



Stoma  
Skin  
Soul



## Ileostomy Hints & Tips

Shelley, Ulcerative Colitis Survivor

# Introduction

## Hints & Tips Ileostomy

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.

“Having my colon removed means that my quality of life, as far as my bowel condition goes, is much better, and that’s obviously lead on to everything else that I think I am now; which is a confident person, a great mum and a patient advocate, and hopefully an inspiration to other ostomates. The basis of that is survival. I think I had to survive to get through all of these other things that now make who I am.”

**Shelley, Ulcerative Colitis Survivor**

The information contained in this brochure is provided as general information only and is not intended to be medical advice. Please see our website for the most up to date information, as guidance can and does sometimes change. Always follow product Instructions For Use and ask your health care professional for more information.

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# General Information About your stoma

## What is an ileostomy (stoma)?

A stoma is a surgically created opening in the gastrointestinal tract or within the urinary system.<sup>1</sup>

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

There are three types of stomas and the type of stoma you will have is called an ileostomy. An ileostomy is created from the small bowel.

The purpose is to allow stool to pass through an opening on your abdomen instead of the usual way through your rectum.

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



Digestive tract

## 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 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.<sup>2</sup>



Ileostomy

# General Information Having an ileostomy

## Why are you having an ileostomy?

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

- Ulcerative colitis
- Crohn's disease
- Familial adenomatous polyposis
- Trauma/perforation
- Cancer

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

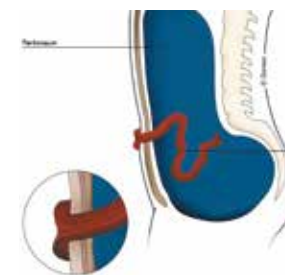
## How is the stoma made?

An ileostomy is made from the small bowel. The bowel is brought through the abdominal wall, turned inside out and stitched to the skin.<sup>3</sup>

## 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.<sup>3</sup>

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.<sup>3</sup>



Ostomy Sideview



Stoma post-op

## General Information

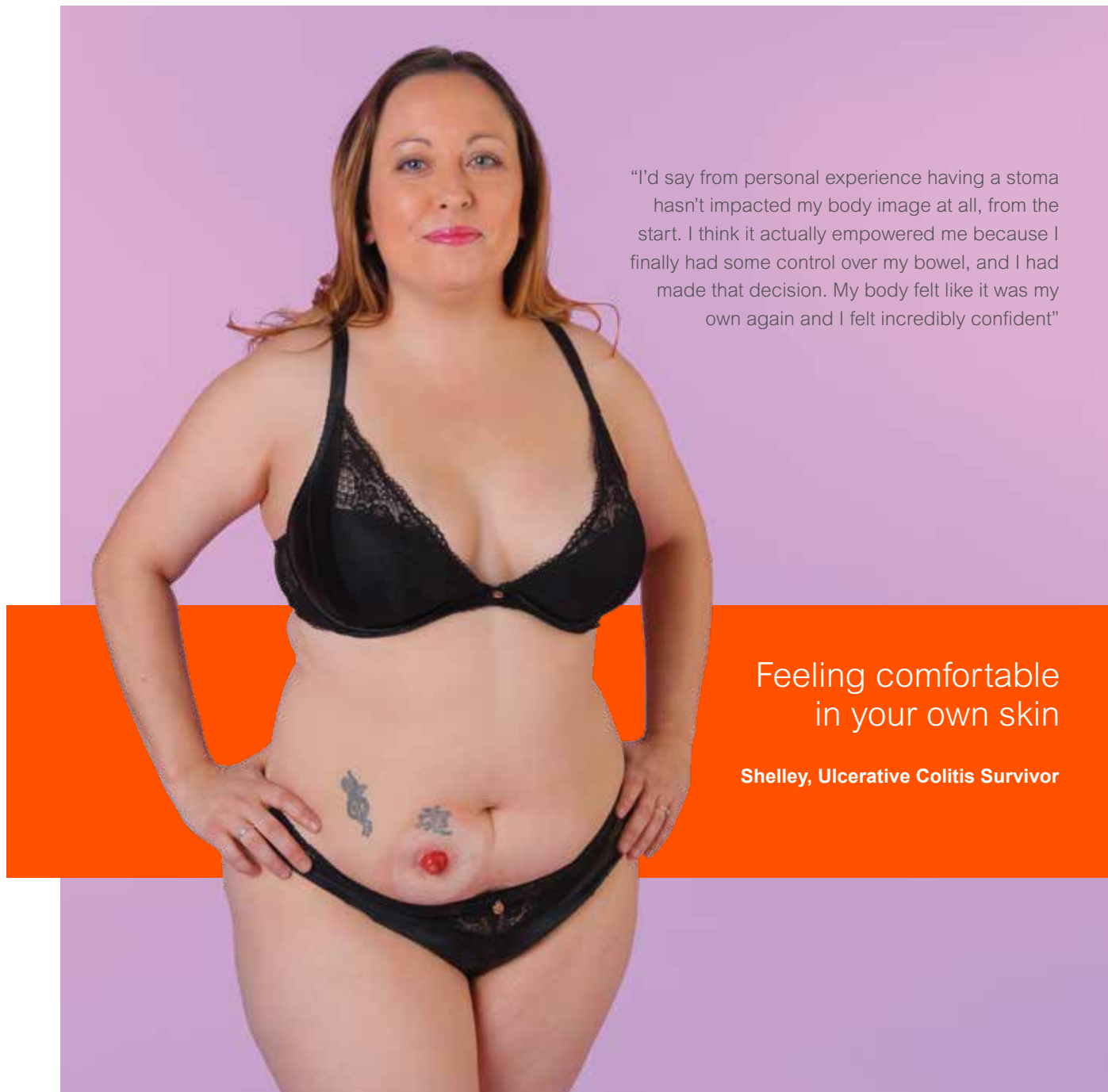
### Where will the stoma be?

It is very helpful that the stoma is positioned correctly as it improves comfort and the fit of your ostomy pouching system/appliance, and helps to ensure that you can wear your normal clothes after surgery and resume your normal activities.<sup>4</sup>

Your stoma care nurse will usually do this with you before surgery. The stoma site should ideally 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.

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.

You may have an opportunity to see an artificial stoma, practice applying a pouch and learn how to open and close the pouch.



"I'd say from personal experience having a stoma hasn't impacted my body image at all, from the start. I think it actually empowered me because I finally had some control over my bowel, and I had made that decision. My body felt like it was my own again and I felt incredibly confident"

Feeling comfortable  
in your own skin

Shelley, Ulcerative Colitis Survivor

## In Hospital

# The first days after surgery

### Waking up with a stoma

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

You may also have additional equipment such as drains, infusions and a urinary catheter.

Initially you may feel weak and emotional. This is perfectly normal as it can take a while to get over surgery.

Later, when your stoma is functioning and in preparation for discharge home your stoma care nurse will help you choose and fit the most appropriate pouching system to meet your needs.

### How does the stoma work?

The waste in your small bowel is usually liquid. The function of the large bowel is to absorb this liquid to make stool thicker. When your large bowel has been removed or bypassed this cannot happen, and the output from the ileostomy will therefore still contain liquid.

Depending on what you eat and drink the output may vary between being watery or a thick, mushy consistency like porridge. Wind will also pass into your pouch.

You may find that your ileostomy functions a few hours after each meal and possibly during the night. Wearing a drainable stoma pouch allows you to empty it regularly. It is important that you do not let your pouch overflow.

## In Hospital

# Care of your stoma

### Care of your stoma and skin

The skin around your ileostomy where your stoma pouch is attached, is called the peristomal area. The adhesive area of your pouch is called the skin barrier and is designed to protect the peristomal skin from the damaging effects of stoma output.

Ileostomy output contains digestive enzymes which are known to cause damage to peristomal skin.

If the peristomal skin becomes uncomfortable, itchy, red or sore, this may indicate some seepage of stoma output onto the skin. If this is occurring contact your stoma care nurse to ensure the best fit for you to avoid leakage under the barrier. If you have leakage, it is recommended that you remove your pouch, clean and dry the peristomal skin and apply a new pouch to your skin. You may need to review the fit of your skin barrier or contact your stoma care nurse if this problem is ongoing.<sup>5</sup>

### 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 that are securely connected by a coupling ring.



Remember, there are no silly questions.



Keep a notebook!



Remember, your stoma is unique to you.

## The Early Days Hints & Tips



- Use non-woven wipes or kitchen towel to dry the skin.
- Many stomas are not round, therefore make sure the skin barrier fits as snugly 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.
- Care must be taken when applying peristomal skin creams. They are often greasy and may prevent the skin barrier from sticking to your skin.
- 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.
- 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 skin barrier 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.

Prior to use, be sure to read the Instructions for Use for information regarding Intended Use, Contraindications, Warnings, Precautions, and Instructions. (See inside back cover).

## In Hospital Changing your appliance

### Changing your appliance

#### You will need:

- Disposal bag
- Non-woven wipes for washing/drying
- Warm water for washing
- New pouch and/or skin barrier
- Scissors for cutting the skin barrier (if required)
- Any accessories you may use



### How to change the pouch

- Secure clothing out of the way (pegs and safety pins may help to hold clothes out of the way).
- Empty your stoma pouch.
- 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.
- Place the used pouch into a disposable bag, tying a knot before placing into a waste bin.
- Wash the stoma and surrounding skin with your dampened non-woven wipes/paper, if you notice some blood on your wipe, be assured this is normal.
- Dry the 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 skin barrier.
- Position the skin barrier over your stoma. Gently press and smooth down with your fingers from the centre to the edge.



When washing the peristomal skin, 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.



## In Hospital/Going Home Disposal

### Disposal of products

Where possible it is good practice to empty your stoma pouch and place in a disposal bag. Please seal before placing in a rubbish bin.

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

### 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.<sup>6</sup>



## Going Home Living with a stoma

### First days and weeks after surgery

At first, it will take time for you to adjust and learn to care for your stoma. But as you recover and gain more strength, you will find it easier, becoming increasingly more confident with your stoma care over time.

The first 2 to 4 weeks after returning home, your daily routine may be slower. 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.

Your abdomen may be swollen and tender after surgery, so wear clothes that make you feel comfortable.

Try moving around regularly, 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. Herniation may be a concern in the early days following surgery. Other support literature is available - please ask your stoma nurse for further advice.

It is often advised not to drive your car during the early weeks following surgery. Seek advice from your stoma nurse. It may be useful to contact your insurance company to check if they have any specific guidance on returning to driving after abdominal surgery.

### Phantom rectum

Following stoma formation it is not uncommon to experience the sensation of wanting to open your bowel in the normal way. If you still have your rectum it can help to sit on the toilet and some mucous or stool may pass. If your rectum has been removed it sometimes helps to just sit on the toilet for the sensation to pass.<sup>7</sup>



Nappy sacks make good disposal bags for used stoma bags.



- Remember to renew your spare kit regularly.
- If you find you are tired in the afternoon it's OK to take a rest in bed.

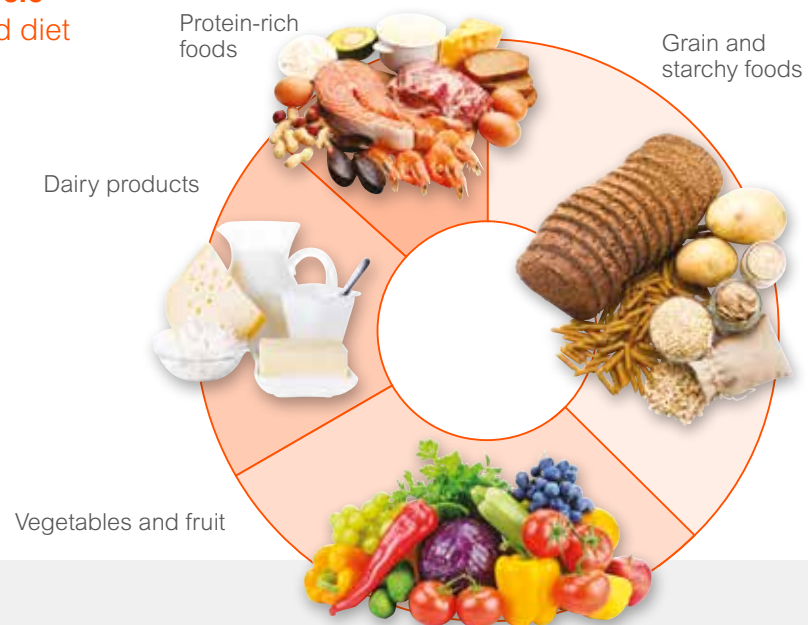
## Going Home

# 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 have any concerns regarding your diet, please discuss this with your stoma care nurse.

### The Food Circle for a balanced diet



### After the first few weeks you should

- Enjoy 3-4 regular meals a day.
- Balance your food intake, try a bit of everything from the food circle.<sup>8</sup>
- Introduce new foods gradually.
- Drink plenty of fluids unless advised otherwise from your health care professional.



Joshua



Always remember to drink plenty fluid each day. It is important to maintain adequate hydration, unless advised otherwise from your health care professional.



# Going Home

## Food management

### Loose watery output

If you think your diarrhoea (loose, watery stools) is caused by illness, tummy upset/ food poisoning, or if the output is more than you would usually see, you should consult your doctor or stoma care nurse.

### Gas/Wind/Flatus

Some people produce more wind than others. If you experienced problems with wind before the surgery this may 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.<sup>9</sup>

### Hints and tips to avoid smell:

- If the skin barrier is secure to your abdomen there should be no 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.

### Foods that may cause wind are:<sup>9</sup>

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

- Green beans, baked beans
- Cauliflower, broccoli
- Onions, garlic
- Cabbage, spinach, brussel sprouts
- Eggs
- Beer and fizzy drinks
- Some spices

## Ileostomy Obstruction/blockage



Some high fibre foods may contribute to blockage<sup>10</sup>

- Celery
- Coconut
- Corn
- Nuts
- Dried fruit
- Popcorn



Drinking and eating  
at the same time  
may cause wind.



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

# Going Home 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 to include the fact that you have a stoma. This ensures that you are covered for all eventualities.

## 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.



Helen

## Traveling By Air Hints & Tips



- Always have enough ostomy or stoma products with you in your hand luggage, in case of emergency.
- Remember to cut and prepare your skin barrier 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, unless advised otherwise by your health care provider, be careful with alcohol and 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.



Every holiday takes planning!



Remember personal travel insurance is essential.

## Traveling By Road Hints & 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 barriers can be sensitive to extremes of heat and cold.

### Food and drink when travelling:

A change in water, either in your own country or abroad, can cause a change in bowel habit. It may be useful to check the visiting country advice regarding food and drink. Follow your regular balanced diet, whilst ensuring you remain hydrated. When in hotter climates it is likely that you will need to drink more water. If you have any concerns about your diet whilst traveling consult with your stoma care nurse.

## Going Home Living with a stoma

### 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.



Pia



- 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.

## Swimming Hints & Tips



- 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 comes in a variety of styles, designs and colours, find what works best for you.



Lauren

## Going Home Going back to work

Your return to work will depend upon your recovery from surgery.

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.

"Together with the stoma care nurse we found the right place for my stoma. It was important for me, that I still could wear my uniform as a policeman."



Scott



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).



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

# Going Home

## Emotions and sexuality

Going through a life-changing illness or injury can create a significant imbalance to your 'normal' world. It can affect your body and your mind and can impact those you love and who love you. How you respond and how you are supported may be influenced by many factors, including the presence of or absence of a partner, the family whom you grew up with (and whether they are close to you now), your personality, your religion, community or social network, and your earlier life experiences.

Who you are, what is important to you and what you expect from life are very personal things. You are unique - and so is your sex life. How much you express and value your sexuality, celebrate and enjoy its place in your life is also different for each person and for that reason, there is no 'normal' when it comes to sex. Different people have different needs and your 'normal' is what is right for you.

One thing you can be certain of is that anything you discuss with the stoma care nurse will be dealt with sensitively and confidentially. If your stoma care nurse feels that someone else might be able to help, or that you would benefit from a referral to another health care professional this will always be discussed with you first. For further information on body image, feelings, relationships, sex and sexuality please ask your stoma nurse for a copy of the Dansac booklet "Your sexual self - after stoma surgery" or by contacting Dansac UK using the number at the back of this booklet.



# Other

## Helpful advice & links

### Medication

Some medications are absorbed at the beginning of the small bowel. Many factors influence the absorption of drugs into the body depending on the type of dosage and the way it is taken. It may be useful to discuss any medication you are taking with your stoma care nurse.<sup>11</sup>

For more sources of information from Dansac, please go to: [www.dansac.com](http://www.dansac.com):

- Living with a stoma
- Contact us



- Confidence comes from getting to know your body again and accepting the changes, as well as having faith in your pouch.
- If you are worried about baring your body entirely, wearing a top or tee shirt or stoma belt, or choosing a pouch cover may help when it comes to lovemaking.



- It is advisable to empty your pouch before intimacy. Sexual activity will not hurt your stoma.
- If you do not feel you are ready for intimacy, talk about it, suggest a time for reviewing the situation and start courting again.





Feeling comfortable  
in your own skin

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*Dedicated to Stoma Care*