

Stoma
Skin
Soul

Urostomy Hints & Tips

Jim, Cancer Dynamo

Introduction

Hints & Tips Urostomy

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 had a stoma now for 10 years, it’s difficult to think back to when I didn’t have it. It’s something you will grow into.

You can definitely still enjoy yourself. There are some limitations but as far as I’m concerned the advantages outweigh the limitations.”

Jim, Cancer Dynamo

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.

Contents

General information about your stoma and your surgery	4
What is a urostomy (stoma)?	4
Why are you having a urostomy?	5
What will the stoma look and feel like?	5
Where will the stoma be?	6
In hospital – The first days after surgery	8
Waking up with a stoma	8
When does the stoma work?	8
Mucous	8
Care of your stoma and skin	9
Hair removal around the stoma	9
Pouching systems	9
Changing your appliance	11
How to change the appliance	11
Disposal of products	12
Going home – Living with a stoma	13
First days and weeks after surgery	13
Food management	14
Travel insurance	16
Ostomy travel certificate	16
When travelling	16
Training & exercise	19
Going back to work	21
Emotions and sexuality	22
Other helpful advice and links	23
Medication	23
Night drainage bag	25
Obtaining a urine sample	25
Phosphate deposit	25
Treatment	25

General Information

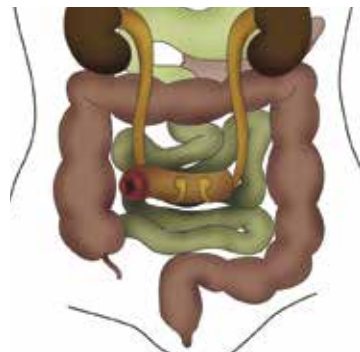
About your stoma

What is a urostomy (stoma)?

There are three different types of stomas: colostomy, ileostomy and urostomy. A stoma is a surgically created opening in the gastrointestinal tract or within the urinary system.¹

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 - a urostomy.

When your bladder is removed, or bypassed, you will need a new way to pass urine. Part of the bowel will be used to divert the urine from your kidneys to the abdominal wall. This new opening is called a urostomy, and is for passing the urine from the body.²



Urinary function after stoma surgery

General Information

Having a urostomy

Why are you having a urostomy?

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

- Congenital problems such as spina bifida, cerebral palsy or malformation of the urinary system.
- Neurological problems or injury to the spine.
- Gynaecological problems.
- Severe incontinence or urinary retention.
- Bladder Cancer.

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.

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. 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. Please note that no two stomas are alike, every stoma is different.³



Stoma



Stoma post-op

General Information

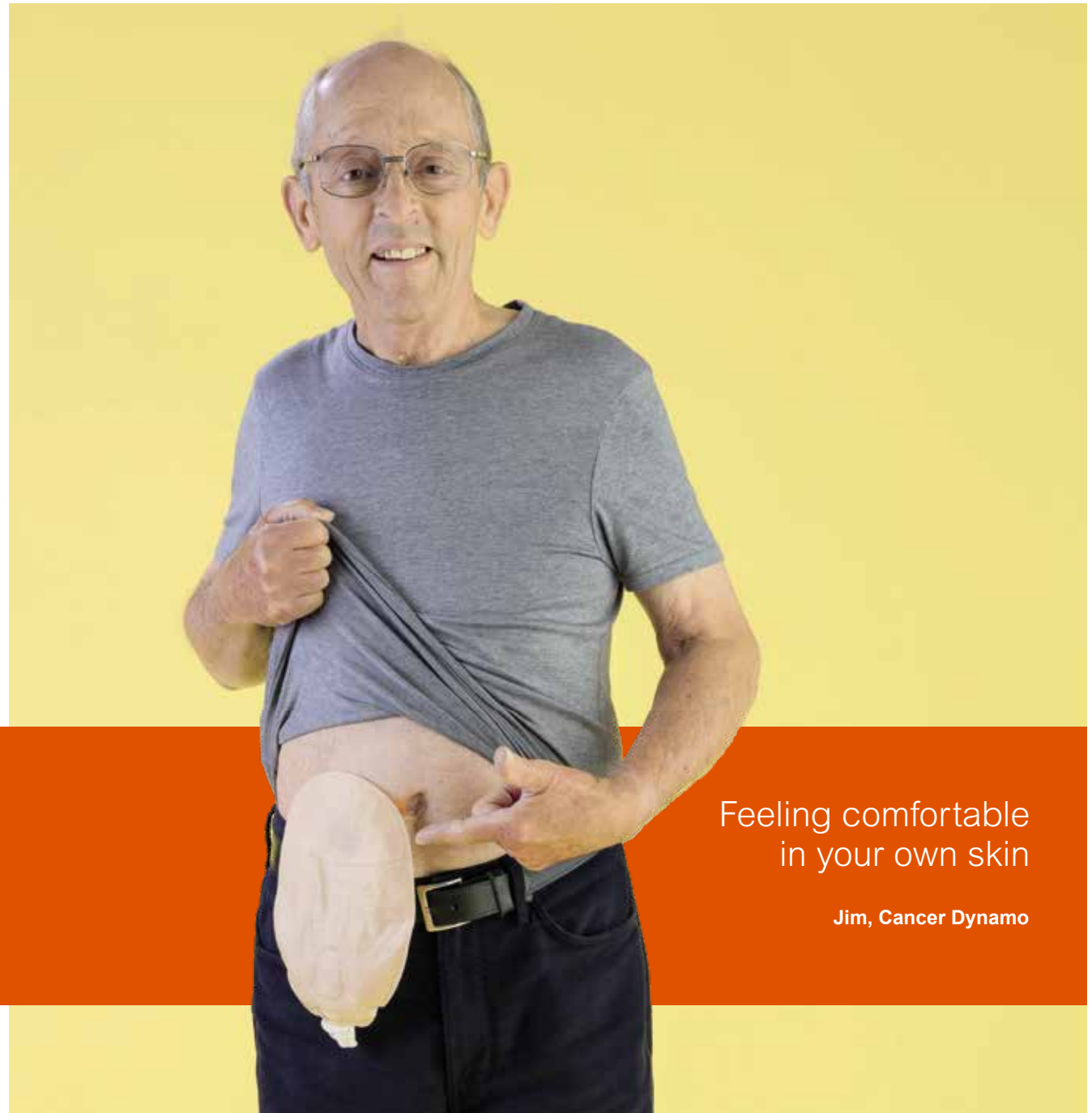
Where will the stoma be?

It is advantageous 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.⁴

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.



Feeling comfortable
in your own skin

Jim, Cancer Dynamo

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 will be wearing a clear pouch which enables the medical and nursing staff to inspect your stoma post operatively.

You may also have drains and infusions. 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.

When does the stoma work?

A urostomy will generally start to function immediately after surgery. The volume will vary in each individual case. At first, the urine may have a slight reddish colour. However, after a few days, the urine will return to its normal colour.

Mucous

Your urostomy is made from a piece of bowel which will continue to produce mucous. The mucous, which is white and sticky, will be passed into the stoma bag and can easily be mistaken for signs of infection.⁴

In Hospital

Care of your stoma

Care of your stoma and skin

The skin around your urostomy, where your stoma pouch is placed, is called the peristomal area. The sticky area of your pouching system is called the skin barrier 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 or pouch. If the peristomal skin becomes uncomfortable, itchy, red or sore, this may indicate some seepage of the stoma output onto the skin. Your pouching system needs to be taken off, the area washed, rinsed and dried and a new pouching system applied. You may need to review the fit of your pouch or contact your stoma care nurse if this problem is ongoing.⁵

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.⁶

Pouching systems

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



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 pouching system 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 appliance

- Secure clothing out of the way (pegs and safety pins may help to hold clothes out of the way).
- Empty your pouch.
- Dampen a few non-woven wipes to help release the skin barrier.
- Remove the used pouch carefully, from top to bottom supporting the skin with the dampened non-woven wipes.
- Wash the stoma and surrounding skin with your dampened non-woven wipes.
- 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/skin barrier.
- Place the used pouch into a small disposal bag, tying a knot before placing into a waste bin.
- Do not forget to carry your spare kit with you when leaving home.



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 pouch and place in a disposal bag. Please seal before placing in a rubbish bin.

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



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 and become quicker and more efficient with your stoma care.

The first 2 to 4 weeks after returning home, your daily routine will 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.

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.

Peristomal 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.



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.

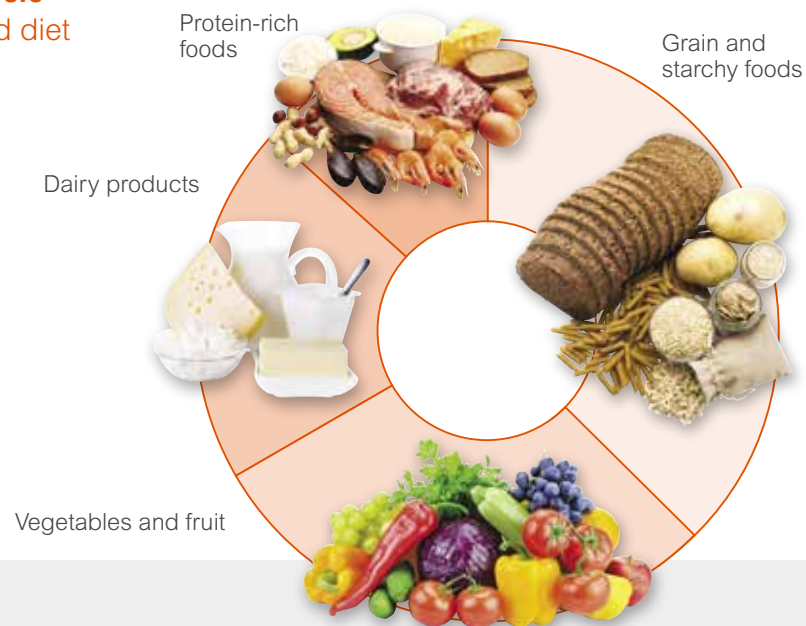
Going Home

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 to eat a bit of everything from the food circle.⁷
- Eat fruit and vegetables each day.
- Drink plenty of fluid unless advised otherwise from your health care provider.

Managing odour



Most people with a urostomy can enjoy a completely normal diet. Some foods such as asparagus and seafood, nutritional supplements, and some medications can cause your urine to have a strong odour.



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

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 and 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 the size, name, order number and manufacturer's name of your stoma equipment with you in case you need replacements. 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 this may affect the skin barrier.
- Keep a night drainage bag handy in case of unexpected traffic.

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 travelling please refer to your stoma care nurse.

When travelling and staying in other accommodation try the following to support your night drainage bag:

- Take a spare pillowcase and two large safety pins. Place the night drainage bag into the pillowcase and attach the pillowcase to the bed/mattress with the safety pins.
- Take a plastic carrier bag without safety holes in it and place the night drainage bag in the carrier on the floor, in case of leakage from the night bag.
- Some stoma bag appliance manufacturers may supply a flat-pack plastic night stand.

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 on 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 from the next 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 'What about sex?' or by contacting Dansac using the number at the back of this booklet.



- 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, 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.
- If you do not feel you are ready for intimacy, talk about it, suggest a time for reviewing the situation and start courting again.

Night Drainage Bag Hints & Tips



- When connecting the urostomy bag to your night drainage system, make sure that you leave some urine in the urostomy bag so that when you connect up this urine flows into the night drainage bag. This will help to prevent airlocks, vacuum and twisting of the urostomy bag, night drainage bag and tubing at night time.
- Some night drainage bags are single-use only. To empty cut the bag open and drain the urine before disposing.
- Empty the re-usable night drainage bag.
- Rinse bag and tubing with clean water, and hang to dry. Wipe outside of bag and tubing with damp cloth as needed.
- Discard when visibly damaged or stained.

Feeling comfortable in your own skin

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