wide range of emotions that can change very quickly. You may want to be held and cared for. You may want to just touch, kiss or fondle your partner. You may not want to have anything to do with anyone. Tell important people in your life how you feel. Tell them that as soon as you begin to feel better, you will be willing to explore friendship, love and intimacy again.

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.

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 judgment. 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.

Making love

WOMEN

Pain during intercourse and lack of interest are not unusual and are usually temporary. The experience can be traumatic and frighten you into believing that your sexual desires and arousal have disappeared forever. On the other hand you may have begun to focus on sexual feelings while still in hospital. Both are normal and it is important that you and your partner understand this if worry or difficulties occur.

When making love, some women may like to wear a sexy mini-slip or short nightgown; crutch-less underwear can be purchased in many places (or made if you are handy with a needle and thread) to disguise and cover the pouch but leaving easy access.

All the conventional lovemaking positions are usually possible when you want to make love. 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 are aware of this so that you can ensure you have appropriate lubrication and perhaps try a position that avoids deep penetration initially.

Some advice during intercourse

- Vaginal dryness:
  - Try using saliva or a water-soluble lubricant.
  - Treatment with a hormone replacement.
  - Oestrogen cream.
- Pain:
  - Change of position during intercourse e.g. you can be on top of your partner. This will allow you to be in charge of the situation and you can easily stop if it starts to hurt.
- Sexual activity will not harm the stoma.
- As long as your appliance is secure, whatever positions you choose should not affect the stoma pouch, the cover or dislodge the appliance.
- A normal size appliance can be folded and taped into a smallershape (see picture).
- Do not mistake your partner’s concern for rejection.
- Any position that is comfortable for you is suitable for sexual activity.

Simon,
colostomy since 2010

MEN

Men may experience difficulty with erection and ejaculation, because the nerves and blood supply involved in male sexual function lie close together and may be bruised during any pelvic surgery.

Your mood can also affect your libido (sexual desire) and have an impact on your ability to have and sustain an erection. Retrograde ejaculation occurs when semen enters the bladder instead of going out through the urethra during ejaculation. The semen is then passed in the urine.

Inability to have an erection, discomfort during tercourse and lack of interest for these reasons are not unusual and are usually temporary. The experience can be traumatic and worrying and frighten you into believing that your sexual desires and arousal have disappeared forever. It is important that you and your partner understand this is likely to be temporary but that if you are concerned you should discuss this with your doctor or stoma care nurse.

Depending on what type of ostomy product you are using, there are several things you can do to make them more discreet. The one important thing to remember is to empty the appliance before making love or to put on a new appliance.

You may want to wear a T-shirt, or to secure the appliance to your body by using band aid strips and /or a cotton cover. This may also stop it rubbing on your and your partner's skin.

When making love, you and your partner might be afraid of hurting the stoma or dislodging the appliance. Intercourse will not harm the stoma and, as long as you have put on your appliance securely, whatever positions you choose should not affect the adhesion of the stoma pouch. However it is useful to know that reaching orgasm can stimulate the stoma to be more active.

Medication

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.
- Do not insert any form of medication into your stoma except under the supervision of your stoma care nurse.
- Seek advice from your pharmacist or stoma care nurse.

Example of some drugs that colour urine/stools

Antacids (indigestion medication) → Colostomy/ileostomy output grey

Warfarin → Urine orange

Some anti-depressants → Urine blue-green

Iron, charcoal, some blood pressure pills → Stools black

Antibiotics → Stools green or urine reddish-brown

Diarrhoea

If you have loose watery stools and need to change your stoma bags more often than usual, this may be caused by illness, tummy upset/food poisoning. If it continues for more than 48 hours you should consult a doctor.

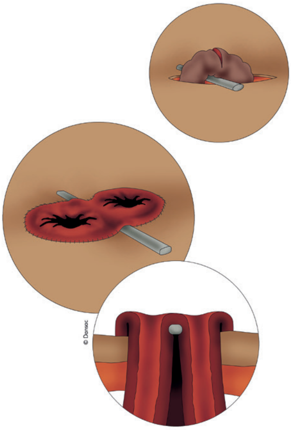
You may find it helpful to wear a drainable stoma bag due to the increased watery output from the stoma.

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

Hints and tips

- Under ripe bananas
- 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
- Arrowroot

Your colostomy may not work every single day, although they invariably do.
If after 3 days, there is no colostomy output and/or you feel unwell consult your doctor or stoma care nurse.



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Temporary colostomy (loop colostomy)

The temporary colostomy 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 flow into the opening that is still connected to your bottom. 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.

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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 - this is called a prolapse and is not dangerous.
- A prolapse is an increased protrusion/lengthening of the stoma.
- A bulge around the stoma may indicate a hernia, contact your stoma care nurse for advice.
- 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.

Colostomy irrigation

Irrigation is a method of emptying the bowel/colon of faecal content by instilling water via the stoma. Regular irrigation enables many people with a colostomy to control their bowel function. It is advisable to discuss with your surgeon if this method is suitable for you.

Irrigation should always be taught by a stoma care nurse.

Irrigation requires access to a toilet and clean water for at least one hour. Normally, this is necessary at a regular time every one or two days. It usually takes 2 to 3 weeks to establish a routine.

Hints and tips

- Irrigate at regular intervals.
- Create a calm and undisturbed atmosphere.
- Discontinue irrigation during illness or diarrhoea. You can resume when well again.
- Peg your clothing out of the way for convenience and hygiene when irrigating.
- Remember that alcohol can dehydrate you and your bowel may absorb a lot of the irrigation fluid, resulting in failed irrigation.
- If your household water goes through a water softener, you should not use this water to irrigate.

Difficulties inserting the cone:

- Try to relax.
- Move the cone around in the stoma opening.

Discomfort or pain when inserting the water:

- Stop water flow.
- Gently massage abdomen.
- Water should not flow in too fast.
- Make sure that the water is neither too hot nor too cold.
- Try to move around and change position.

Lilljan,
colostomy since 1992

If the water doesn't flow in:

- Increase the height of the water container.

If the water doesn't flow out

- Try changing your position.
- Move around.
- Try having a hot drink.

If stoma works between irrigations:

- You may need additional time to complete your irrigation procedure successfully.
- You may need shorter intervals between irrigations.
- You may need to increase the amount of water used.

1-piece appliance

When travelling:

- Always carry irrigation set, sleeves and appliances in hand luggage.
- Remember hanger or hook with adhesive to hang up water container.
- Use only safe drinking water or still bottled water to irrigate.

Contact your stoma care nurse if you need any help.

2-piece appliance

Pouching systems

There are 2 systems to choose from – a one piece system and a two piece system.

A one piece system consists of a pouch with an integrated skin barrier.

A two piece system consists of a pouch and separate skin barrier or wafer that are securely connected by a coupling ring.

Kits

Spare kit

- A clean new stoma pouch or stoma pouch and skin barrier (cut and ready for use)
- Pouch clip if needed
- Non-woven wipes
- Disposal bag

Travel kit

- Hook
- Pegs
- Wet and dry wipes
- Hand washing gel
- Stoma pouches
- Skin barriers
- Any accessory products you may use
- Disposal bag
- Scissors

Other sources of information from Dansac

- Your Personal Journal
- What about sex?
- Getting fit after surgery
- Teen with a stoma
- Care at Home Ileostomy
- Skin Essentials brochure
- Websites

  - www.dansac.com.au

  - www.dansac.co.nz

  - www.estoma.com

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Dansac Australia
PO Box 375
Box Hill, 3128
Victoria, Australia
1800 880 851
www.dansac.com.au

Dansac New Zealand
PO Box 62-027
Mt Wellington
Auckland
0800 678 669
www.dansac.co.nz

dansac