



Crohn's and
Colitis Canada
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BETTER THAN EVER

LIVING LIFE WITH AN OSTOMY



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BETTER THAN EVER

The world feels like it has changed; you or a loved one has recently undergone surgery and now has either an colostomy or an ileostomy. The thought of an ostomy may be overwhelming.

Are you asking yourself things like: How will I cope? Will others know? Will there be a smell or sound coming from the pouch? How do I bathe or shower? Can I participate in sports? How will my partner react to this “thing” and will I still be attractive?

In spite of how you are feeling today, Crohn's and Colitis Canada wants to reassure you that your life is about to get much better.

Post-surgery, you are going to discover that the removal of the diseased portion of your bowel improves your health and that an ostomy (both a colostomy and an ileostomy) can fit into your lifestyle. You will discover that an ostomy will not hold you back from the things you want to do. The information we have in this booklet can help you successfully adjust to having an ostomy and live your life to the fullest. Life doesn't end with an ostomy – it can be better than ever.

HOW CAN AN OSTOMY BE BETTER?



Your first reaction may well be “How can this be better?” Understandably, you may feel angry and upset about the changes happening to your body and the need to wear an ostomy appliance. In spite of that, there are advantages. First and foremost, the section of diseased bowel that has caused you so much trouble in the past has now been removed. With that comes relief of pain, abdominal cramping and diarrhea associated with an inflamed intestine. Your health will improve, your energy levels will increase and your zest for life will revive.

Even better, those desperate urges to find a bathroom at inconvenient times have also been eliminated. You now have the security of knowing that you can venture out into the world without having every bathroom in the vicinity mapped out “just in case.” An ostomy does not tie you down or limit you – it gives you freedom! You can live a normal, active life – just like everyone else.

CROHN'S DISEASE AND ULCERATIVE COLITIS

Crohn's disease and ulcerative colitis are both conditions that are known as inflammatory bowel disease (IBD). For people with Crohn's or colitis, the symptoms of an inflamed intestine can be painful and debilitating. Certainly the symptoms can be very disruptive to a person's lifestyle.

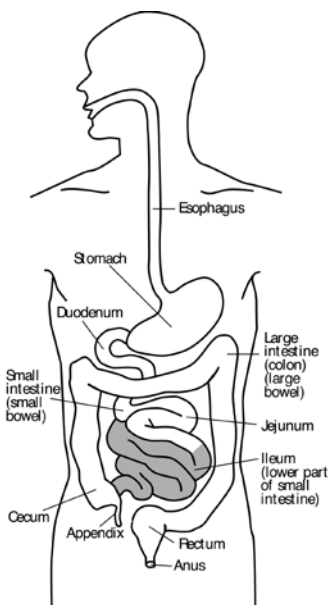
Fortunately, modern medicine has a vast array of tools to help people with Crohn's or colitis, which include medication and surgery. This booklet addresses one of the possible outcomes of surgery, known as an ostomy.

Crohn's and Colitis Canada understands that having an ostomy is a significant physical and emotional event in a person's life. For that reason, we want to provide you with an introduction to what an ostomy is and information to help you successfully manage your colostomy or ileostomy.

You will find that talking with people who have gone through what you are facing will give you the support and encouragement needed to help you get back to your physical and emotional well-being.

You will also find out that you are not alone. Crohn's and Colitis Canada is here to help you!

THE DIGESTIVE TRACT ("GI" TRACT)



Let's begin with an overview of your digestive tract. The digestive tract or gastrointestinal (GI) tract is a system of tubes that starts at your mouth and ends at your anus. When you eat and drink, food travels through your esophagus (the tube from your mouth to your stomach), then on to the stomach, small intestine (small bowel or ileum), large intestine (large bowel

or colon), your rectum and finally your anus. Nutrients are absorbed in the small intestine and water is absorbed from the feces as it passes through the colon.

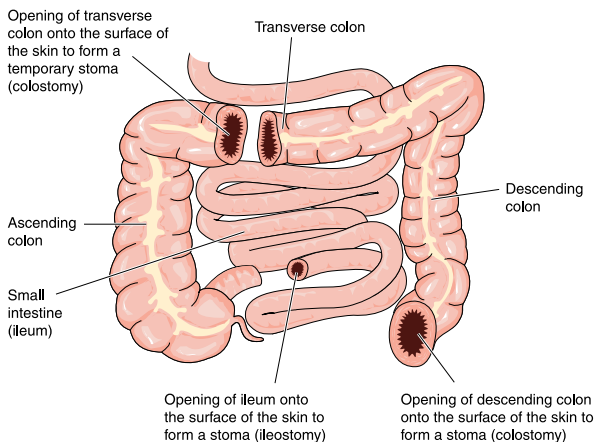
Crohn's disease and ulcerative colitis inflame the lining of the GI tract and disrupt your body's ability to digest food, absorb nutrients and eliminate waste in a healthy manner. As a result, you might have abdominal pain, cramping, gas, bloating, fatigue, diarrhea (possibly bloody) and loss of appetite.

In spite of medication, sometimes a person's disease does not respond adequately to treatment. If you and your doctor decide that it is necessary to remove part of your affected bowel, an ostomy (permanent or temporary) may result from the surgical procedure.

WHAT IS AN OSTOMY?

A quick look at the following table gives you the basic definitions for different aspects of the ostomy. For more information on surgery and Crohn's disease and ulcerative colitis, please see our booklet *The Cutting Edge*.

Description	
Ostomy	General word for both the surgery and the result of the intestine brought to the surface of the abdomen. Ostomies are performed to assist the body pass feces as required.
Stoma	The ostomy creates an opening on the abdominal wall called the stoma. The stoma is the exposed end of the intestine and is the opening from which feces and mucus pass out of the body.
Colostomy	Colostomies are a type of ostomy formed when a section of the colon (also known as the large bowel) is removed and the end is brought out to the surface of the abdomen. A colostomy can be permanent or temporary, depending on your diagnosis and surgical procedure.
Ileostomy	<p>Permanent ileostomies are formed when all of the colon and part of the small bowel is removed. The end of the small bowel (known as the ileum) is brought out to the surface of the abdomen.</p> <p>Temporary ileostomies allow the colon to heal. After the colon has had a chance to recuperate, the ileum and the upper end of the colon are re-attached and the individual can once again pass feces through the anus.</p>
Ostomy Appliances	Appliances are used to collect feces that are expelled through the stoma; they consist of skin barriers and a pouch for the feces. The ostomy appliance has a skin barrier that sticks to your skin and holds the odor-proof pouch to your abdomen.



THE STOMA

A healthy stoma will be moist and dark pink to red in colour. Immediately after surgery it will be large and swollen, but after six to eight weeks it will shrink to its final size. Stoma sizes vary depending on whether it is a colostomy or ileostomy. Ileostomies are smaller and can be about the size of a nickel or quarter. Colostomies are larger and can be the size of a quarter or a loonie. The stoma has no nerve endings for pain or touch. This means that you will not feel the stoma when you are touching or cleaning it.

For that reason you need to examine your stoma daily with the help of a mirror, to check that the skin looks healthy. Because the stoma is rich in blood vessels, it may bleed slightly when you clean it or change your ostomy appliance; this is normal and not a cause for alarm. You will also need to check the skin around the stoma (the peristomal skin) to ensure that there is no redness or peristomal skin sores. Peristomal skin and stoma care are very important parts of your daily hygiene routine. The stoma is the end of your intestine. From time to time you will observe rhythmic contractions called "peristalsis". This action moves feces through your intestine and into your odour-proof pouch rather than out of your anus. Some people experience mild cramping when the bowel moves but more often you will not know when you have passed stool.

Speak with your Enterostomal Therapy Nurse (ETN) about caring for your stoma. ETNs are experts in caring for and teaching you and your family about ostomies.

Contact the Canadian Association for Enterostomal Therapy at www.caet.ca and the United Ostomy Association (UOA) at www.ostomycanada.ca for more information.

THE APPLIANCES

There are many kinds of ostomy appliances available, suitable for your particular need and lifestyle. Your ETN will help you select the right one and you can be confident that you can work, play and exercise just like everyone else. No one will know you have an ostomy unless you want to tell them. Here is a simple overview of some of the ostomy appliances.



Appliances are generally made up of two main parts: the skin barrier and the pouch (for collecting the feces). These are sold as a "one-piece" (skin barrier and pouch are together) or a "two-piece" (skin barrier and pouch are separate). The two-piece system allows you to keep the skin barrier on for a few days and allows you to change only the pouch as needed.

The skin barrier has "skin-friendly" adhesive and sticks to your abdominal skin. The skin barrier fits snugly around your stoma, leaving approximately 1/8" around it. Barriers can be standard or extended wear, pre-sized or cut to fit and flat or convex.



An ETN will help find the best type for you. The ostomy pouch attaches to a skin barrier. It can be either closed or drainable. Drainable pouches will have either clamps or built-in locks. Most pouches are made from "rustle-free" material, have odour-proof barriers, can be clear or opaque and have filters that permit the release of gas (but not odour). They are made to be "low profile" so you can wear them with confidence, even if you are wearing a tight T-shirt.

CARE OF YOUR POUCH

Your ETN will give you advice on caring for your ostomy pouch. Here's a general idea of how to empty or change your pouch.

Emptying Your Pouch

If you have a drainable pouch, you will want to empty it when it is one third full. Sit on or beside the toilet, holding the end of the pouch up. After releasing the closing device (such as a clamp), slowly unroll the end over the toilet and slowly squeeze the stool out of the pouch. After it is empty, wipe the inside and outside of the clamp and the end piece with toilet paper. You can rinse out the pouch with water before re-clamping. You should change your pouch and skin barrier at least once or twice a week but if you have any irritation around the skin, you should change the skin barrier right away.

Occasionally you will notice that gas is collecting in the pouch even if there is no stool. If so, unclamp the pouch, release the gas and squeeze it out of the pouch, and then re-close. Do not puncture the pouch to release gas, as this will cause leakage of feces and the uncontrolled release of odour.



CHANGING YOUR POUCH

If you have a closed pouch, you will need to discard it after it becomes one-third full. Depending on whether you have a "one-piece" or "two-piece" pouching system, the skin barrier may also have to be changed at the same time. If you have a "one-piece" system, gently peel away the skin barrier until you have released the pouch from your abdomen. After emptying the feces from the ostomy pouch into the toilet, place the pouch into a plastic bag and throw it in the garbage. Clean around the stoma and peristomal skin to remove feces. Dry the skin, and apply your new pouch.

With a "two-piece" system, you will not need to change your skin barrier each time. In this case, simply attach the new pouch onto the skin barrier.

BATHING AND SHOWERING

Feel free to bathe or shower with your ostomy. It is up to you whether or not you wear a pouch, however remember that your stoma will continue to function and feces could be released during this time. Use water to clean the stoma and peristomal skin.

If you use soap do not use soaps that have lotions in them and be sure that all soap is removed from your skin. Don't worry about water getting into the stoma as peristalsis will push it out.

DO OR DIET?

One of the best things about your life after surgery is that you can gradually resume eating your favourite foods. If they did not bother you before your surgery, they probably will not bother you after your surgery. Go easy on your food intake immediately after your surgery and with the advice of your dietitian, you can gradually introduce your regular diet over a period of about six weeks.

If you have an ileostomy you will need to increase your daily fluid intake because the removal of your colon means you do not absorb water, salt and potassium as well as you did before. It will be important for you to drink at least eight glasses of non-caffeinated beverage every day and increase your intake of sodium and potassium. People who have a colostomy need to ensure that they are eating healthy, balanced meals. Also, if you have a colostomy there are usually no restrictions to your diet.

GAS AND ODOURS

Whether we have an ostomy or not, we all develop gas (flatus) or strong smelling feces as a result of the foods we eat. As much as we would like to think that this doesn't happen to us – this is normal. When you have an ostomy gas will be expelled into your pouch, making it "puff up," possibly with a strong odour. Some people find that foods such as asparagus, milk, beer, spicy foods and strong cheeses increase the tendency of gas. Unpleasant odour could also be coming from feces passed after eating foods such as fish, chicken, fried eggs, onions, beans and cabbage. You can reduce some odour by adding deodorizing tablets or liquids to your pouch and eating foods such as yogurt, buttermilk and fresh parsley. In spite of these lists, you will need to experiment to find out what foods work for you.



CONSTIPATION AND DIARRHEA

It is normal for everyone (with or without an ostomy) to experience diarrhea or constipation. Things like the flu, certain medications and an unhealthy diet can affect your intestine and can cause diarrhea or constipation. These effects are not necessarily related to Crohn's disease or ulcerative colitis.

If you have diarrhea, be sure to drink more fluids to avoid dehydration, particularly if you have an ileostomy. Avoid foods that you know make your feces more watery such as fresh fruits, vegetables, garlic, onions and milk. If you have a colostomy and are constipated, try increasing the foods mentioned above and consider drinking fruit juices such as prune juice to get things moving. Do not take over-the-counter medications if you are experiencing diarrhea or constipation without consulting your doctor.

FOOD BLOCKAGE

If you have an ileostomy, you should know the warning signs of a food blockage. On occasion, food can become lodged in the small intestine.

If it does, you will notice a continual flow of very smelly, watery stool and experience symptoms like bloating, cramping, or nausea and the stoma may begin to swell. If the blockage worsens, you will cease to pass any feces.

If you have a partial blockage, do NOT eat solid food or take a laxative. DO try things like walking, massaging the abdomen, having a warm bath or shower and drinking warm fluids. Also, try lying on your back, tucking your knees to your chest and rocking your legs from side to side. If these do not relieve your blockage within a few hours, or you start to vomit or notice you are not passing feces, go to the emergency department at the hospital.

MEDICATIONS

Any medication that you take “by mouth” (orally) has to pass through your intestines. Since you may only have part of your small or large intestine, the way you absorb medication now changes. For example, vitamins in your food may not be absorbed as well with the removal of part of your intestine. Your doctor may advise you to take supplements. Also, be aware that any medications that are coated or time-released will not work effectively if you have an ileostomy because you no longer have a large intestine to absorb them. Ask your doctor or pharmacist for help in choosing the most appropriate medication for you. If you are taking birth control pills, speak with your doctor to ensure your medication is still effective. Antibiotics can also cause watery, strong-smelling stool or diarrhea – this is normal.

SPORTS AND WORK

Once your doctor has given you the “All clear,” your colostomy or ileostomy will not limit your participation in anything you want to do. Get out and re-engage in all the work and activities that you enjoy. Swim, play football or hockey, train in karate, go walking or running – whatever you want to do. Simply, keep in mind to make some adjustments to your ostomy appliance for greater security. Wearing a support belt is popular idea.

Speak to your ETN to find out what ostomy pouching systems will work best for whatever you have planned. You will be delighted to find out about the many flexible and variable options that will support your busy lifestyle.

DRESS FOR SUCCESS



The clothes you loved to wear before your surgery are the clothes you can wear again afterwards. Having an ostomy will not force you to go out and buy a whole new wardrobe. You can wear anything you want from tight to relaxed fit and you can be confident that you will look great! Just be kind to your stoma and avoid rubbing it with a belt or waistband. The low-profile, non-rustling pouches available today are not noticeable underneath clothing – so go on – wear whatever outfit you want and know that you look as good as you feel.

PACK YOUR BAGS



You're going places! Now that you don't have to worry about running to the bathroom at unexpected times, you have the freedom to travel wherever you want. Just be sure to pack all the supplies that you need and then double the quantity for safety. If you are flying, put your supplies in your carry-on luggage (minus the scissors). It is a good idea to have a letter signed by your doctor or ETN describing the medical reasons for your stoma, and ostomy supplies. Any prescribed medication should be carried on-board in their original, labeled containers. It is also a good idea to have a list of your prescriptions and phone number of your doctor. With today's ever-changing airline security rules it is recommended that

you contact your airline before flying to find out what the security requirements are before you get to the airport.

If you are driving, do not leave your ostomy supplies in the glove compartment or the trunk in case they become overheated and damaged.

Emergency kits are a great idea; pack items such as zip lock bags (for disposal of stool), an extra clamp, a pre-cut skin barrier, extra pouches, moist towelettes and a mirror.

Now you are ready to travel! Just be sure to eat sensibly and drink plenty of non-caffeinated fluids while you are away. In some countries, it is better to avoid eating anything that has been rinsed with local water, including fresh fruits and vegetables. Also, avoid ice cubes in your drinks when traveling in a different country.

It's a good idea to buy travel insurance for an emergency situation. Not that you are any more likely to need it now than before your surgery, but it's better to be safe.

LOVING YOURSELF

When you first have an ostomy, it is natural for you to feel many different emotions such as fear, anger, sadness or shame. You wonder, "Why me?" and may even live life in denial. Some people cope with these feelings by withdrawing from their friends and family. Some may also become overly dependent on others, feeling helpless and overwhelmed. There is no "right" reaction at a time like this, these feelings are normal.

Express your feelings with loved ones and be open to their support as you journey through your emotional adjustments. It may be a good idea to seek help from a professional who can help you along the path to self-acceptance. You will accomplish this on your own time and at your own pace.

LOVING OTHERS

We have been talking about many of the important aspects of a whole and happy life, and your relationship with a life partner is one of them. At first, you may feel embarrassed or self-conscious about your stoma. You may feel anxious about the way your partner now views you, but ask yourself this: Who is really feeling awkward about your stoma – is it you or is it your partner?

There is no reason you can't be physically intimate with someone just because you have an ostomy. However there may be emotional barriers to your ability to relax and enjoy the moment. Your journey to self-acceptance is a process, one that takes time. As you regain your confidence and sense of control over the situation, your desire to be intimate again with your partner will also return.

In the meantime, remember that intimacy is not just about sex. It is about caring for the other person; it is also about hugging and kissing. It is about communication and emotional bonding before it is ever about physical intimacy. So talk with your partner about your feelings and be sure to find out how they are feeling as well. It is, after all, a two-way street.

When you do get to the point where you and your partner feel ready to have sex again, try these tips for making the experience more pleasurable for both of you:

- Empty your pouch before having sex so you can relax and not worry about leaks
- You could secure your pouch by wearing a soft belt
- Try using a mini-pouch or a closed pouch
- If you are feeling a little self-conscious, try wearing a piece of clothing such as a tank top or shirt to cover your pouch
- Try different positions with your partner to find out what is most comfortable and pleasurable for both of you



Understand that “for better or worse”, this is another stage in your recovery process. Take it one step at a time and do not put pressure on yourself or your partner; relax and have fun.

For more information, please read Crohn’s and Colitis Canada’s “The Heart of the Matter” brochure. Available by visiting crohnsandcolitis.ca.

GET OUT THERE AND FEEL BETTER THAN EVER!

If you have just had a colostomy or an ileostomy, you are now poised to regain your health and your freedom. It may not seem that way immediately, but as you learn to manage your ostomy you will discover that you have more energy and can enjoy life again.

ABOUT CROHN'S AND COLITIS CANADA

Crohn's and Colitis Canada is the only national, volunteer-based charity focused on finding the cures for Crohn's disease and ulcerative colitis and improving the lives of children and adults affected by these diseases. We are one of the top two health charity funders of Crohn's and colitis research in the world and the largest non-governmental funder in Canada. We are transforming the lives of people affected by Crohn's and colitis (the two main forms of inflammatory bowel disease) through research, patient programs, advocacy, and awareness.

Our Crohn's & Colitis – Make it stop. For life. campaign will raise \$100 million by 2020 to advance our mission.

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For more information on Crohn's disease or ulcerative colitis visit our website **crohnsandcolitis.ca** or call 1-800-387-1479

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