



# Renfrew County Ostomy Support Group



## A HANDBOOK FOR NEW OSTOMY PATIENTS

written and compiled by the Vancouver Chapter  
of the United Ostomy Association of Canada

**RENFREW COUNTY EDITION**





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written and compiled by the Vancouver Chapter of the United Ostomy Association of Canada, in conjunction with the Hamilton & District Ostomy Association and the Renfrew County Ostomy Support Group.

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### **IMPORTANT NOTICE:**

This publication contains practical advice and tips for managing and learning to live with an ostomy, and is meant to supplement, but not replace, the information given to you by your doctor, ET nurse or other health care professional.

The information in this publication is of a general nature, not specific medical, or other professional, advice. If you need medical, or other professional advice or assistance, consult your doctor or ET nurse as soon as possible.

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This edition is a version of the original publication by the Vancouver chapter of the UAOC, modified by the Hamilton & District Ostomy Association. The Renfrew County Ostomy Support Group acknowledges with gratitude, permission to modify and reproduce this handbook for the benefit of ostomates living here in Renfrew County.

In North America alone, there are approximately 70,000 new ostomy surgeries performed every year. If you are reading this, chances are you have had ostomy surgery or are about to.

Colostomies, ileostomies and urostomies are performed on people ranging in age from infants to the elderly, for a wide variety of causes. Birth defects, disease, complications from other surgeries or childbirth, and severe injury are all reasons why ostomy surgery may be necessary. Whether the ostomy is permanent or temporary, it can be a difficult adjustment for the patient, and for their family and loved ones.

This handbook is based on the experience of those who have had ostomy surgery and/or live with an ostomy. We've been through what you may be experiencing and understand the frustrations and fears you may have. It is our hope that this handbook can help answer your questions and reassure you that there is much good life to be lived after ostomy surgery.

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## CHOOSING THE RIGHT APPLIANCE



## **CHOOSING THE RIGHT APPLIANCE**

First of all, a bit of clarification on terminology. You may have already heard different terms and are confused about just what exactly they refer to. 'Bag' or 'pouch' refers to the part that collects waste. 'Flange', 'barrier', 'wafer' or 'faceplate' all refer to the part that sticks to your body. Your caregivers may use different names for this part but they all refer to the same thing. The general term 'appliance' refers to the entire system (one or two-piece) that is used.

Appliances, whether they are one or two-piece can also come in 'closed end' or 'drainable' models. A drainable pouch has a clip or velcro closing on the end that can be undone to release waste. A closed-end pouch has no opening or clip, and is removed and discarded instead of emptied. Many pouches are now made with filters near the top which allow gas to escape without odour.

The material that the barrier (or flange) is made out of can come in different types, too. Some are called standard wear and others are extended wear. In general, a standard wear barrier is used when stool is semi-formed or formed. An extended wear barrier is usually used when a stoma drains urine or stool that is loose or liquid. The extended wear barrier does not break down like a standard wear barrier when it comes in contact with liquid waste.

Most hospitals employ one or more ET nurses, who are also referred to as enterostomal nurses. These are nurses who have taken specialized training in ostomy care. You will be discharged from the hospital with a supply of appliances chosen by your ET nurse to get you started. After that you must purchase your own. But where to start and what to buy? The variety of appliances available can seem bewildering at first. Two-piece, one piece, closed, drainable, different sizes, different brands – how does one choose? No one expects you to learn it all at once. You may find that the product introduced to you by your ET nurse or hospital works well and stay with that, or you may not be satisfied with the look or performance of your first type of appliance. We encourage all new patients to learn about different brands and types and to try new appliances. Your ostomy may be

permanent or it may be temporary – either way you owe it to yourself to find and wear the best possible choice for you for as long as you will have the ostomy.

The United Ostomy Association of Canada does not endorse one brand or type over another – all have merit. What works well for one patient may not suit another, and what one person swears by others don't like. Everyone has different needs and preferences. The most prevalent brands in our area are Coloplast, Convatec and Hollister. Sometimes your ET nurse can give you something different if you call and ask. Another option is to contact the manufacturers directly. All have websites and toll-free numbers you can access for free samples. This is a good way to 'test drive' a new type of appliance without spending a lot of money. Call the suppliers up, tell them what sort of ostomy you have, and what your particular concerns are. It can take several weeks for samples to arrive, so be patient. If you don't care for what was sent, you can ask for more samples. Companies want you to try their products! It's definitely worth your time to check out what they have to offer. You can also attend open houses sponsored by various pharmacies to talk directly with ostomy sales representatives and get samples. It is beyond the scope of this publication to discuss all systems and brands, but this is a short guideline. For numbers to call, see manufacturers' listings in the back of this handbook.

## **TWO-PIECE VS ONE-PIECE APPLIANCES**

A two-piece appliance is composed of two parts: the flange, which sticks to your skin, and the pouch, which snaps or sticks onto the flange. A one-piece appliance has the flange combined with the pouch. There are advantages and disadvantages to both:

### **Two-Piece Advantages**

- easier to 'burp', that is, allow gas to escape. This is a useful feature for ileostomates/colostomates who find that filters work poorly once dampened
- a smaller or larger pouch can be substituted without having to change the entire flange

- some have a 'floating flange' which is a type of flange that has an extra flexible joint at the circular ring. This can be an advantage for those with poorer hand dexterity who have difficulty snapping a pouch onto a flange, or for those whose abdomen is very tender and pressing down to attach a pouch is uncomfortable.

### **Two-piece disadvantages**

- tend to be bulkier and more visible under clothing, although with the newer thin and flexible flanges this is less of a problem than in years past
- more appliance 'inventory' to purchase, match and keep track of

### **One-piece advantages**

- fewer components to apply
- feel lighter, more flexible and have a lower profile under clothing

### **One-piece disadvantages**

- can cost more if you are using closed-end models (you'll need to throw them away every time you empty)

## **CONVEX APPLIANCES**

If you have a very short, or flush stoma, you will probably need to use what is called a convex appliance. These are available in one or two-piece the same as standard appliances. The difference between a convex and a regular appliance is the flange is shaped in such a fashion around the opening so that when applied, it presses down on the skin around the flush stoma. This makes the stoma stick out more. Stomas that are too short or flush do not always drain into the bag properly, causing leakage, so a convex flange may correct the problem. If you think your ostomy falls into this category, you should ask your ET if a convex flange might work better for you.

## **POUCH LINERS**

These are flushable, very thin plastic liners that fit inside a two-piece pouch. When it comes time to empty, you simply remove the liner and flush it down the toilet, leaving your pouch empty and clean. These are popular with those who prefer using a closed-end appliance. At pennies per unit, flushable liners can help save costs on appliances if this is a concern. The company that markets these is Vancouver-based; you can inquire about them from your ostomy supplier.



## FOODS, DIET AND NUTRITION



## **RESUMING A NORMAL DIET AFTER SURGERY**

After surgery and the bowels have healed, many ostomates are able to return to their previous eating habits without much alteration. However, ostomy surgery that affects the large or small bowel may change how your body processes food. Therefore, you should exercise some caution and common sense when eating after you leave the hospital. This applies as well to those who have undergone radiation to the pelvic area, as portions of the remaining bowel can be irritated by this treatment.

It was once thought that many types of foods were strictly off-limits, to ileostomates in particular, but this need not always be the case. You need to learn how your new body reacts to the foods you used to eat, and how to carefully re-introduce these items back into your diet. You need not fear mealtimes, just exercise moderation to start and **CHEW YOUR FOOD WELL**. Soups, blender drinks and soft cooked items are gentle on a healing system. Raw fruits and vegetables or their skins may be hard to pass through your system. Although fibre is good for you and necessary for a balanced diet, you may need to experiment with what agrees and what does not. Fibre is not as necessary for those with ileostomies. Below are some common foods and hints on how to safely eat them for those recently returned home from ostomy surgery. (See lists on pages 15 to 16).

### **VEGETABLES**

Vegetables like celery, asparagus, and broccoli can have long fibrous strands running through them. Such strands are hard to digest and can 'ball up' causing a painful blockage. When eating such vegetables, peel off the outer tough stalk, or eat only the tender 'hearts.'

Asparagus can cause odour in the urine. Onions can produce odour in the stool. Broccoli, cauliflower, and turnips are gas producers. Whatever gave you gas before will continue to give you gas.

For some people, mushrooms, especially fresh ones, are notorious for going through the system undigested or causing blockages. Slice them thin and yes... chew, chew chew. Corn on the cob, canned corn and popcorn are also often the cause of bowel obstructions or blockages. Eat these in

moderation. If in doubt about trying a vegetable for the first time, peel the skin, and steam or soft-cook it. Beets can turn waste pink or red – this is harmless.

## **FRUIT**

Fresh fruit can, and should, be included in a well balanced diet. If you are having trouble digesting oranges or grapefruit, try squeezing the juice and discard the skin and pulp. Try peeling apples, pears, plums and peaches to start off. Be cautious with fresh coconut. You may be able to eat all of the above items right away, however, post-surgery it's best to approach fruit with caution and moderation. Keep in mind that fruit is also a natural laxative that may increase bathroom visits. (for colostomies and ileostomies)

## **NUTS AND MEATS**

Hard nuts such as peanuts, almonds and hazelnuts should be introduced in very small amounts and chewed well. Peanut butter will act as a stool thickener in some people, which can help with diarrhea. Most meats and poultry do not present major problems but steak, chops, roasts or hamburger must be carefully chewed and consumed in moderation. High fat items, heavy casings on sausage, and gristle may be more difficult to digest after ileostomy/colostomy surgery. Eat slowly, avoid the gristle and limit your intake.

## **SPICY FOODS**

Heavily spiced foods and sauces can act as cathartics (cause loose stool and gas producers).

### **FOODS THAT INCREASE ODOUR**

asparagus	broccoli	brussels sprouts
cabbage	cauliflower	beans
eggs	fish	onions
some spices		

## **FOODS THAT INCREASE GAS**

beans	beer	carbonated soda
broccoli	brussels sprouts	cabbage
cauliflower	corn	cucumbers
mushrooms	peas	radishes
spinach	dairy products	excess sugar

## **FOODS THAT THICKEN STOOL (SLOW OUTPUT)**

applesauce	bananas	cheese
boiled milk	marshmallows	pasta
creamy peanut butter	pretzels	rice
bread	tapioca	toast
yogurt	bagels	oatmeal

## **FOODS THAT LOOSEN STOOL**

green beans	beer	broccoli
fresh fruits	grape juice	raw vegetables
prunes/juice	spicy foods	fried foods
chocolate	spinach	leafy green
aspartame	Nutrasweet	vegetables

## **HIGH-FIBER FOODS THAT MAY CAUSE BLOCKAGES**

dried fruit	grapefruit	nuts
corn	raisins	celery
popcorn	coconut	seeds
coleslaw	Chinese vegetables	oranges
meats with casings		

## **CAN YOU STILL DRINK ALCOHOL?**

Yes! And you may find that gastrointestinal upsets associated with alcohol that used to occur before surgery are now gone with the removal of the diseased bowel. A word of caution however: those with ileostomies are at greater risk of dehydration when drinking alcohol. Have water on the side, or extra juice or pop along with your drink. Unless a fair amount of the large colon was removed, colostomates are in little danger of dehydration when drinking liquor. Beer and carbonated drinks can produce gas. Some medications are less effective if taken with alcohol – be sure to follow instructions. Alcohol may give you loose output or extra output, or it may have no effect on waste at all. Everybody's different.

Urostomates need not fear dehydration but you will be making more trips to the bathroom to empty your appliance.

## **PRESCRIPTION DRUGS AND OVER THE COUNTER REMEDIES**

Prescription and non-prescription drugs as well as vitamins are absorbed primarily through the intestines, therefore if you have had a significant portion of your bowel removed, absorption of these substances can be affected.

While the chemical nature of most drugs allows absorption along a significant length of the intestinal tract, the shorter the functional intestine, the less will be absorbed. Only a very few drugs, such as alcohol, can be absorbed to any great extent through the stomach.

Absorption of medications can vary depending on the size and type of pill (ie tablet or capsule). Chewable tablets are effective if they are chewed well; in most cases they are better absorbed than capsules or compressed tablets.

Ostomates who have a significant portion of their intestine removed may achieve better absorption by emptying the contents of a capsule into applesauce, or crushing a compressed tablet and adding the powder to food. A word of caution, though – not all tablets can safely be crushed, and not all capsules should be emptied. Generally speaking, time-release tablets should not be crushed, nor should time-release capsules be emptied. The result could be 12 to 24 hours worth of medication being released all at once.

Time release medications should be avoided by ileostomates or discussed with their pharmacist.

Enteric-coated tablets should not be crushed. The reason those tablets are coated is to prevent irritating the lining of the stomach. If possible, avoid this type of tablet as they can pass intact through your system.

**FOLLOW INSTRUCTIONS FOR TAKING ALL DRUGS.** If in doubt about an over-the-counter drug, or how different drugs may interact, consult your pharmacist or doctor.

## **CAN YOU CONTROL THE AMOUNT OF WASTE PRODUCED BY SELECTIVE DIET?**

Obviously, if you stop eating, you will have little or no output. Starving yourself or limiting liquids to avoid producing waste is foolish and dangerous. NEVER restrict fluid intake – the consequences of dehydration are serious for an ostomate. Sticking to regular mealtimes can help you learn your body's behaviour patterns and anticipate the times when your output is lowest. Some people eat less at certain times of the day or evening in order to help make their stoma less active. Skipping meals entirely will not stop ileostomy output however, and can produce more gas than if you ate a regular meal.

Some foods do produce more waste than others, for example, things that contain cellulose will produce more residue and hence, more output. Cellulose is the chief component of plants, so it stands to reason that consumption of most fruits and vegetables will increase output. Refined grains such as white rice or white bread produce relatively little residue, as do things like eggs, cheese or chicken. Examples of foods that thicken or slow output are oatmeal, peanut butter, marshmallows and bananas. Drinking large amounts of fluids will not affect stool output; it will increase urine output. Bear in mind that you cannot control your ostomy completely with selective diet.

## **USE OF IMODIUM AND SIMILAR PRODUCTS**

Give your body time to settle down after you leave hospital. Some colostomates can have loose stool for several weeks or longer after surgery. This should sort itself out in time without the use of antidiarrhea agents. Even after you have healed completely, you may have periodic bouts of diarrhea the same as a person with an intact digestive tract – it can happen to anybody. But before reaching for an antidiarrheal you should first consider what you may have recently consumed that might be the cause. In most cases, periodic looseness will sort itself out after a day or two without the need to take anything.

However, patients with chronically overactive colostomies and ileostomies sometimes use agents such as Imodium to help control things. These should be used only if the situation is chronic and not improving by watching your diet. Follow directions and do not exceed the recommended dosage. Lomotil is another antidiarrheal available only by prescription; its use should be discussed with your doctor. Occasional diarrhea is not a cause for panic; as much as possible give your body time to adjust on its own. If you take Pepto Bismol, be aware that your stool will turn black. This is harmless.





# GENERAL MANAGEMENT



# GENERAL MANAGEMENT

## **HOW OFTEN SHOULD YOU CHANGE YOUR APPLIANCE?**

Whether you choose a two or one piece system, 7 days is the recommended maximum time a flange should be on your body. Some people can successfully stretch this to 10 or even 14 days without compromising skin health or hygiene, but don't try to set records. Three to four days is perfectly acceptable wear-time.

How long you choose to wear, or can wear a flange depends on how your skin reacts to being covered with this material, your technique in applying, and upon the placement of the stoma itself. Some people get too itchy to keep one on for more than a few days. Some can keep an appliance on for long periods of time without any discomfort. Some people have the sort of skin and ostomy placement that won't hold a flange on properly without using an ostomy belt or extra products. And some people can change their entire appliance every day without irritating their skin. We're all different.

## **HOW DO YOU EMPTY YOUR POUCH?**

Most people sit to empty their pouch. Let it fall between your legs, release the clip or valve and let things fall into the toilet. Colostomates and ileostomates should wipe the inside of the pouch end with tissue before re-clipping to avoid odour. Some people prefer to kneel, facing the toilet although this can be hard on the knees. Some prefer to stand – if you prefer this method you should put some tissue in the toilet bowl first to control splashing.

## **HOW OFTEN SHOULD YOU EMPTY?**

All categories – colostomy, ileostomy and urostomy – should empty when the appliance becomes one third full, or sooner. Waiting longer than this can make you uncomfortable, puts unnecessary strain on the flange and can contribute to leakage. How many times do most people empty per day? This varies depending on type of ostomy, what you've been eating and drinking and also on what your tolerance is for having waste present in the bag. Very generally speaking, colostomates empty 3-4 times a day, ileostomates 6 to 8 times a day and possibly during the night as well, urostomates 10 to

12 times per day. If you want to empty more frequently than this, by all means do so. It's your body and you should do what you need to feel clean and comfortable. Many urostomates use a night drainage system. (See next topic)

## **NIGHT DRAINAGE SYSTEMS FOR UROSTOMATES**

Urine will collect in the appliance continuously throughout the day and night. Urostomates should use a night drainage system rather than rely on waking up during the night to empty a full appliance. Letting a urostomy appliance get overfull during the night is asking for leakage. Night drainage systems consist of a tube which is connected to the drain spout at the bottom of your appliance, and then connected to either a collection bag or bottle kept beside your bed. Most of the major suppliers make night drainage tubing and collection devices. You should discuss these products and how to use them with your ETnurse.

## **HOW SHOULD YOU CLEAN YOUR APPLIANCE?**

Trying to clean inside an appliance while you're still wearing it is largely a waste of time (not to mention near impossible). You should wipe inside the end of both one and two piece appliances with toilet paper after each empty to avoid odour. If stool is 'pancaking' inside or near the top of your pouch you can use a plastic squirt bottle of water to rinse this out. (Take care that you don't flush water around the stoma as this may get under the flange.) Adding a few drops of ostomy lubricating deodorant or baby oil inside the pouch before applying it helps waste slide to the bottom rather than collecting at the top.

If you wear a flange with a two-piece system, sometimes the inside of the ring can become soiled which bothers some people. Q tips can help clean this but don't make yourself crazy trying to get the flange ring 100% clean. You're going to cover it anyway once the pouch is applied.

Urostomates should clean the night drainage system every day – it's advisable to use a mild vinegar/water solution and flush the tubing and collection device. Some manufacturers also market cleaning products specifically for your urostomy gear.

## HOW SHOULD YOU DISPOSE OF USED APPLIANCES?

People can get way too complicated about this. Once you've drained the pouch into the toilet, put it (and the flange if you are changing that as well) in a plastic bag like one of those you get from the grocery store, or a small zip lock bag. Buy yourself a little plastic waste basket with a lid and keep it under the bathroom sink. Put your bagged waste in there and take it out regularly. If you're in a public washroom and must dispose of a used appliance and don't have a plastic bag, wrap it up in toilet paper and put it in the nearest wastebasket. Ladies have the added advantage of having disposal units for menstrual products inside public cubicles – you can use these. Far too many people are anxious about this subject – believe us, nobody is watching what you throw away and so long as you're tidy, nobody cares. Ostomy waste is not radioactive, folks.

## COLOSTOMY IRRIGATION

Those with a descending or sigmoid colostomy have another option for managing their ostomy. Irrigation is a water enema administered through the stoma, either once a day or once every other day. The procedure takes about an hour in the privacy of your own bathroom, and requires a minimum of specialized equipment. Irrigation works on the principle that if all or most of the large bowel is emptied at one time, it will take 24 - 48 hours for stool to output again. ***Irrigators who achieve good control can be freed from wearing, emptying and changing standard ostomy bags, and report a dramatic improvement in quality of life.*** In between irrigations, the stoma is inactive, or produces very small amounts of stool, allowing the individual to wear only ostomy caps, patches or mini-bags to protect the stoma. To be a candidate, you must have a reasonable amount of hand/eye coordination, the capacity to learn and remember a simple sequence of steps and the motivation to control your body. If your bowel habits were regular before surgery, your chances are good that your remaining colon will respond well to irrigation. If bowel irritability was common before your surgery, or if you were prone to diarrhea, irrigation may not be much of an improvement for you. If you have a hernia, or serious heart or kidney disease, you should see your ET nurse or doctor to discuss the advisability of irrigation.

Irrigation can be safely commenced once your incisions and stoma have healed completely. If you are required to undergo chemo or radiation after surgery it may be advisable to wait until you have completed treatment before trying irrigation, although in some cases where patients tolerate treatment well, you might be able to start sooner. You will need to contact your ET nurse for an appointment to receive instruction on technique and what equipment to purchase. (If you want the nurse to do the procedure with you for the first time, you should let them know so they can book an adequate amount of time for your session. Otherwise, you can start at home after verbal instruction.) Patients with a urostomy, ileostomy, or ascending colostomy cannot irrigate. In rare cases, transverse colostomies can irrigate but results are generally too poor to justify the effort. If you have been told that you cannot stop irrigation once you start because the bowel will no longer work, or that you must adhere to a rigid timetable, this is simply not true. You can stop anytime you wish if irrigation does not suit your lifestyle and although it is recommended that you adopt a routine timetable for elimination [much as you probably did prior to surgery] this can be modified to suit your own schedule.

We strongly encourage descending or sigmoid colostomates to look into irrigation.

## **MISCELLANEOUS PRODUCTS**

### **Paste**

Paste comes in tubes or as packaged sticks which can be squeezed or moulded by hand. Paste is often misused and, it could be argued, mis-named. (It could be said that 'putty' might be a better term). This product should not be used as an adhesive. The main purpose of paste is to fill in any uneven areas on the skin under the flange to make the skin level, and gain a good seal to the flange. The second function of paste is as a caulking material around the base of the stoma to keep discharge from leaking at the base and getting under the wafer. Apply a small bead of paste, like putting toothpaste on a brush, around the opening in the flange. Let this sit for a minute to give the alcohol a chance to evaporate. Do not spread the paste. If you want to remove paste from your skin, let it dry out a little first. Don't worry if a little bit is left on your skin. Recap the paste tube immediately after use to prevent it from drying out. You don't need paste if your skin is even and the appliance is staying on well.

## **Powder**

Skin barrier powder may sometimes be recommended by your ET to dry a raw, weepy area on your skin. To apply, clean the irritated area with water and pat as dry as you can. Lightly dust the powder over the affected area and smooth it evenly. Blow or brush off the excess and apply your pouch as usual over top. Some people dab or spray a skin sealant over the powder before applying their flange.

## **Skin Sealant**

Skin sealant (sometimes called barrier film or skin prep) puts a plasticlike coating on the skin. It comes in the form of sprays, wipes and gels. A sealant may help if you have skin that tears easily, have problems with leakage or are using an ostomy skin barrier powder. Some people who have dry or oily skin find that their pouching system sticks better when they use a skin sealant. Most skin sealants contain alcohol which will sting on open areas of skin, or skin that is sensitive.

No-alcohol sprays and wipes such as Cavilon may be used if regular sealants are too irritating. Nexcare No Sting Bandage is also alcohol free and does essentially the same job as Cavilon.

## **Ostomy Adhesive**

Adhesive cements and sprays are not as widely used these days, but may be helpful for those who are having a lot of trouble keeping a flange in place. A light, even coating should be applied and given time to dry before applying the flange. It is important to follow manufacturer's instructions, as many adhesives require 3 to 5 minutes to dry properly.

## **Adhesive Remover**

A sticky residue can sometimes build up on your skin. Ideally, you should remove this with mild soap and water, but if it's not coming off you may need to use an adhesive remover. After using this product you should wash the skin well with mild soap and water, then rinse and dry completely.

## **Tapes**

Common brands are Micropore or "pink tape" and can be purchased over the counter at most drug stores. These products are skin-friendly (can be removed without damaging the skin) and can help keep a hard-to-stick

flange secure. People often tape the edges of their flange as insurance if engaging in sports or swimming although most appliances these days hold up well in water.

### **Absorbent Gel**

Some manufacturers make absorbent gel products designed specifically to convert liquid ileostomy waste into a more solid and easily managed consistency. Gel can be in powder form or packaged in a dissolvable film packet which is dropped into the pouch each time the pouch is emptied or cleansed. As the pouch fills, the packet dissolves and liquid waste becomes more solid, reducing pouch noise and the chances of peristomal irritation. Ask your supplier or ET about this product.

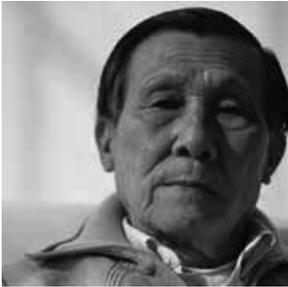
### **Ostomy Belts**

An alternative way to keep your appliance in place during vigorous activity is to wear an ostomy belt. These are elastic belts that hook onto the small loops on your pouch or flange. Ostomy belts are also helpful in holding the flange snugly to the body, preserving the seal and helping prevent leakage.

## **ALL THESE PRODUCTS! DOES EVERYBODY HAVE TO USE ALL THIS STUFF?**

No – many people with ostomies use none of the above products. It depends on your skin and stoma type – some folks have very dry or very oily skin, some are prone to irritation, some have a hard-to-fit stoma due to sitting, shape, scarring or body type. Your own stoma and skin may fit none of these categories and you don't necessarily have to use skin sealants, paste and the like. It helps to know about these products if you run into problems with leakage or skin irritation, otherwise you may not need to use them at all. If you've been using a lot of products and wonder if you really need to, try an appliance change or two without them. Whenever possible, make your routine as simple as you can. "Less is Better" really applies in ostomy care.





## POTENTIAL PROBLEMS & HOW TO AVOID THEM



# POTENTIAL PROBLEMS AND HOW TO AVOID THEM

The following conditions are not necessarily common, but they can happen. Knowing how to identify, treat and avoid them will help you prevent them.

## **BOWEL OBSTRUCTIONS: HOW TO KNOW IF YOU HAVE ONE, AND WHAT TO DO BEFORE YOU CALL THE DOCTOR**

Bowel obstructions, or blockages, can occur in colostomies but are more common with ileostomies. An obstruction is usually caused by eating something fibrous or difficult to digest, such as popcorn, celery, or tough meats to name a few. Eating too quickly, not chewing your food well enough, or introducing solid foods too quickly to your system after surgery can result in a bowel blockage. Blockages can be mild and resolve themselves, or they may be extremely painful and require hospitalization. It's important that you know how to avoid them, how to identify them if you think you have one, and what to do should you experience a blockage.

Signs and symptoms of a possible blockage:

- Swollen stoma
- Distention of the abdomen
- Minimal or no stomal output
- Cramping and pain
- Nausea and vomiting

Symptoms may become severe or they may last for more than 24 hours. There are several things you should do if you suspect you have a bowel obstruction and several things you absolutely should not do:

### **DO NOT:**

- eat solid food
- take laxatives or pain killers
- insert anything in the stoma

**DO:**

- stop eating
- drink non-carbonated fluids; warm fluids may help
- check to see if the stoma is badly swollen, if so you should remove the flange and replace it with one that has a larger opening
- soak in a hot bath to relax the abdominal muscles
- massage the abdomen or try a knee-to-chest position; walk
- call your doctor or go to emergency if severe symptoms are not going away
- have someone drive you to hospital

Treatment for severe blockage may include an IV to replace the fluid, sodium, and potassium you have lost and the administration of pain medication. An X-ray or other diagnostic test may be conducted to determine the source of the obstruction. Depending on the patient and the suspected culprit for the obstruction, a tube may be inserted into the stomach via your nose to decompress built-up pressure.

Be alert to the early signs and symptoms of bowel obstruction. A partial blockage usually displays itself through cramping abdominal pain, watery output with a foul odour, and possible abdominal distention and stomal swelling followed by nausea and vomiting. A complete blockage with an ileostomy is evident when there is total absence of output for more than 4 hours, severe cramping pain, abdominal and stomal swelling, and nausea and vomiting.

Some common blockage-causing foods are popcorn, nuts, heavy fibre (such as that found in the stalks of celery), fruit skins, and poorly chewed meat. Strip tough fibre out of celery stalks and peel fruits such as apples. Cut meat into small pieces and chew your food properly rather than washing your food down with liquid. Introduce fresh fruit and vegetables slowly to your system, in small amounts.

## DEHYDRATION

The large intestine does not play a major part in absorbing nutrition; although it absorbs some minerals, notably salt, its main job is to extract water from waste coming from the small intestine. If all or much of the large intestine is removed, the patient loses this natural 'rehydrator' and can be at risk for dehydration. Therefore, dehydration affects ileostomies more than any other type of ostomy. Thirst is not always an accurate measure of your body's needs; those with ileostomies should develop the habit of drinking water throughout the day. (8 to 10 glasses per day is recommended.)

### SYMPTOMS :

**Mild Dehydration:** (increase fluid intake – and for babies, call a medical professional): Thirst, dry lips, dry mouth, flushed skin, fatigue, irritability, headache, urine begins to darken in colour, urine output decreases.

**Moderate Dehydration:** (call a medical professional): All of the signs of mild dehydration, plus: skin doesn't bounce back quickly when pressed, very dry mouth, sunken eyes, (in infant - sunken fontanel, the soft spot on the head), output of urine will be limited and colour of urine will be dark yellow, cramps, stiff and/or painful joints, severe irritability, fatigue, severe headache and increased heartrate

**Severe Dehydration:** (call emergency number): All of the signs of mild and moderate dehydration, plus: blue lips, blotchy skin, confusion, lethargy, cold hands and feet, rapid breathing, rapid and weak pulse, low blood pressure, dizziness, fainting, high fever, inability to pee or cry tears, disinterest in drinking fluid

**Ileostomates should make a habit of drinking more fluids per day than they did before surgery.**

## HERNIAS

A hernia is a portion of intestine that bulges out of a weakened area of the muscle wall of the abdomen. In those with an ostomy, the area around the stoma can be susceptible to hernia in some individuals.

### **Contributing causes of stoma hernia:**

- Coughing, being overweight or having developed an infection in the wound at the time the stoma was made
- Improper lifting, lifting too heavy an object anytime after surgery (less than 5 lb for 6 to 8 weeks post-operatively is recommended)
- Engaging in strenuous sports

Hernias develop most often in ostomates around the stoma. Because a small circle of abdominal muscle was removed during surgery to bring the intestine to the surface, a weak spot was created. Lifting too heavy a load can cause the intestine to protrude through this gap. In some individuals even sneezing, coughing or standing up can make the bowel bulge through this weak spot. The size of a hernia may increase as time goes by. Stoma hernias are rarely painful, but are usually uncomfortable and can become extremely inconvenient. They may make it difficult to attach a bag properly and sometimes their sheer size is an embarrassment as they can be seen beneath clothes.

Although it is a rare complication, the intestine can sometimes become trapped or kinked within the hernia and become obstructed. Even more seriously the intestine may then lose its blood supply, known as strangulation. This is very painful and can require emergency surgery to untwist the intestine. Regardless of inconvenience or pain, hernias are defects in the abdominal wall and should not be ignored simply because they might not hurt. There are surgeons who advocate that small stoma hernias that are not causing any symptoms do not need any treatment. Furthermore, if they do need treatment it should not be by operation in the first instance but by wearing a wide, firm hernia belt. This is probably true with small hernias, in people who are very elderly and infirm or people for whom an anaesthetic would be dangerous (serious heart or breathing problems, for example.) Operative repair of a stoma hernia may be necessary to improve the quality of life, prevent progressive enlargement of the hernia and make it easier to manage the stoma.

Again, do not lift anything heavy right after surgery. (under 5 lbs for the first 6 to 8 weeks) Give your muscles time to heal and introduce physical activities slowly and gently.

## **FOLLICULITIS**

Folliculitis is an inflammation of the hair follicles and happens most often in men. It is usually caused by traumatic hair removal, for example, hair under the flange is pulled out when the flange is removed. If your skin has become irritated with this, usually the use of a skin protective powder will permit the skin to heal.

If you suspect you may have folliculitis, you should see your ET nurse to confirm and treat the problem.

Men can avoid this condition by carefully shaving the skin that will be covered by the flange. You can use either an electric or safety razor for this. Shaving in the direction of hair growth may help avoid skin irritation. Tip: if you're nervous about shaving so close to your stoma, an empty cardboard toilet roll makes a good shield around it.

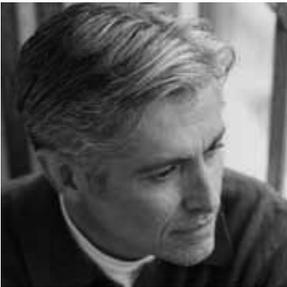
## **PROLAPSED STOMA**

A prolapsed stoma is a stoma that begins to hang noticeably farther and farther out of your body without retracting. This is not normal and should be reported to your ET nurse.

It's normal for your stoma to change in length slightly throughout the day but this should not be confused with a true prolapse. Your stoma can look contracted and almost flush with your skin, minutes later it may appear soft and look longer. This minor variation in length is normal stoma behaviour. It can react to cold or being handled by stoma look shorter or longer. They can look, and feel, either hard or soft depending on whether or not contraction is happening. What is not normal is if you notice your stoma is looking consistently longer and starting to hang out of your body more than usual. Measure your stoma's length after six weeks and if you notice it is getting longer, you should have your ET nurse check it. Prolapsed stomas are inconvenient contracting and 'shortening' up. Peristaltic waves can also make the and more prone to injury. There is no 'standard' stoma length – they can be less than half an inch long, or up to an inch and a quarter.



## COMMON CONCERNS



# COMMON CONCERNS

## LEAKS AND ODOUR

It's everyone's greatest nightmare: getting a leak or smelling bad. Although leaks and accidents can and do happen to all of us, they are by no means the norm and you should not accept constant leakage as a part of living with an ostomy. Most of the time accidents are caused by the appliance not being put on correctly, or by being poorly fitted and it's common for beginners to make errors.

## COMMON CAUSES OF LEAKAGE:

- The flange opening not cut to the right size. The flange opening should be cut approximately 1/16" larger than the stoma diameter. If it's too big waste can get under the flange onto your skin. If it's too small your stoma will be pinched, or displace itself under the flange. A new stoma will shrink in circumference for up to 8 weeks after surgery. It should be measured with each appliance change, with the new flange cut accordingly.
- Wearing the same flange for too long. A poorly placed stoma. You may need to adjust your beltline if it's interfering with how the stoma empties.
- Dislodging or loosening the flange during physical activity. You might consider using an ostomy belt to keep the flange on firmly.
- A very flush stoma that does not exit waste into the bag properly. Consider using convex flanges to correct this problem.
- Flanges not sticking properly. Your skin needs to be completely dry and clean before applying the flange. Avoid using soaps that leave a residue. An uneven abdomen can make it difficult for the flange to stick properly; you may need to use ostomy paste or a skin barrier ring to achieve a good firm fit.
- Folds or creases. If skin folds or creases have developed and leakages are always along the crease, wafer pieces or ostomy paste can be used to build up the area in order to avoid leakage. See your ET nurse for 'how-to' information.
- Peristomal skin irritation. Pouches don't stick well to irritated skin, so perform meticulous skin care to avoid irritated or denuded skin or a rash. If any of these problems develop, see your ET nurse as soon as possible.

- Improper pouch angle. If the pouch doesn't hang vertically, the weight of its contents can exercise an uneven pull on the wafer, and cause leakage. Every ostomate must find his or her optimal angle, based on individual body configuration.
- Waiting too long to empty the pouch. Pouches should be emptied when one-third full or sooner. If allowed to overfill, the weight of the waste can break the seal and cause leakage.
- Extremely warm temperatures. Leakage in warm temperatures may be due to wafer 'melt-out'. More frequent pouch changes or a change in wafer material may be required to avoid leakage.
- Pouch wear and tear. If you are stretching your wear times to a week or more, leakage may be due to the wafer wearing out. Try more frequent pouch changes.
- Faulty appliances. Although it is not common, some batches of appliances can leave the factory with flaws. If you suspect your appliances have pinholes or faulty seams you should stop using items from that box, and report and return the unused items to your supplier. Manufacturers want and need to know if their products are not performing! *(Note: please don't send used faulty appliances through the mail . . . the manufacturer will take your word for it, honest.)*

## **WHAT ARE SKIN BARRIER RINGS AND HOW DO YOU USE THEM?**

People with chronic leakage and fitting problems, or very sensitive skin may find using skin barrier rings beneficial. The rings, or seals, as they are sometimes called, are similar to a flange, but made out of different material that is hypoallergenic and soothing to the skin. Rings come in two sizes and can be moulded or stretched by hand to custom fit around the stoma, and increase the adhesion of the flange, which is applied over top. Sometimes pieces of the ring material are all that's required to address a small problem area. You should see your ET for help learning to apply a barrier ring correctly. 'Eakin Seals' has been the most recognizable and popular brand of ring for many years, however, rival companies are developing their own versions. Each brand is worth your time to check out. Ask your supplier what's new on the market.

## ODOUR CONTROL

This is one of peoples' first major concerns. Colostomies tend to emit more odour than ileostomies because of the bacterial abundance in the colon. When sigmoid and descending colostomies are irrigated, odour is much less evident. Ileostomates experience almost continual peristaltic waves which sweep the ileum and prevent stagnation of the intestinal contents, thereby eliminating much of the bacterial growth that occurs with colostomies. Urine has a characteristic smell, but a foul odour could be a sign of infection. Certain foods will affect the odour of both feces and urine – eggs, onions, spicy foods, cabbage, and fish to name a few – you may want to cut down on your consumption of these if odour is bothering you. Proper appliance application is critical to avoid odour-causing leaks. Here are some other tips and products:

**Pouch deodorant.** All the major companies offer bottles of liquid ostomy deodorant. Try all the different products as individual body chemistry makes a difference in how well each brand works. A few drops of this in the pouch can help dispel unwanted smell. If you find these products too expensive cheaper alternatives are to put some regular mouthwash, toothpaste, peppermint or cinnamon in the pouch. Ostomy manufacturers are coming out now with gels and liquids that function as both pouch lubricant and deodorizer at the same time.

**CLEAN THE TAIL OF YOUR DRAINABLE POUCH!** Emptying regularly is important but just as important to odour control is wiping out the inside of the end of the pouch tail before you replace the clip.

Try to keep stool from collecting, or “pancaking” at the top of your pouch, as this can contribute to leaks and wafer undermining. Pancaking is a common annoyance, especially if you are spending a lot of time lying down or sitting. Clothing that restricts the top of the pouch can also cause pancaking. Try putting a tablespoon of mineral oil inside the top of the bag when you change it to help things slide to the bottom. Vegetable sprays work too, as do lubricating products from ostomy manufacturers.

Internal deodorant products. A popular over-the-counter tablet is Devrom (bismuth subgallate) available through your ostomy products supplier or at some pharmacies. These are chewable tablets taken right after you eat a meal, or more frequently throughout the day depending on how much effect you want. The usual dose is one or two tablets at a time. Devrom is pretty effective if you take it regularly and most people report it eliminates or reduces gas and stool odour. The drawbacks are you have to carry and remember to take the tablets. You can also purchase chlorophyll capsules at your local health food store, which produce a similar effect, that of neutralizing the bacteria which produces excess odour in fecal matter and gas. Devrom can turn your stool very dark and chlorophyll can turn your stool green. This is harmless. You'll need to experiment with internal deodorants to find which work better, and how much to take.

Powdered charcoal supplements are ineffective and can contribute to blockages in some individuals. Do not take these internally for odour control.

- Cranberry juice helps reduce odor for urostomates.
- Eat parsley! Next time you get a sandwich with parsley garnish don't throw it away! It's one of nature's best deodorizers.

You can spray room deodorant in the bathroom if you dislike the smell after you have emptied your appliance. Candles and incense work too. Some manufacturers market ostomy sprays you can use for this purpose.

Some people find that their appliances develop an odour that they dislike despite their best efforts to keep everything clean. Everybody's body chemistry is different and some folks can wear one brand without annoyance while others think it smells funny. If your appliance is fitting you well, you're not getting leaks and nobody else can smell anything but you still don't think it smells right, you might consider trying other brands. Changing the pouch more frequently often helps.

You'll be more self-conscious about scent for a while after you have an ostomy. This sensitivity will diminish over time as you gain in confidence and realize nobody is smelling anything.

## **SEX AND INTIMACY**

Resuming sexual relations after surgery can be an anxious time. What do you do with the bag? What if your partner finds it offensive? How do you tell a prospective partner about the ostomy? Can you have sex at all?

The answer to the last question is yes, of course. Women with an ostomy have no physical impediment to intercourse, although stenosis (narrowing) of the vaginal canal is a common side effect if your surgery required removal of the anal sphincter. If the anus has been removed, intercourse may be uncomfortable or painful. Generous use of lubricant is key, as is a gentle partner. Stenosis of this sort usually eases over time in sexually active women.

Men may face more challenges. Erectile dysfunction is more common after urostomy surgery than ileostomy or colostomy surgery. How long this lasts will vary depending on:

- type of surgery performed and how invasive it was; how much nerve damage may have occurred the man's age at time of surgery
- his general health condition

Returning to sexual relations may happen after a few weeks, or it may take months. For men, if you have healed well and are otherwise in good recovering health after six months and are still not happy with your sexual performance, you should see your doctor. Male impotence can hit anyone, not just those with an ostomy and your doctor has heard this before. Treatment prescribed usually consists of oral medication such as Viagra, Cialis or Livitra. In all cases, dosage, method, and possible side effects must be thoroughly discussed with your doctor.

## **PRACTICAL CONSIDERATIONS DURING INTIMACY**

It goes without saying that you should empty your appliance before intimacy and take care that you are clean and have no odour. Folding the bag up and taping it to your abdomen can get it out of the way and stop it from distracting you. (More than you're already distracted, that is.) If you are feeling self-conscious sometimes camisoles or lingerie from the "Adults Only" store can make things more discreet for the ladies. Men may keep a T-shirt on so

the appliance is less obvious. The plastic in some appliances can rustle in an annoying manner – those with fabric covering are quieter. It's a good idea to have some tissue, or a towel nearby in case of surprises. All ostomy manufacturers make appliances that can be used during intimacy – stoma caps or mini-bags. These are much smaller than a standard pouch and very discreet. How long they are effective depends greatly on what sort of ostomy you have and what its output patterns are. Colostomies tend to work slowly and only during certain times of the day, so you can expect to get several hours' use out of a cap or mini. Ileostomies will get much less time, depending on when you last ate. (Ileostomates often choose their intimate moments before eating in order to have less worries during sex.) Caps are not advised for urostomates; minibags will not have the capacity to last very long, either. Regardless of what kind of ostomy you have, if you want to give these products a try you should wear one for a while before engaging in sex to see how effective it's going to be.

When and how you choose to resume sexual relations is a very personal decision; above all remember that communication with your spouse or partner is essential. Talk about intimacy in advance and try not to put too much pressure on each other to do everything you did before right away. Remember that your spouse or partner may be as nervous and self-conscious as you are!

If your sexual practices before included outfits or other sexual paraphernalia there is no reason to give these up, just bear in mind that leather, lace and what have you must not cut into or restrict the stoma itself. If your rectum has been removed, anal sex is obviously no longer an option. For those who have been reconnected either via an internal pouch, or directly to the anal sphincter, anal sex is not recommended. Last, you should never insert anything into the stoma itself during sex – sexual misadventures of this sort, although uncommon, do happen and can result in serious injury. You've been through enough already to risk landing in surgery again.

Single people often worry about how to tell a new partner about their ostomy. How and when do you tell? Get to know the person before making the decision to take the relationship to the next step. When the time is right, explain to them that you've had surgery that has left you with some alterations to your body that will have an impact on intimacy. Answer any

questions honestly and simply. Never spring an ostomy on a new sexual partner without telling them well beforehand – you’ll be putting both of you in a potentially embarrassing situation. Just as it took time for you to get used to your body, others will need time, too.

Sexual rejection is hurtful for anyone, not just those with an ostomy. If someone you are interested in is suddenly not interested in YOU after they learn you have an ostomy, consider this a clear sign that they were not the right person for you in the first place. You must move on and remember there are many others out there with a less shallow outlook. Don’t let fear of rejection keep you from finding the right partner.



## SPORTS & EXERCISE



# SPORTS & EXERCISE

You should begin walking in moderation after your surgery and do this regularly, every day after you get home. Walking stimulates the return of bowel function and will get you back on the road to regaining the muscle you lost while in hospital. Whatever sports you may have played in the past, you can enjoy them again with few exceptions. Common sense is required, of course and this mean NO heavy lifting during the weeks immediately following surgery. Unless your surgery was done laparoscopically, your abdominal muscles will have been weakened by incisions and must be given adequate time to heal. Improper lifting, or lifting too heavy a weight too soon could cause a hernia. Again, NO lifting, not even a vacuum cleaner or laundry hamper for those first few weeks and then only introduce light loads gradually and carefully. If you want to return to the gym you can do this but you should avoid abdominal exercises for a while, and then only introduce these in gradual, gentle amounts. A personal trainer, if you can afford one, can work with you to develop a safe exercise regime.

Ostomates who regain previous fitness levels can and do return to a huge variety of sports and exercise – running, swimming, biking, snorkelling, golf, hiking, hunting, yoga, riding, team sports, triathlon – you name it. The list includes contact team sports as well - professional footballers have played with an ostomy. Unless your chosen sport before was power lifting or wrestling, you will probably be able to do it again.

## **PROTECTING THE STOMA DURING SPORTS**

Stomas are fairly hardy, but some common sense rules apply. Stomas should be protected from direct physical blows, from too tight clothing, and from rigid objects (ie: belt buckles) over them. Ostomates engaged in contact sports should protect their stomas by wearing a stoma guard and if desired, an abdominal /surgical support belt as well.

A stoma guard is similar in function to a male athletic cup and is held in place with an ostomy belt. Abdominal/surgical support belts aren't 'belts' per se, but more like corsets that close in front with velcro. They come in different sizes; you can make them as tight or loose as

you want. It's like wearing armour and can boost confidence if you're anxious about being bumped in crowds or groups. They can be worn under clothes but they're bulky and rather restricting.

The main danger to a stoma during strenuous sports is being cut or lacerated. Because the stoma itself has no nerve endings, you can be injured without knowing it. Causes of stomal laceration include shifting of the wafer, too small an opening, and rigid items too close to it. You don't want to overdo things, but stomas can withstand a bit of rough and tumble.

## **KEEPING THE APPLIANCE ON DURING SPORTS**

Ostomy belts are useful, as is taping the appliance around the edges. If you sweat a lot, you should check your flange periodically – you might need to change if a game is ongoing and you feel the appliance slipping.

## **AND VERY IMPORTANT...**

**HYDRATION.** Especially for ileostomates – drink lots of water if you're exercising, playing sports or just out for a long walk.

## **TRAVELLING, CAMPING AND PLACES FAR FROM HOME**

The cardinal and never-to-be-broken rule of air travel is: **CARRY ALL SUPPLIES ON BOARD IN YOUR HAND LUGGAGE.** No matter how reliable the airline, **NEVER** pack supplies in checked luggage. Lost supplies can be hard to locate and replace. At best, you'll waste valuable holiday time finding what you need. If you cut your own flanges, do so before you travel. Some lengths of ostomy scissors are now allowed onboard flights if you explain their use, but you can't be sure they won't be confiscated. Pack your scissors in checked luggage, and cut everything you'll need beforehand.

Current airline restrictions prohibit liquids over a very small amount from being taken onboard a flight. This can pose a problem on long flights for ileostomates who must maintain their fluid intake. If you cannot purchase water or juice in restricted areas, ask the cabin attendant for water or juice at the earliest opportunity.

Customs officials may or may not ask to inspect your hand luggage - if they do, don't worry about it. If asked what this is, tell them you have an ostomy and these are your appliances. They may or may not understand what an ileostomy or urostomy is; colostomy is generally a more familiar term. Security scans will not damage your appliances.

If your travels include long flights or bus rides, you may want to wear a larger appliance for this. Urostomates who know they may face unusually long delays between bathroom breaks may want to consider a leg bag. Ask for an aisle seat as close to the bathrooms on a plane as available; choose the back of a bus that has toilet facilities. For other modes of transportation, such as trains, just make note of where the toilets are. Cruise ships are an easy travel choice for ostomates plus they all have medical centres on board. A word of caution, however – 'medical centre' does not necessarily mean they stock ostomy supplies. Most do not and although the ship's doctor will be happy to issue a medical prescription for appliance purchase at the next port of call, the next port of call could be days away. **TAKE ALL SUPPLIES WITH YOU, ALWAYS.** Never rely on being able to purchase things 'along the way'.

The other cardinal rule of travelling with an ostomy is "PACK AT LEAST TWICE WHAT YOU THINK YOU'LL NEED". One good bout of traveller's diarrhea can go through a lot of appliances in a hurry!

Seat belts in cars or airplanes can pose a problem if they cut across your stoma. This may be uncomfortable and/or the stoma may not drain properly into the pouch. You may need to loosen the belt, or place padding between the stoma and the belt to even out the pressure.

If you like to hike and camp, take an adequate supply of plastic bags with you to deal with disposal. Don't you DARE bury used appliances in the woods!! Pack out all your non-biodegradable ostomy waste. Your water needs may be greater, so plan ahead for adequate safe water sources. An extra small pocket flashlight (something you can hold in your mouth so your hands are free) can be handy if you have to take care of things in the dark. Camping supply stores also market small lightweight headlamps that work well, too.

And one last thing . . . no, your bag is not going to blow up in an airplane. This is a myth, folks. It doesn't happen.

## **USING PUBLIC WASHROOMS**

If you need to empty your appliance in a public washroom, do it the same way you would at home. It's a good idea to carry a basic change kit with you when out and about if your ostomy is a busy one; if you need to change your appliance you can do this in a cubicle although finding a spot to set things down will require some ingenuity. You have a legitimate reason to use the handicapped stall if you need to change the appliance. If you've left quite a smell in the stall a spray or two with a little ostomy room deodorizer is a considerate thing to do for the next user but really, how many 'normal' people do that?

Don't rush or feel guilty about taking up extra time in a public stall. You do what you need to do. If you're feeling self-conscious about using a public washroom, consider this: before you had your surgery, how much attention did YOU pay to others in a public washroom? Chances are the only person who might take any notice of you will be another ostomate. People really aren't interested in what you're doing – they just want to do their business and get on with things. So should you.





## SPECIAL GROUP CONCERNS



# SPECIAL GROUP CONCERNS

## THE ELDERLY

Senior patients can face extra challenges not the least of which is fear of loss of independence with an ostomy. It's especially important that elderly patients (and their families, if possible) receive adequate instruction and coaching on appliance management before they leave hospital. As with almost all new patients, the senior ostomate will receive home care for a period of time to help them and their family adjust. The elderly patient's ET and doctor will assess how much assistance the person may need. Older patients are as capable of managing an ostomy as those much younger, but they may need more time to learn and remember new routines.

As we grow older, our skin loses elasticity and becomes thinner and drier, thus becoming prone to wrinkles and irritation. These changes can become problems for those who must wear an appliance all the time. To prevent leakage as the skin becomes more wrinkled, one should stand up straight when changing the appliance (using a mirror may help you see what you are doing).

The skin over the entire body tends to bruise more easily and heal more slowly as we age. Seniors need to be more careful when removing an appliance. Use two hands to remove the barrier – one to hold the skin down so it isn't being stretched unnecessarily, and the other to pull the flange off.

Arthritis and lessening dexterity can make it more difficult to snap a two-piece appliance together. You might consider a one-piece appliance to make this easier. Using scissors to cut the flange hole can get harder if your hands are stiff; order appliances with a pre-cut opening if cutting is becoming a chore.

## **INFANTS AND CHILDREN**

The same general rules apply for ostomy management with infants and children, although the appliances will of course be smaller. Unless specifically recommended by your ET nurse, do not use skin preps, paste and the like – your baby’s skin is tender and probably doesn’t need these products, anyway. You should check your baby’s appliance with each diaper change to ensure it isn’t leaking or slipping. You can bathe your little one without an appliance on, although in the case of a urostomy, you should check with your doctor about immersing your baby in water with an uncovered stoma. Lotions, creams and powders should be kept off the skin around the stoma. You can diaper your infant with the pouch in or outside of the diaper, depending on the location of the stoma. Try different ways to see what works best.

One of the biggest challenges can be trying to change the appliance on an active infant! If you can, plan a pouch change when your baby is quieter, perhaps in the morning or after a bath. Choose a time when you know the stoma will be less active. If your baby is upset and crying, wait for a bit. Cuddle him or her and give them time to calm down. When they’re in a happier mood, the whole process will go more smoothly for both of you!

Having your spouse nearby, or an older sibling can be an advantage – the extra hands may be needed plus another person can entertain or distract an active baby during a pouch change.

Babies and small children are naturally curious and will pick or pull at the appliance once they discover it. One piece outfits can help discourage this exploration.

## **OSTOMATES RECEIVING CHEMOTHERAPY**

What chemotherapy drugs your oncologist decides you should receive will vary depending on your cancer stage and type of cancer. You will be coached regarding how to deal with potential side effects. Chemo drugs may have no effect on your skin or stoma, or you may experience some changes:

## **ALL OSTOMIES:**

### **1. Peristomal skin reactions**

- Skin is more difficult to heal due to increased or decreased blood counts. Take extra care when removing the flange – use two hands
- Chemotherapy may cause deep red or purple skin discoloration under the pouch faceplate. Small red spots may appear under the flange due to decreased platelet counts as on other areas of skin – let your physician know if this occurs.

### **2. Stoma Reactions**

- Stomatitis - small ulcers may appear on the stoma as on the rest of the gastrointestinal tract. Your physician may recommend that stoma irrigation be stopped until stomatitis resolves itself. Don't use solvents or irritating substances on the stoma.
- Due to decreased platelet count, the stoma may bleed when touched.
- Peristomal skin may be more prone to infection.

## **COLOSTOMIES AND ILEOSTOMIES**

### **1. Diarrhea**

- Possible reaction to chemotherapy; monitor amount of stool output; inform physician if increased significantly above normal.
- Drink adequate amounts of fluids. Nausea can sometimes make drinking enough fluids difficult; if you're having trouble, be sure you're taking your anti-nausea medication properly.
- Eat foods to help thicken stool, ie. applesauce, cheese, white rice, bananas, peanut butter, plain tea and boiled milk.
- Stay away from fatty foods, highly spiced foods and foods or beverages which cause gas or cramping.
- Potassium is lost in diarrhea and needs to be replaced. Foods high in potassium include orange juice, potatoes, bananas, soybeans, avocados, apricots, pomegranates, parsnips and turnips. Gatorade and similar sports drinks do not have high amounts of potassium, but can be helpful if that's all you can get down.

## **2. Constipation**

- An occasional reaction to chemotherapy (may also be a reaction to some pain medications such as codeine)
- Drink adequate amounts of fluid, as above. Prune juice daily may be helpful.
- Eat foods with a laxative effect, ie: raw fruits and vegetables, chocolate, coffee, cereals, bran, whole wheat bread, dried fruit and nuts. (Remember to be cautious and eat dried fruit, nuts and raw foods in moderation. Start with small amounts and chew THOROUGHLY.)
- Try to stay away from strong laxatives

## **UROSTOMIES**

Check carefully for skin infections, especially yeast, which can look like a rash, red spots, or weeping, irritated areas. Your ET nurse should check your skin if you suspect a yeast infection. Some chemotherapy may turn urine colours – don't be alarmed. Adriamycin turns urine red, methotrexate turns urine yellow. If any blood is noted in the urine, report this to your physician immediately. Some chemotherapy drugs need to be adequately flushed from the kidneys – cytosan, cisplatinum. Drink LOTS of water.

## **GAY AND LESBIAN OSTOMATES**

Gay and lesbian ostomates have all the same issues as the straight population, with the added concern that some may be uncomfortable seeking support outside of the gay community. Please – be upfront with your nurse or doctor about your orientation. It will help them avoid assumptions regarding your sexual activities and social situation. If you wish to speak with another gay ostomate, ask your ET nurse. They've had gay patients before and can often put you in touch with them. In addition, your local UOAC chapter can often connect you with a gay or lesbian member or associate.

If your surgery has or is going to involve the anus/rectum, it's imperative that sexually active gay men discuss this with their surgeon as this activity may no longer be an option.

## MUSLIM OSTOMATES

The Islamic faith has very definitive rules that must be followed in preparation and during the time of prayers. The question has arisen about the wearing of a pouch during the time of prayer. Mr. Mohamed Hanafy Ahmed, when he was the General Manager of ConvaTec, Middle East, petitioned Fatwa Commission of the AL-AZHAR University for a ruling. The Fatwa Commission is the official Islamic body governing such matters worldwide and is located in Cairo, Egypt. The following submission is an English translation of the official response as a service to ostomates of the Islamic faith.

Question -

“There is a large group of patients afflicted by colon and bladder cancer where the malignant tumor has to be removed together with the vital organ of the body so as to prevent the spread of disease. In such cases the natural opening of the body is by-passed and replaced by a stoma in the abdomen to work as an outlet through which urine or stool is emitted in an involuntary manner. Pouches used for collecting such matter are replaced when necessary.

At the time of prayers, the stoma patient is unable to change the pouch. Is it possible for such a patient to pray while the pouch is carrying such excrements and what is the rule in such a case ?”

Answer -

Praised be Allah, Lord of all creatures and peace and prayers be upon the master of messengers Mohamed, his Kin and his followers.

“In answer to this question, we reply that whoever is in such a situation is considered to have a religiously legitimate excuse. Since a stoma patient cannot replace the pouch for each prayer, he may perform absolution at the onset of each prayer interval. He may then pray as many times as he may wish during this prayer interval. At the onset of a new prayer interval, the absolution performed in the last interval is no longer valid and the stoma patient should perform a new absolution for the new prayer interval and so on (for each of the five prayer intervals.)

Chairman of Fatwa Commission of AL-AZHAR

Abd Allah Abd-Alkalik Al Mishad

8 Jumada 1, 1407

8 January 1987



## MOST COMMONLY ASKED QUESTIONS



# MOST COMMONLY ASKED QUESTIONS

## **CAN YOU BATHE AND SHOWER? DO YOU HAVE TO WEAR THE APPLIANCE WHILE DOING THIS? CAN YOU GO IN A HOT TUB?**

YES OF COURSE you can bathe and shower. You can take the entire appliance off too, if you want. (Remember, though that you can't re-use the flange; a fresh one must be applied.) Showering is good for your skin circulation and makes you feel wonderfully clean. Plus it's nice to take that appliance right off on occasion. A shower head that is set to a hard spray may feel uncomfortable on the peristomal skin (the skin right next to the stoma) so you may need to adjust the spray to a more gentle setting. But unless you've got a real blaster of a shower you won't hurt your stoma if the spray hits it. If it feels comfortable, spray away. If not, cover your stoma with your hand or stand in such a manner that it's out of the line of fire. What if your ostomy starts working while you're in the shower? Don't worry about it. Rinse yourself and the tub/stall extra well and throw a little cleaner down the drain. You can take long baths too but ileostomies and urostomies should keep the appliance on for this. Tape the filter closed. Your flange will begin to melt off the longer you're in there and may need to be replaced when you get out. All ostomates can go in a hot tub as well, but you may want to tape the edges of the flange so it'll hold. You may need to change the flange when you get out if it's melted down too much.

## **CAN YOU SWIM? SNORKEL? DIVE?**

Definitely. If you have a filter on your appliance this should be taped so water doesn't damage the filter. Filters work poorly or not at all once they're wet or even damp. Some people tape the flange edges, some don't. If you've changed your flange before swimming it's a good idea to wait an hour before going in to make sure it has adhered properly. If you wear any sort of wet suit for water sports you should of course empty the appliance before suiting up and you may need to come back up to re-empty sooner than your diving companions. You don't necessarily have to buy special swim suits to go swimming. One piece or two-piece swimsuits that are high enough to cover the appliance work well for women. Consider buying something with a pattern or a skirt to make the outline of the appliance less

visible. Board shorts are a popular choice for men who may opt to also wear biking shorts underneath for extra security. Remember that the great majority of 'normal' people have lumps, bumps and imperfections on their bodies – very few of us are model-perfect in the first place – and nobody is going to be staring at you. There are ostomy swimwear companies that make custom clothing if regular suits aren't working for you.

## **WHAT IF IT MAKES A NOISE IN PUBLIC?**

There is no way to stop your ostomy from expelling gas. Ileostomies and colostomies can and will emit gas, which may or may not be audible to others. Snug clothing can help muffle a noisy stoma, as can a hand or forearm pressed over it. Stoma noises often sound the same as a rumbling stomach and since the sound is coming from the front of your body people often assume it's just your stomach if they notice any sound at all. Ambient noise or clothing makes most stoma noises inaudible, but if this is embarrassing you, consider cutting down on or eliminating gas-producing food or drink. Bear in mind that you're going to be hyper-sensitive to your own stoma sounds for a while. What sounds loud to you may not even be noticed by others. A polite 'Excuse me' works as well!

## **SOMETIMES THE STOMA BLEEDS — WHAT DO I DO?**

Stomas will bleed if cleaned too roughly, if the appliance is improperly applied, or if you accidentally scratch them with fingernails or cloth. This is normal and looks like spotting; it should stop soon if you dab the spots with tissue. Some stomas will bleed more easily than others, and certain medications (such as aspirin) can increase the likelihood of bleeding. Prolonged bleeding, increased amount of bleeding or very easy bleeding may indicate other problems and should be reported.

## **NOTHING HAS COME OUT ALL DAY — IS SOMETHING WRONG?**

Just as people with an intact set of bowels can get constipated, so can you if you have a colostomy. So long as you feel well otherwise, periodic inactivity doesn't mean anything is wrong. Drink grape or prune juice if things haven't moved in a 24 hour period. Give your body a chance to sort itself out before resorting to laxatives, and if you do, take such products sparingly.

Prolonged lack of output from an ileostomy or urostomy is NOT normal and should be reported to your doctor or ET.

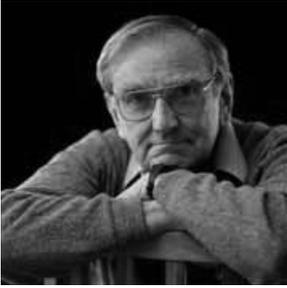
## **CAN I WEAR THE SAME CLOTHES AS BEFORE?**

In most cases, yes! Make sure, if possible, to have your stoma site properly located by an ET nurse before surgery. It should be placed in a spot that won't be irritated by the type of clothing you like to wear. While you are healing you may want to wear garments with a loose waistband, such as track pants. Swelling in your abdomen after surgery will subside and in most cases, patients can return to the wardrobe they liked before surgery and this can include form-fitting outfits. If you liked wearing extremely tight jeans or pants before, unfortunately it might be best to give those away. Pants that are really tight over the stoma won't allow waste to drop properly into the bag.

Depending on body type, some stomas may have to be located higher than usual. If this is the case with you, you can opt to wear pants or skirts higher in the waist. Or, you can take the opposite approach and wear your clothing lower on the hips with a shirt worn out over top. Men sometimes find suspenders to be a good addition to their wardrobe.

## **WHEN CAN I RETURN TO WORK?**

Your doctor will be the best judge of when you are fit enough to resume work. If your job involved heavy physical activity, you need to let your doctor know this so he or she can recommend any changes in duties that may be necessary. In most cases patients can resume their former employment without problems. It can take months to regain former strength and stamina however, so you should discuss the possibility of shorter hours or part-time shifts with your employer for the first few weeks. It's also best to explain that you may need to take more bathroom breaks than before. (It could also be possible that you won't need to use the bathroom as often as you did before!)



## TIPS & TRICKS



## TIPS AND TRICKS

- The best tip for changing an ileostomy is to be prepared and organized before you start, and do your change as efficiently as possible. The more you wipe and fool around with the stoma, the more opportunity it will have to produce output when you least want it to.
- To help stop ileostomy discharge during a change, delay eating a meal and eat a couple of marshmallows up to 30 minutes before changing the appliance.
- Put a few drops of baby oil or spray some Pam inside the top of the pouch to prevent stool from collecting at the top.
- Use two hands to remove a flange – one to hold the skin down and the other to gently peel the flange off. Try to minimize how much you are stretching or pulling on the skin.
- Write the day you change your appliance in ink on the outside of the barrier itself to help you remember when it's time to change again, or keep a calendar in the bathroom for this purpose..
- If using a hairdrier to speed up drying of the peristomal skin (the skin next to the stoma) during a change keep it on LOW setting. High heat can burn delicate stoma tissues.
- If your paste tube has become too hard to squeeze, put it in a glass of hot water for 20 minutes.
- If you are being admitted to hospital for tests or any other reason, take your own ostomy supplies with you! The hospital may not stock what meets your particular needs, or attending nurses may not be familiar with ostomies. Even if the hospital has what you require, it may take a bit of time to locate it.
- If shaving abdominal hair, use an empty cardboard toilet roll as a shield around the stoma. Shave in the direction of hair growth.
- Oatmeal added to your bath can relieve itchy skin. Pour some oatmeal into a cloth bag or a piece of cheesecloth, tie it shut and put it into the bathwater. You can also use the oatmeal bag like a sponge to soothe irritated skin.

- Don't use alcohol to clean the peristomal skin.
- Don't use the same pouch too long. Seven days is the maximum recommended. Pouches become saturated with odour which cannot be removed.
- If you use skin sealant, make sure it dries completely before applying the flange.
- Pay attention to skin problems. Address signs of skin irritation immediately. If you're not sure what to do, call your ET.
- Don't wrap the drainable pouch tail around and around the clamp before closing it. This will not make the clamp work better, it will just spring it out of shape. Replace your old clamp with a new one if it shows signs of loosening.
- Don't let the pouch get full before emptying. Excess weight will separate a two-piece system and will also put too much weight on the skin barrier resulting possibly in multiple problems. Empty the pouch when it is about one-third full, or sooner.
- You don't need to wear gloves to change your appliance. When you were discharged from hospital, your kit may have contained latex gloves. Since your nurses and doctors usually wore gloves when tending to you, you might be led to believe you should always wear gloves when changing your appliance. There is no need to wear such things while maintaining personal hygiene. (Have you had children? Did you wear gloves when changing your little ones' diapers? Of course not. You're no more unclean than they were.)
- If urine is collected for urinalysis be sure your doctor and nurse know a sterile specimen must be taken directly from your stoma and not from the pouch. Bacteria builds up in the pouch quickly and may give false test results. If they are not sure how to do this, do the following.

- remove your pouch
  - clean the stoma
  - bend over
  - catch the urine in a sterile cup
  - Try tips from other ostomates that might apply to issues you have but remember everyone is different. What works for one person may not work for another but it's worth a try.
- Perhaps the most important bit of advice is don't get down on yourself if you make mistakes! We've all made mistakes and sometimes we still do. Learn from any errors you may make and keep moving forward.



## EMOTIONAL ISSUES FOR THE PATIENT AND THEIR FAMILY



## COMING HOME

You will be discharged from hospital after your doctor and/or ET nurse is confident that you have recovered sufficiently from your surgery and understand the basics of stoma management. No doubt you will be glad to be in familiar surroundings again but coming home with a new ostomy can be a difficult time. The reality of what has happened may hit once you are out of the hospital, away from the everyday routine of the ward, once the visitors and flowers are gone. It may be a shock to discover that you feel worse, emotionally, when you get home. You wouldn't be the only one who has felt that way.

Give yourself time. You'll feel weak and uncomfortable during the early weeks or months and may wonder if you'll ever feel like your old self again. The task of caring for a new ostomy can seem overwhelming and you may feel dismayed at all the new things you need to do and remember. You may experience sadness, frustration, anger or depression – all these feelings are normal and we all went through them in the beginning. Just as it takes time for the body to heal, it also takes time to heal emotionally from this kind of surgery. It's common to have negative feelings and far better to release them through tears or talking than to bottle them up. Negative feelings or withdrawal cannot be allowed to become a way of life, however. Fundamental management techniques must be learned, and new experiences or problems that may develop can be met and managed as they occur. As you learn and master the skills needed, you will gain in confidence.

You don't have to like your ostomy. You DO have to learn how to live with it.

Ostomy patients can fear being shunned or pitied by others. We have all felt the dread of losing our independence, our self-confidence and our dignity. Such reactions are universal and valid. It's important, however, for the new ostomate to realize that how they see themselves will be how others see them. If you are embarrassed and ashamed, those around you will reflect that. If you think you can't do something and refuse to try, others will gradually assume you are incapable. You have a responsibility to live your life fully and to provide an example of triumph over adversity, courage over despair and pride over pity.

There is no answer for “Why Me?” No illness or injury is fair. Rather than question why this has happened to you, give some thought to how you will live your life from this point on, for you have indeed been given a second chance. Not all patients get to come home from hospital. You did.

## **SPOUSES, FAMILY AND CAREGIVERS**

This is a change in your life, too. Your loved one may cope well with the ostomy and resume former activities at a surprising rate. Some individuals need more time to regain their confidence. There is no set timetable, we all adjust at our own speed. It is important however, for a new patient to resume their normal routine as before, and to learn to manage their ostomy by themselves. Unless your family member is physically unable to change their own appliance, they should not be relying on you to do this for them. Independence is vital to regaining self-esteem. Dealing with a new ostomy can be frustrating so encouragement and patience may be needed.

Just as a new ostomy patient can feel overwhelmed with it all, you may feel overwhelmed yourself. If this is the case, seek out other spouses or caregivers with whom you can share your feelings. SASO (Spouses and Significant Others) is a volunteer group formed by spouses and partners of ostomates for the purpose of providing support and encouragement to the spouses, partners, parents, families, friends or caregivers of new patients. Contact your local UOAC chapter for SASO contacts in your area.

## **ABOUT THE VANCOUVER UOA**

The Vancouver Chapter of the United Ostomy Association began as the dream of Miss May Fawcett, a forthright, outspoken, Fort Macleod, Alberta, school teacher who moved to Vancouver in the 1950's and worked as a salesperson for a major Vancouver printer, until her passing in St. Paul's Hospital in 1987.

May had her ileostomy surgery in 1967 at St. Paul's and soon discovered there was no organized help or support for ostomates in British Columbia. Once they left the hospital, new ostomates pretty much had to experiment and figure things out on their own with the help of eager, but inexperienced salespersons in the ostomy appliance retail shops. Miss Fawcett, mercifully, set out to change all that.

In 1968, with the help of her surgeon, Dr. E. N. McHammond and his brilliant and dedicated associate, the now retired, Dr. Kenneth Atkinson, May set about organizing a local support group for new and existing ostomates in the Vancouver area and in the summer of 1968 the Ileostomy Association of British Columbia (IABC) was registered as a non-profit Society with the Provincial Government in Victoria, with May as President and Bea Brail as Treasurer. There were 30 members, annual membership fees were \$3.00 and monthly meetings were held at G. F. Strong Rehabilitation Centre at 900 West 27th.

From the beginning the IABC affiliated with the United Ostomy Association in the USA, headquartered in Los Angeles. Miss Fawcett also volunteered as a Provincial Representative and was instrumental in organizing Ostomy Chapters throughout British Columbia and Alberta.

In November of 1970 the IABC became the United Ostomy Association of British Columbia and later the Vancouver Chapter of the UOA.

On June 12, 2000, the Vancouver Chapter, along with almost all other Canadian Chapters, bid a fond thank you to the wonderfully helpful UOA in the USA and joined the new Canadian group, the United Ostomy Association of Canada. The UOAC was formed in 1991, after lengthy and tireless efforts of the late Allan Porter of the Hamilton, Ontario chapter.

The Vancouver Chapter serves North and West Vancouver, Burnaby, Richmond and Vancouver.

## **RENFREW COUNTY OSTOMY SUPPORT GROUP**

The Renfrew County Ostomy Support Group was established because of a lack of support mechanisms for ostomates in the health system.

Many ostomates in Renfrew County found very limited support mechanisms in place following their surgery. Patients often found themselves having to experiment and learn how to take care of themselves and their appliances. The only practical support in the field was from companies supplying ostomy appliances and from ostomy nurses in Ottawa - a long drive for many whose mobility was limited.

This shortage of resources in Renfrew County caused serious problems for ostomates who needed help. With growing frustration and with strong feelings of isolation, a small group of ostomates came together to share their stories and to discuss the practices which allowed them to cope and to deal with the problems that made normal living difficult. This peer network gradually expanded. It became clear that there was real benefit to the sharing of experiences and practices.

In 2012, with much appreciated help from the already established Ottawa Ostomy Support Group, the Renfrew County Ostomy Support Group was established as a grass roots organization to help patients cope with the life altering conditions brought about through ostomy surgery.

The Group focuses on bringing ostomates together in semi-annual meetings to address problems, provide education and discuss experiences in a safe, non-judgemental environment. The meetings include helpful presentations from suppliers, health care professionals and ostomates.

The best outcomes have resulted from the informal discussions after Group meetings where ostomates benefit from the advice of peers who have made the adjustment. Practical help is provided through a system of clinics held throughout the county by qualified ostomy nurses. Historically, the clinics have been sponsored by suppliers and retailers. However, in 2018, the clinics were delivered by Carefor, Pembroke through funds provided as a grant from the Champlain LHIN. The Group advocates for adequate financial support through programs such as the Federal Accessibility Tax Credit and the Provincial Assistive Devices Program. An ongoing priority has been to increase awareness amongst health professionals of the day to day needs of recovering patients.

### **OUR MISSION**

We are a not-for-profit, grass roots organization, most of whom are ostomates themselves. Volunteers help those with ostomies and their families to live happy, normal lives. Our work is focused on support education, advocacy and collaboration

**If you would like to connect with a volunteer, please call: 613-638-6220.**

*Medical professionals please note: Volunteers provide encouragement and support. We DO NOT give medical advice or physical care.*

## OSTOMY MANUFACTURERS

The most prevalent brands of ostomy products in Canada are Convatec, Coloplast and Hollister. Less well-known but definitely worth a look companies are BBraun, Colo-majic and Active Lifestyle Products. We strongly encourage all those with an ostomy to try new products and experiment to find the best possible match for your needs. **Ostomy companies want you to try their products!** Don't be shy about contacting them. All will supply free samples upon request. This is an ideal way to 'test-drive' different products without cost. The following companies have toll-free numbers you can call to request samples. When calling, you should specify the type of ostomy you have, what your stoma size is, and any particular concerns you may have.

Not sure what size your stoma is? You should have been given a measuring template by your ostomy nurse, or you will find one in your current ostomy supplies. If you have misplaced or lost these, your nurse or any supplier will gladly give you one free of charge.

It can take time and some trial and error to find the right products for you. Free samples can take up to several weeks to arrive, so be patient.

### CONVATEC

Toll-free phone: 1-800-465-6302 or 613-266-1401

[www.convatec.com](http://www.convatec.com)

Monday to Friday, 8:00 am to 7:00 pm

### COLOPLAST

Toll-free phone: 1-866-293-6349 or 613-240-3863

[www.coloplast.com](http://www.coloplast.com)

Monday to Friday, 8:00 am to 6:00 pm

### HOLLISTER

Toll-free phone: 1-800-263-7400 or 613-296-8707

[www.hollister.com](http://www.hollister.com)

Monday to Friday, 7:00 am to 5:45 pm

ACTIVE LIFESTYLE PRODUCTS 877-820-7008

COLO-MAJIC DISTRIBUTION CANADA 866-611-6028

## **OSTOMY SUPPLIERS**

The pharmacies below have a product selection on site. If you are not sure where to go, consult your ostomy nurse for an ostomy appliance retailer nearest to you. Not all retailers have a large stock of ostomy supplies, but many can special order supplies to suit the needs of individuals. Almost all pharmacies have senior's days approximately once per month. Ask your pharmacist for the details of how to take advantage of this price reduction.

### **Mulvihill Drug Mart**

1231 Pembroke Street West - 613-735-1079 contact Nancy

### **Rexall Pharmacy Group**

215 Pembroke Street East - 613-732-1931 contact Theresa

### **Aikenhead's Drug Store**

222 Raglan Street Renfrew -613-432-8866

### **Conway's Pharmacy**

251 Bridge Street Eganville 613-628-0208

### **Village Pharmacy**

7 Lake Street Killaloe -613-757-2281

### **Cahoon's Pharmacy**

95 Deep River Road -613-584-1116

### **Rexall Drug Store**

22 Baskin Drive E. Arnprior -613-623-6591

**Lorraine's Pharmasave**

19566 Opeongo Line Barry's Bay -613-756-2013 contact Gloria

**Pharmasave**

1188 Highway 60 Golden Lake -613-635-1112 contact Livia

## **OSTOMY HEALTH RESOURCES**

### **Nurses Specialized in Wound Ostomy and Continence (NSWOCs)**

In addition to specialist nurses in Ottawa there are a number of NSWOCs throughout Renfrew County:

**Kelly Mazerone** - Arnprior - kellym@access-healthcare.com

**Jennifer Niitynen** - Beachburg 613-312-9799

**Jessica Denomy** - Renfrew - denomyj@renfrewhosp.com

### **Area Hospitals**

**Pembroke Regional Hospital** 613-732-2811

**Renfrew Victoria Hospital** 613-432-4851

**St. Francis Memorial Hospital Barry's Bay** 613-756-3044

**Arnprior and Distric Memorial Hospital** 613-623-3166

**Deep River and District Hospital** 613-584-9118

## **THE OSTOMY GRANT PROGRAM IN ONTARIO ASSISTIVE DEVICES PROGRAM (ADP)**

### 1. Who is eligible?

Ontario residents who have a permanent colostomy, ileostomy, urostomy, ileal conduit or continent pouch/reservoir

### 2. Who is not eligible?

- a) Persons who have had surgery resulting in a temporary ostomy
- b) Persons who reside in chronic care hospitals or Ministry of Community and Social services Residential Facilities or Ministry of Health facilities, as these facilities provide ostomy supplies to their residents.
- c) Persons receiving financial assistance for their ostomy supplies from the Workplace Safety & Insurance board (WSIB) or Group A Veterans

### 3. Grant Application Form – Obtain the form from:

**Ministry of Health and Long-Term Care**

**Assistive Devices Program**

**5700 Yonge Street, 7th floor**

**Toronto, ON M2M 4K5**

**416-327-8804 Toronto**

**1-800-268-6021 Toll-free**

**1-800-387-5559 TDD (for the Deaf)**

Fill out the form in full.

Have a doctor or nurse practitioner sign and date the bottom of the form.

Send the completed form to the above address.

### 4. Grant Amount

If you have one ostomy, you are eligible to receive \$975 yearly. If you have two ostomies, for example, a colostomy and a urostomy, you will receive \$1,950 per year. If you are receiving social assistance benefits under Ontario Works, Ontario Disability Support Program or Assistance to Children with Severe Disabilities, you are eligible to receive \$800 per ostomy. Residents of Long Term Care facilities are eligible for \$800 per ostomy.

5. Payment

Two cheques in equal amounts, the first about six weeks after application receipt, and the other about six months later. To set up direct deposit, call 1-800-267-9458

6. Renewal

Every two years ADP sends a renewal form to be filled out in full.

Promptly fill it out to continue receiving the grant. Failure to notify ADP of address, name or bank changes, or loss of OHIP card will result in delay of payment. It is very important to send in the renewal promptly.

## **OTHER RESOURCES**

1. Private insurance plans may cover overages from what ADP pays.

Check with your insurance company regarding reimbursement for your additional costs. Please keep all receipts to verify costs.

2. Veterans Affairs can be contacted for a Veteran's coverage.

## **USEFUL WEBSITES**

The internet has radically changed how we gather information and network with other ostomates. From product information, advances in treatment and surgical technique, to fellowship and support, there is a wealth of information on line. Just as we encourage new ostomates to try different products and to join and participate in local UOAC chapters, we encourage those with access to a computer to look into some of the following sites. They will inform, entertain, reassure, and above all, let you know you are not alone.

## **OSTOMY FORUMS**

These forums deal with every conceivable ostomy type, issue and concern. All are free, as anonymous as you wish, and moderated for taste and privacy. These are not chat rooms, although some have chat areas.

### **Shaz's Ostomy Pages**

**(<http://st80.startlogic.com/~ostomate/cgi-bin/yabb2/YaBB.pl>)**

This site is the largest forum to date; Australian in origin. Participants are world-wide with over 2,000 members.

### **A Young Person's Guide to an Ostomy**

**(<http://www.ostomyland.com/cgi-bin/yabb/YaBB.pl>)**

British forum with world-wide participants. Good subsections for all categories.

### **UOAA Ostomy Forum**

**(<http://www.uoaa.org/forum/viewforum.php?f=2&sid=4522f8de40871f8f31dbc4c1cbc59d8d>)**

This replaces the previously disbanded UOA forum and is United States-based. This forum is world-wide, active and growing.

### **Ostomy Association of Southwestern Indiana**

**(<http://p207.ezboard.com/bostomyforum66946>)**

Recommended for its extensive newsletter archives/tips & tricks sections. Electronic newsletter is available free online.

### **CARECURE Community**

**(<http://carecure.org/forum/search.php?searchid=335369>)**

Although this area is primarily devoted to providing a forum for those with spinal cord injuries, there is a sub-section for those with both an SCI and an ostomy.

## **OSTOMY ASSOCIATION WEBSITES**

### **United Ostomy Association of Canada Inc.**

[www.ostomycanada.ca](http://www.ostomycanada.ca)

### **Vancouver United Ostomy Association**

[www.vcn.bc.ca/ostomyvr](http://www.vcn.bc.ca/ostomyvr)

### **Renfrew County Ostomy Support Group**

[www.renfrewcountystomy.ca](http://www.renfrewcountystomy.ca)

### **Niagara Ostomy Association**

[www.niagaraostomy.freewebsitehosting.ca](http://www.niagaraostomy.freewebsitehosting.ca)

### **Ostomy Toronto**

[www.ostomytoronto.com](http://www.ostomytoronto.com)

### **United Ostomy Support Group, Ottawa Inc.**

[www.ostomyottawa.ca](http://www.ostomyottawa.ca)

### **International Ostomy Association**

[www.ostomyinternational.org](http://www.ostomyinternational.org)

### **United Ostomy Association of America**

[www.uoaa.org](http://www.uoaa.org)

## **MISCELLANEOUS WEBSITES**

### **Colorectal Cancer Association of Canada**

[www.ccac-accc.ca](http://www.ccac-accc.ca)

### **Canadian Society of Intestinal Research**

[www.badgut.com](http://www.badgut.com)

### **Canadian Cancer Society**

[www.cancer.ca](http://www.cancer.ca)

### **Crohn's and Colitis Foundation of Canada**

[www.cfcf.ca](http://www.cfcf.ca)

### **Dial-a-Dietitian (free nutritional advice — BC-based)**

[www.dialadietitian.org](http://www.dialadietitian.org)

### **Canadian Paraplegic Association**

[www.canparaplegic.org](http://www.canparaplegic.org)

### **Canadian Association of Enterostomal Therapy**

[www.caet.ca](http://www.caet.ca)

### **Spina Bifida and Hydrocephalus Association of Canada**

[www.sbhac.ca](http://www.sbhac.ca)

### **Community Care Access Centres**

[www.ccac-ont.ca](http://www.ccac-ont.ca)

UOA Vancouver, Canada wishes to thank the following publications, associations, websites and manufacturers for reference material:

United Ostomy Association of Canada  
Evansville Re-route  
Ostomy International Magazine  
Metro Halifax Ostomy News  
Regina Ostomy Newsletter  
The British Hernia Centre  
Ottawa Ostomy News  
Coquitlam UOA  
Ostomy Toronto  
Prince George Ostomy Hotline  
Coloplast  
Convatec  
Hollister  
CyMed  
Nu Hope  
Marlen  
Ostomy International  
Winnipeg Ostomy Association  
New Directions, Ft. Worth, TX  
Stratford & District, ON  
Mayo Clinic On-line  
Wound, Ostomy and Continence Nurses' Society

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