

**This booklet is dedicated to those
who have throughout the years
provided their knowledge and experience
so that we may all benefit**

This booklet has been compiled by

**†
Jennie Archer
Stoma Care Department
St Mark's Hospital**

**Aided by
"Inside Out"
Stoma Support Group**

I had my colostomy not long after I was born. I live a very active and full life: I eat and drink to my heart's content. I travel near and far, without any major problems. I have worked in a very physically demanding job. I am married to a wonderful, understanding lady and have an eight-year-old son. Just before his birth I received a urostomy, which now gives me a greater balance. (*aged 54*)

"I live a full and normal life; I eat and drink what I want, I travel, work full-time, have relationships with men and try to live life to the full" (female ileostomy patient aged 25)

GENERAL TIPS

- Always keep your stoma care equipment in a cool place
- Order appliances well in advance (keep a minimum of 2 weeks supply), but don't keep excessive stocks.
- If an appliance belt is worn, always wear it at stoma level to avoid upward drag.
- Always carry a spare kit in your handbag or pocket (can include pouch, flange if used, a clip if used, rubbish bag, wipes and an air freshener if used).
- Hypoallergenic baby wipes are useful for cleaning when out, if there is no water, but plain water is better for general cleaning with either soft wipes or kitchen roll.
- Keys for disabled toilets are available from RADAR by telephoning them on 020 7250 3222 – cost currently £5.
- Mattress covers for single and double beds are available through Salts Medilink for extra protection and peace of mind when on holiday, staying with friends or at home. For details ring Salts Medilink on 0800 626 388.
- Learn your limitations and accept that you are not superhuman. There will be times when you are pushed to the limit, so when you need time out, take it.
- If you experience a little blood appearing when you wash or clean your stoma, don't worry. This is quite normal, due to the blood vessels being very superficial and easily damaged. Try being more gentle with cleaning. This bleeding usually stops after a few minutes.
- If you notice blood coming out of the stoma aperture, get in touch with your doctor or stoma care nurse as soon as possible.

SOLUTIONS TO PROBLEMS

Will I smell, now that I have a stoma? NO! If the appliance is fitted properly there should be no odour, except when changing or emptying the appliance. When changing the appliance a deodorant spray can be sprayed into the air, before the appliance is removed.

(Colostomy - [http://www.colostomy.com](#)) - this is because if the bag has a filter, to release the wind, there is carbon in the filter that absorbs the smell. Some foods can make the faeces smell more, and some foods can reduce odour, this is discussed below.

(Urostomy) – if the urine changes smell, you may have a urine infection, see your GP.

Food that may increase the odour of your faeces:-

asparagus, baked beans, broccoli, Brussels sprouts, cabbage, cauliflower, cucumber, eggs, fish, garlic, green vegetables, onions, peanut butter, some spices, strong cheese

Avoid these foods if the smell is unacceptable to you, but remember that you can only smell the faeces when you change your appliance.

Food that may reduce the odour of your faeces:-

Peppermint oil capsules, fresh parsley, charcoal tablets (available from health food stores), yoghurt and buttermilk, help reduce the smell for some people. A soluble aspirin or some vanilla essence can be placed in a colostomy or ileostomy appliance to help prevent troublesome odours.

Vinegar added to fish dishes helps to eliminate the traditional fishy odour, and also helps to get rid of fish smells at clean up time.

Will my stoma always be so noisy? At first your stoma will pass a lot of wind (flatus), but this soon settles down, especially once you begin to eat 'normally'.

What makes your stoma produce wind? There can be a variety of reasons that your stoma may be 'windy'. If you were prone to wind before your operation, you will still, probably, get wind now you have a colostomy/ileostomy. However, there are some simple ways to reduce the amount of wind your stoma produces:-

- chew your food properly
- don't gulp your food down
- don't chew with your mouth open
- don't talk when eating
- pour out a fizzy drink and leave it for 10 minutes before drinking, to help get rid of some of the bubbles
- eat regular meals - don't leave big gaps in between meals

There are reports that Yakult yoghurt drinks or bio yoghurts (found in the yoghurt section in most supermarkets) help to alleviate the bad bacteria in the gut which cause wind.

Food and drinks that can increase the gas/wind passed by your stoma:-

beans, beer, broccoli, Brussels sprouts, cabbage, carbonated drinks, cauliflower, cucumber, eggs, fruit, green vegetables, high fibre cereals (eg muesli) mushrooms, nuts, onions, peas, spinach, sweetcorn, fatty foods (pan-fried or deep-fried food), rich cream foods.

Avoid these foods and drinks if the level of wind is unacceptable to you, but remember that you can have stoma appliances with filters which will release the wind, but without the smell (because of the carbon inside the filter).

(Colostomy) What will my faeces be like with a colostomy? Initially after surgery there will probably be no output from your stoma, maybe a bit of bloody fluid, then once the bowel begins to work, after a day or two (usually) the colostomy will pass smelly wind, and then liquid faeces. This will gradually thicken up, as you begin to eat and drink more.

Colostomists - Can I control my bowel motions? NO! However, if you had a bowel pattern prior to surgery, once your body has adjusted then you may find this returns, after a few weeks. Most people pass motions once a day, although some are only every other day, whilst others are twice a day.

Will I pass anything through my bottom? If you still have a rectum you may pass mucous. This is made by the bowel and not harmful. If you get the feeling you need to pass a bowel motion, sit on the toilet. If any blood is passed, see your GP.

I still get the urge to go to the toilet through my bottom – is this normal? Some people do get “phantom rectum” if their rectum is removed. If this occurs, sit on the toilet and the feeling usually passes. If you still have a rectum, see comments above.

What if I do get diarrhoea? This may be for a number of reasons, such as an illness i.e. flu, the food you have eaten or you may have picked up a bug. It could also be due to a change of medication (antibiotics prescribed for an infection elsewhere in the body i.e. a chest infection). It may be due to an over indulgence in alcohol, or emotional upset, stress or strain. If you get diarrhoea you will need to increase the amount of fluid that you drink. If you irrigate you should stop irrigating until the diarrhoea stops. If symptoms persist you should see your GP.

Food and drinks that may cause you to have loose faeces:-

Beer or other alcohol, broccoli, chocolate, fresh fruit (except bananas), grape juice, green beans, prunes or prune juice, spicy foods, spinach, some artificial sweeteners such as sorbitol or saccharin. Avoid these foods or drinks if the loose faeces are unacceptable to you (these foods can also be taken if you suffer from constipation to relieve the symptoms).

Foods and drink that may thicken your faeces:-

Applesauce, bananas, buttermilk, cheese, marshmallows, (boiled) milk, noodles, creamy peanut butter (not crunchy), rice, tapioca pudding, toast, yoghurt.

How to slow down stoma activity before changing appliances.

Eat a tablespoon of creamy peanut butter beforehand or eat four or five marshmallows fifteen minutes before changing.

How to prevent constipation:-

- eat regularly
- increase the amount of fruit and vegetables that you eat
- take gentle exercise

- use a 'bulker' i.e. bran in your diet – two teaspoons of bran twice a day will help keep the stools soft.
- Increase fluids, especially when increasing fibre, to 1.5 – 2 litres daily on average unless directed otherwise.

Foods which cause a change in colour of your faeces

Beetroot, blueberries, iron pills, liquorice, red food dye, strawberries.

(Colostomy) You may have considered irrigation. This is when the colon is 'washed out' via the stoma. This allows you to be free from a bowel motion for longer periods of time. Speak to your local stoma care nurse if you require more information. ***Or a stoma cap*** – used to hold back faeces for a period of time – see your stoma care nurse.

What happens when you take a bath or shower? You can bathe as you would before you stoma was formed, either with or without the appliance on. The water will not be able to get inside your stoma. However, you must ensure that the area around your stoma is free from soap, after your bath, before you re-apply your stoma appliance. Or you can choose a soap or cleanser that is residue-free.

Skin care is important. The area of skin around the stoma (the peri-stomal skin) should always be healthy and look like the skin elsewhere on your abdomen. To help prevent the skin from becoming sore you need to fit the appliance properly, if you are having difficulty with this you need to see your stoma care nurse. If you see any swelling, redness or a rash you may have irritated skin. Irritated skin is not always painful, but it can be. If you notice these problems for more than two consecutive changes you should contact your stoma care nurse.

Will you be able to wear your 'usual' clothes? YES! The stoma nurse is usually able to site the stoma so that it will be possible to wear your 'usual' clothes. So long as the actual stoma is not underneath a waistband or belt there should not be a problem. Most appliances are very thin and discreet and will not show under your clothes, nobody will know that you are wearing an appliance, unless you want them to. If you swim or sunbathe, wear patterned swimwear, instead of a solid colour. Men can wear supports, women can wear support knickers or girdles. These are available from a variety of companies that specialise in clothing for people with stomas, and are reasonably priced; some are even available on prescription. See your stoma care nurse for information.

Rounding off the square edges of a firm wafer, or skin barrier, will decrease the chance of the belt catching on the corners.

(Ileostomy) Male ostomates who suffer painful collisions between the pouch tail clip and key organs should try angling the pouch toward a trouser leg instead of pointing it straight down. Wear briefs and pass the pouch through a leg opening in the brief to hold it in place.

Will you be able to exercise or take part in sports? YES! Having a colostomy should not prevent you from exercising and apart from heavy lifting or rough contact sport there is unlikely to be a reason that you cannot enjoy sport as you did before your surgery. It is important to start gradually, and even consult your doctor before commencing sport, in the initial stages after surgery. Swimming is possible, but it is a good idea to ensure that the pouch is empty before you go swimming. When your stoma appliance is exposed to water, the adhesive seal becomes even more secure because the adhesive properties are enhanced around water. If you don't believe this, notice that your stoma appliance is more difficult to remove in a bath.

Other sporting activities such as football or tennis present no major problems once your stoma is in place but you need to build up your fitness (just like anyone else after a major operation) and can wear a special belt to keep the appliance in place. If there is a risk of your stoma being hit in contact sports, you could obtain a stoma guard – discuss this with your stoma nurse.

Watch out for signs of dehydration – make sure you adequately replace any fluid lost as a result of sport.

Information about bottled water

Drink natural mineral water whenever possible. It helps to replenish vital bodily minerals, does not contain additives and comes from a safe, untainted source.

Don't be fooled by labels which say "table" water or "natural" or "pure". Look for the words: *Natural Spring Water* or *Natural Mineral Water* – anything else may be no better than your own tap water – just more expensive.

Will you be able to return to work? YES, you should be able to. You will need time to recover, and this is usually six to eight weeks, and even then you should check with your doctor before returning to work. Returning part-time to start with can be helpful for testing your stamina and seeing how you cope. Some jobs (ie those involving heavy lifting) might not be suitable for someone with a stoma – your nurse would be able to advise you.

Will you be able to travel? YES! Having a stoma should not stop you travelling, even abroad.

Ensure your travel insurance is from a reputable company and does not exclude "pre-existing conditions". If you are having problems with insurance because of age, try Age Concern or the patient associations (BCA, ia, UA or Fittleworth – 0800 378846)

Prepare a checklist of things to take such as bags, flanges, disposable bags, wipes, creams etc. Calculate the number required for normal usage in that period and **double it!**

- ◆ Colostomists may find it useful to take a few drainable bags with them in case of stomach upsets – easier to drain.

- ◆ **Urostomists** – if you have a long journey, a leg bag may be attached on to your existing bag, in order to increase the volume it can hold. Ensure you have emptied prior to commencing your journey. Always carry a spare bag with you which you can get at easily.

If you travel abroad, take your medical supplies as your hand luggage, in case your luggage goes astray - it is possible to have more than your usual quota because you have a stoma, but you must discuss this with the airline in advance.

When fastening your seat belt, ensure that it is above or below the stoma, not over it, to prevent any accidental damage to the stoma.

The changes in cabin pressure (in a plane) can cause you to produce more wind. This can be overcome, see above – if your bags do not have filters, charcoal filters can be added. Avoid fizzy drinks.

Book an aisle seat, so that you can get to the toilet quicker. There are cards available to allow you to go to the front of the toilet queue because you have a stoma. **Tip:** use the toilets before meals are served as there is more of a rush after meals.

Do not leave your stoma products in a hot car, as this will weaken the adhesive. A cool bag may come in handy for carrying your stoma appliances when out in the sun/heat – heat can affect the adhesive.

Cotton pouch covers are available to help prevent your pouch sticking to your skin when hot.

When you are on holiday the change in water, climate and food can upset anyone, with or without a stoma, so take some simple precautions:-

- drink more, to replace the amount of you are losing in sweat, though only drink bottled as tap water (soft or hard) can have an adverse effect on your stools. Remember – at least 2 litres a day keeps the doctor away. See information about bottled water above.
- Colostomy irrigators – if you don't drink the water, don't irrigate with it either. It is advisable to use bottled water, but if you have to use tap water, boil it first.
- Ileostomists - it is particularly important to ensure you do not become dehydrated. As well as water intake, drink cola that has been allowed to go flat – it contains the majority of the nutrients lost in dehydration.
- Avoid ice, and salads that may have been washed in tap water.
- Be cautious of highly spiced food if you are not used to it.
- It is probably advisable to have antidiarrhoeal medication with you in case of an emergency and fluid replacement powder. Propriety brands are fine for most ostomists, **but ileostomists should use the World Health Organisation's recipe – 2.5g Sodium Bicarbonate, 3.5g Salt, 20g Glucose – this can be flavoured with orange juice.** If you do get a stomach bug the usual medication can be taken. Eating marshmallows will help to reduce loose stools.

If you go swimming, remember to cover the filter, or make sure that you are not wearing a bag that dissolves in water (see above). You can get smaller bags if desired.

Do not try to remove your pouch immediately after bathing as the adhesive is stronger when wet and this may cause sore skin.

Travel certificates explaining in several languages that you are an ostomist are available from your Stoma Care Nurse. Form E111 is available from the Post Office and tells you which countries or treatments are free in the European Community, plus where you might have to pay.

Familiarise yourself with the procedure for obtaining medical supplies abroad and have emergency contacts available as a precaution.

Will you be able to continue to enjoy personal and sexual relationships?

Sexual activity will not harm your stoma and it is usually possible for men and women to still have children after a stoma formation, men and women can still parent children after they have a colostomy. If you are going to have close or sexual relations, it is advisable to empty the pouch beforehand. During such times it is possible to wear a stoma cap or a smaller appliance. You will probably have chosen an appliance that is opaque, so the contents of the stoma appliance are not readily visible. A cummerbund can hide the appliance and keep it close to your body.

How do you get more appliances? The GP will write you a prescription. Initially, the stoma nurse will write to your GP to inform him of your choice of appliance. Then you can either get the chemist to order the appliances for you, as with your tablets, or you can use a delivery company – in this case the products are delivered to your door discreetly, the company will also provide wipes and rubbish bags, and will cut the appliances to fit you. Either way you will need to get the prescription from your GP.

Will you have to pay for the prescription? That depends. If you had free prescription before your surgery, then they will still be free i.e. if you are under 16 years of age, or over the retirement age. If your stoma is permanent then you will be exempt from prescription charges for any prescription. If however your colostomy is temporary and you are not already exempt you will probably have to pay for your prescriptions. However, to make this cheaper for you, you can pay *****for 3 months, **6 months or a year, and this will cover you for any of your prescriptions. You will need to get a *** from****

Getting a good night's sleep

Avoid heavy snacks before bed-time, alcohol, caffeinated drinks ie coffee, cola and tea

Getting help with Water Bills

You will have to meet the following conditions:

- (a) You must pay metered charges rather than water rates
- (b) You must be in receipt of one or more of the following benefits:
- Income support
 - Income based jobseeker's allowance
 - Working families tax credit
 - Disabled persons' tax credit
 - Housing benefit
 - Council tax benefit
- (c) You must be diagnosed with eczema, incontinence or an abdominal stoma
- (d) As a result of your condition, you are obliged to use a significant volume of water

If you meet the various criteria you will not have to pay more than your local water company's average annual domestic water and/or sewerage charges. These are set by the Office of Water Services each year. At the end of each year, your water consumption is checked and if you, in fact, used less than the average charges, you will be refunded the difference.

Telephone Support Group for irrigators

If you are experiencing difficulties or worries concerning irrigation and want to talk to a volunteer who has been "through it", you might like to contact one of the following:

| | | | |
|-------------------|--|-------------------------|--|
| Blackpool | Stella 01253 894505 (daytime) | Rayleigh | Lorraine 01268 776529 |
| Burford | Robert 01993 823272 | South Croydon | Patricia 020 8688 7882 |
| Darlington | Ann 01325 250115 (afternoons only) | Southend Sea | on Hilary 01702 306926 (afternoons/evenings) |
| Holt | Constance 01263 7112598 | Teignmouth | Helena 01626 773227 |
| Maidstone | Vicky 01622 675664 | Telford | John 01952 507265 |
| Newcastle | Emma 0191 2433702 | Wisbech | Jean 01945 464744 |

Urostomates

You should be able to enjoy a completely normal diet. You may have heard it said that it is helpful to create an acidic urine pH which helps to prevent infection. To help this process, cranberry juice and bio yoghurt, or preferably live yoghurt are excellent.

If you notice blood coming out of the stoma aperture, get in touch with your doctor or stoma care nurse as soon as possible. It may be caused by a urinary infection and will easily be cleared up, but should be investigated.

Night drainage bags – when flushing a night drainage bag through, add a teaspoon of ordinary vinegar to the water for a cheap and effective cleaner. Most people use night drainage bags for one week.

List of Useful Addresses

Ia, Ileostomy & Internal Pouch Support Group
Amblehurst House
PO Box 23
Mansfield
Notts NG18 4TT
Tel: 01623 28099

Ua, Urostomy Association
Buckland
Beaumont Park
Danbury
Essex CM3 4DE
Tel: 01245 224294

BCA, British Colostomy Association
15 Station Road
Reading
Berks RG1 1LG
Tel: 01734 391537

Fittleworth
(Independent supplier of all prescribable ostomy items)
Tel: 0800 378846