



PATIENT & CAREGIVER EDUCATION

Caring for Your Ileostomy or Colostomy

This information will help you care for your ileostomy or colostomy.

An ostomy is an opening created during surgery. A piece of your intestine is brought to the outside of your abdomen (belly) so that bowel movements (stool) and gas can exit your body. The part of your intestine that's on the outside of your body is called a stoma. Your stoma will look red and moist, similar to the inside of your mouth. Your stoma will be swollen right after surgery, but the size will decrease in 6 to 8 weeks. You won't feel any pain or pressure within your stoma. You also won't feel any sensations of heat or cold.

Some ostomies are permanent, while others are temporary. Your surgeon will tell you if your ostomy is permanent or temporary.

Having an ostomy is a big change for most people. We have written this resource with the help of people who have an ostomy. We hope it will help prevent problems and give you tips that can make your daily life easier. Your wound, ostomy, continence (WOC) nurse will go over this information with you.

Types of Ostomies

An ostomy can be made out of the small intestine or colon (large intestine). When a piece of the small intestine is used to create an ostomy, it's called an ileostomy. When a piece of the colon is used to create an ostomy, it's called a colostomy.

The consistency of your bowel movements from your ostomy will depend on the part of your intestine that's used to create the ostomy. Your bowel movements may be liquid, soft, or solid.

The most common types of ostomies are:

Ileostomy

- Created from the part of the small intestine called the ileum.
- Bowel movements are loose or watery.
- Stoma is usually located on the right lower side of the abdomen.

Ascending colostomy

- Created out of the ascending colon.
- Bowel movements are loose or watery.
- Stoma is usually located on the right side of the abdomen.

Descending colostomy

- Created out of the descending colon.
- Bowel movements are usually soft.
- Stoma is usually located on the left side of the abdomen.

Sigmoid colostomy

- Created out of the last part of the colon.
- Bowel movements can be soft or firm.
- Stoma is usually located on the left side of the abdomen.

Loop ostomy

- Can be made out of any part of the small intestine or colon.
- There are 2 openings in the stoma instead of 1. Many times, only 1 opening can be seen. This type of ostomy is often temporary.

In some surgeries, a second opening is created on the abdomen called a mucous fistula. It secretes left over bowel movements or a mucus-like fluid and leads to

the rectum. If you have a mucous fistula, your WOC nurse will teach you how to care for it while you're in the hospital. Usually, a small pouch or dressing is placed over the mucous fistula. It will need to be cleaned with water and emptied. Once there is no drainage, the mucus fistula can be covered with a pad and tape.

Learning to Care for Your Ostomy

Your WOC nurse and nursing staff will teach you how to care for your stoma and ostomy while you're in the hospital. When you're discharged from the hospital, you'll be given the basic supplies you need to care for your ostomy. During your post-operative appointment, a WOC nurse will re-evaluate your ostomy supplies and will show you how to order them. There's a list of medical suppliers at the end of this resource.

Your WOC nurse and nursing staff will also arrange for a visiting nurse to come to your home after you're discharged from the hospital. They will teach you how to care for your stoma and adjust to being home. If you have any questions or problems once you're home, call your WOC nurse or social worker.

Pouching systems

After your surgery, you will wear an odor-proof pouching system over your ostomy. The pouching system is made up of a skin barrier (wafer) and a collection pouch. There are many different sizes and styles of pouching systems. Most pouching systems are either a 1-piece system in which the pouch is attached to the skin barrier, or a 2-piece system in which the pouch can be taken off of the skin barrier. With both types, the pouch attaches to your abdomen by the skin barrier and is fitted over and around your stoma to collect your bowel movements and gas. The skin barrier protects the skin around your stoma from getting irritated by bowel movement leakage.

Your WOC nurse will help you find the best pouching system for your stoma. As the size of your stoma changes, you may need to change your pouching system.

Some people find it helpful to buy a fitted waterproof mattress cover, bed pads, or cloth under-pads to place over the mattress and bed sheets. This protects the bed in case the pouch accidentally leaks during the night.

Emptying your pouch

Empty your pouch when it's almost halfway full. The pouch shouldn't become overly full. Your WOC nurse will teach you how to empty your pouch.

If you squeeze every bit of air out your pouch, the sides are likely to stick together and make it more difficult to collect bowel movements. There are lubricants to help keep this from happening. This is more of an issue if your bowel movements are thicker. If your bowel movements are thinner, you can use a thickening product in the pouch to help thicken them. Your WOC nurse will help you determine which product you should use.

Changing your pouching system

Your WOC nurse will teach you how to change your pouching system. Generally, you should change your pouching system every 3 to 5 days. If you have leakage, change it immediately. This is to protect the skin around your stoma from getting irritated from bowel movement leakage. If you have any leakage or irritation that has lasted for a few days, call your WOC nurse.

Lifestyle Issues

Body image and depression

After people learn that they have cancer, they often view their bodies in a different way. Surgery, chemotherapy, and radiation therapy can change the way a body looks and works. This may be especially true when someone has a new ostomy. Some people feel disgust. This is normal given the shame in many cultures of talking about bowel movements. Other people feel sadness at the loss or change in their bodies. They view their ostomy with negative thoughts and feelings. However, others view their ostomy more positively and see it as an answer to difficult symptoms, such as bowel incontinence (trouble controlling your bowel movements), or as the path to survival. You may have both positive and negative feelings. As you adjust to living with an ostomy and get used to how it looks and works, you'll feel better about your body. It may help you cope better if you:

- Look at your stoma to help you get comfortable with it.

- Remind yourself about the positive aspects of your ostomy.
- Talk with other people with ostomies. You may learn good coping techniques and this may help you regain a sense of normalcy.
- Get counseling to help you improve your body image, feelings, and quality of life. At Memorial Sloan Kettering (MSK), counseling is available from social workers and at the Counseling Center. You can reach the Social Work Department at 212-639-7020 and the Counseling Center at 646-888-0200.

Nutrition

Your doctor will give you dietary guidelines to follow after your surgery. You'll also meet with a dietitian while you're in the hospital to review these guidelines.

Below are some recommended guidelines if you have an ileostomy:

- Stay hydrated
 - Drink 8 to 10 (8-ounce) glasses of liquids a day.
 - Limit your intake of caffeine and alcohol. They can dehydrate you.
 - Limit foods high in fiber and high in simple sugars (such as glucose, sucrose, fructose), as they can dehydrate you.
- Keep in mind that the foods that upset your stomach before your surgery will have the same effect after your surgery. If you feel bloating and pain after eating a certain food, remove it from your diet. Try eating it again in a few weeks. If you're still having pain and bloating after eating this food, avoid it.
- Some people with ostomies choose to limit gas by regulating their diet. The following can increase gas:
 - Foods such as cabbage and broccoli
 - Carbonated beverages
 - Drinking through a straw
 - Chewing gum
- If you have tried limiting gas and still have a problem, talk with your WOC

nurse. They may suggest using pouches with charcoal filters. The filter can help prevent the buildup of gas and avoid inflation of the pouch. Some people also find it useful to use pouches with filters for airplane travel.

- Don't prick your pouch to release built-up gas because this will destroy the pouch's odor proof system.
- Don't scrub your pouch with water. This will deactivate the filter.
- If you're constipated (having fewer bowel movements than what's normal for you):
 - Drink more liquids.
 - Eat foods that are high in fiber, such as fruits, vegetables, and bran.
 - Walk around.

If you have an ileostomy, don't take any kind of laxative. It can cause severe dehydration and other problems.

Medication

If you have an ileostomy, your body may not be able to completely absorb some medications. This happens because your bowel is shortened and some medications are absorbed slowly. This happens most often with:

- Pills with enteric coating (a special coating that prevents pills from being absorbed until they reach the small intestine)
- Sustained-release or extended release medications (designed to release a medication in the body slowly over an extended period of time)

Ask your doctor if you're taking these types of medications. If you see a tablet in your pouch that isn't absorbed, call your doctor.

Don't crush pills unless your doctor or pharmacist says you can do so. Taking crushed pills can cause problems with digestion.

Exercise

Talk with your doctor about what exercise is right for you. For most people,

walking and light stretching are good exercises to do while recovering from surgery. You should avoid lifting or pushing anything heavier than 10 pounds for 2 to 3 months after your surgery. This includes housework such as vacuuming or mowing the lawn. If this will be a problem for you, talk with your doctor.

Don't do sit-ups, pushups, or any strenuous exercise for 2 to 3 months after your surgery. This will help prevent a hernia (bulging of an organ or tissue) or weakening of a muscle near your stoma. It will also help prevent a stomal hernia (bulging out of your stoma).

Odor control

Pouching systems are designed to be odor proof. Unless you're leaking bowel movements underneath the wafer, there should be no odor while the pouching system is attached. However, if odor is a problem for you, there are deodorants that you can put into the pouch to help. Some examples are drops, charcoal tablets, or lubricating gel. You may need to experiment to find one that works best for you. There are also deodorants you can take orally (by mouth) to decrease your bowel movement's odor. Check with your doctor or nurse before using any of these.

Many pouches have a built-in charcoal filter. This vents the gas and filters it at the same time to prevent odor. There are also filters that can be bought separately and attached to the pouch, or you can apply a small plastic vent on each pouch. This vent allows gas to be released without opening the pouch.

Some people find it useful to empty the pouch at bedtime. This is done because gas could continue to build overnight and fill the pouch.

Sexual activity

Talk with your doctor about when it's safe to resume sexual activity. Generally, this is after your incision is healed, about 2 months after your surgery. As long as excessive pressure isn't placed on your stoma, there should be no harm done to it. Do not use your stoma as a sexual orifice.

For many people, returning to a normal sex life will come naturally. This happens as your concerns decrease and your feelings about your body become more positive. Try to stay intimate with your partner as much as possible. Use kind

words, meaningful touch, and hugs.

Check to see if your pouching system fits well and if there's any odor. Some people prefer to cover their pouching system with a cloth band or wrap, shirt, or lingerie during sexual activity. You can buy ready-made covers from many ostomy supply companies. Some companies also make a pouch with a cotton cover attached to it.

You may also plan your sexual activity for times when you're less likely to be actively draining or after irrigation. For more information about irrigation, see the section titled "Frequently Asked Questions About Ostomy Care".

Talk with your doctor or nurse if surgery or radiation therapy caused changes that make it hard to have sex. Examples are erectile dysfunction (difficulty getting or keeping an erection) in men or vaginal dryness, pain, or tightness in women. If these problems don't get better, you can talk with a sexual health specialist. MSK has a Sexual Health Program to help people address the impact of their disease and treatment on sexuality.

The United Ostomy Associations of America, Inc. (www.ostomy.org or 800-826-0826) has information on sex for both men and women with ostomies.

Other good sources of information are the following resources published by the American Cancer Society. You can get these resources by calling 800-ACS-2345 (800-227-2345) or by going to the links below.

Sexuality for the Man With Cancer: www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html

Sexuality for the Woman With Cancer: www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer.html

Showering, bathing, and swimming

You can shower with your pouching system on or off. However, if you have an ileostomy, you may want to keep the pouch on during the shower due to possible

drainage of bowel movements while showering. You can also use waterproof tape around the edges of the wafer. Depending on your skin and the type of pouch, you can place a piece of plastic over the whole pouching system to keep it from getting wet, but this isn't always necessary.

When you take a bath or swim, keep your pouching system on. Most people can wear the same swimsuit they wore before their surgery. However, it may not be possible to wear hip-high swimsuits for men or hip-high, two-piece swimsuits for women.

Work

You can go back to work as soon as you feel ready and your doctor approves. Unless you tell them, people won't know that you have an ostomy. It's highly unlikely that the pouching system will be visible. You will probably be able to wear most of the same clothes you wore before your surgery.

Travel

Bring extra pouching systems with you wherever you go, even if it's only a short trip or a doctor's appointment. If you're going to be away from home for several hours, think about where you're going and mentally prepare yourself. Some people feel anxiety the first few times they travel. If you feel anxious, you may be able to lower your stress by thinking ahead. First, think about where the bathroom is located and what you may need. Second, get the supplies you plan to take with you. Place 2 of every item in a travel bag. This way, if you have an emergency or are away from home longer than you expect, you will be prepared. Remember to bring:

- Pouches
- Wafers
- Clamps (if you have a pouching system with a clamp closure)
- Paper towels

When you're traveling by air:

- Pack your ostomy supplies in at least 2 places, such as in your carry-on and

checked luggage.

- Take extra supplies in case you're stranded where supplies may not be available.
- You may want to bring a letter from your doctor stating your need for ostomy supplies, as well as a private area be used in case of an extended search by TSA agents.
- If you're traveling to a foreign country, it's a good idea to have ostomy information written in that language. One of the 70 member associations of the International Ostomy Association may be able to help with this translation, as well as with locating supplies while visiting their country. For more information, visit www.ostomyinternational.org.
- You may want to carry photocopies of the catalogue pages displaying and explaining your equipment for TSA agents.
- The United Ostomy Association of America web site, (www.uoaa.org) has information and helpful 'travel tips' that can be printed and used.

Call Your Doctor or Nurse if You:

- Vomit
- Have a colostomy and haven't had a bowel movement for 3 days
- Have an ileostomy and haven't had a bowel movement for 3 to 6 hours
- Develop abdominal pain or symptoms of dehydration (this is more common for those with an ileostomy), including:
 - Increased thirst
 - Dry mouth
 - Loss of appetite
 - Weakness
 - Decreased urine output
 - Dark amber colored urine

- Muscle, abdominal, or leg cramps
- Feeling faint
- More bowel movements than usual or changes in consistency
- Increased frequency of emptying pouch

Frequently Asked Questions About Ostomy Care

What is irrigation and will I be able to do it?

Irrigation is a type of enema that eliminates the need for wearing a pouching system over the stoma. This means you wouldn't have any bowel movements between the irrigations. Irrigation is done every day or every other day. People who have a sigmoid colostomy may be able to irrigate. Most people who have had an abdominal perineal resection have a sigmoid colostomy. **People with an ileostomy should never irrigate because it can cause dehydration.**

You also cannot irrigate:

- If you have a stomal hernia (bulge around the stoma).
- While you're getting chemotherapy.
- While you're getting radiation therapy.

Ask your doctor or WOC nurse for more information about irrigation.

What color should my stoma be?

Your stoma should be a deep pink or red color at all times. While it's working to move bowel movements out of your body, you may notice a slight change in its color. This should only be for a few seconds to a minute. If your stoma looks dark red, grey, brown, or black, call your doctor immediately.

Is it normal for my stoma to bleed when I touch it or change my pouching system?

Your stoma has many blood vessels, so it may bleed easily with touch or irritation.

It's common to have a small amount of blood on the tissue when cleaning your stoma. The bleeding should stop on its own within a few minutes. If you're on a blood thinner or aspirin, you may bleed more easily and for a longer period of time. If you bleed a lot or if the bleeding doesn't stop after 5 to 10 minutes, apply pressure to the area and call your doctor. If you notice blood in your bowel movements or coming from the inside of your stoma, call your doctor immediately.

The area around my stoma seems to bulge. Is this normal?

If you have a change in the curve around your stoma, tell your doctor or WOC nurse. You may have a stomal hernia. This happens because the abdominal wall muscle is weak and causes a bulge to form in the area around the stoma. Your doctor or WOC nurse will examine you to see if you have a stomal hernia.

People with a stomal hernia don't usually have any symptoms. Surgery isn't needed unless you have a complication, including a blockage or twisting of the herniated bowel.

If you have any of the following symptoms, call your doctor or nurse:

- Nausea
- Vomiting
- Pain
- Abdominal bloating, and lack of gas and bowel movements in your pouch

If you have a stomal hernia, your WOC nurse can measure you for a custom-made hernia support belt. These belts don't cure the hernia, but they can prevent it from getting worse by giving it support. A girdle or biking shorts with a hole cut out for your pouch may also work well as an alternative to the custom-fitted hernia belt.

How do I wear a belt over my stoma?

Try to wear the belt above or below your stoma. If the belt is worn directly over your stoma, it can cause:

- Irritation

- Bleeding
- An overgrowth of tissue

While you're wearing the belt, position your pouch downward or to the side. You can also fold it, depending on your preference.

What do I do if I have leakage of bowel movements under my wafer?

If you're having leakage, tell your WOC nurse. You may need a different pouching system that fits better to avoid this problem.

Is there anything I should do to prepare for tests, such as scans with contrast dye?

Always take an extra set of supplies when going to the doctor for tests because you may have to remove your pouching system.

If you live 1 hour or longer away from the hospital, be ready to change or empty your bag during the trip home. The contrast dye may empty into your pouch in 1 or 2 hours, but it can take longer.

Do I need to wear gloves when I change my pouching system?

This is a personal choice. There is no risk of infection from changing your pouching system. However, some people prefer to wear gloves because some bowel movements could come in contact with your fingers.

If I have an ileostomy, is it normal to still pass bowel movements or mucous from my rectum?

Depending on the type of surgery you had, you may pass left over bowel movements or mucous from your rectum. This should decrease over time, but it may be useful to wear a pad and apply a zinc ointment (such as Desitin®) around your anus to prevent irritation.

What should I do if I am admitted to the hospital?

If you're admitted to the hospital, you may want to bring 1 or 2 extra sets of

supplies with you, just in case they stock a different product or they have run out of the product you use.

Video Resources



Please visit www.mskcc.org/pe/change_ostomy to watch this video.

This video will teach you how to change your ostomy appliance.



Please visit www.mskcc.org/pe/empty_pouch to watch this video.

This video will teach you how to empty your velcro end closure pouch.



Please visit www.mskcc.org/pe/skin_stoma to watch this video.

This video will teach you how to care for irritated skin around your stoma.

Support Groups

You may find it helpful to join our ostomy group for colorectal patients. This is a live, online support group in which people can share their experiences and provide practical and emotional support for one another. Discussions are guided by a social worker and nurse. The group is open to everyone, including non-MSK patients. The group is held every other month on the 3rd Thursday of the month from 4:00 PM to 5:00 PM. To learn more about the program or to register for the program contact virtualprograms@mskcc.org.

On the United Ostomy Associations of America (UOAA) website, you can search for UOAA-affiliated online and in-person support groups for people with ostomies. To find a group, go to www.ostomy.org/supportgroups.html.

Local hospitals may also offer ostomy support groups.

Ordering Supplies

Speak with your WOC nurse about ordering supplies. They are familiar with the latest products on the market. You can also call companies to ask for samples of their products.

Mail order medical supply companies

Listed below are some mail order medical supply companies. Some accept Medicare and other types of insurance. Call the company directly to ask if they take your insurance. If they don't, call your insurance company to get a list of suppliers that do. These companies will mail the supplies to you every month. You don't usually need a prescription to order the supplies. The company will work with your doctor's office and your insurance company. These companies offer a wide variety of products. Call and ask for their catalogue or view it online.

Byram Healthcare

877-902-9726

www.byramhealthcare.com

CCS Medical

800-260-8193

www.ccsmed.com

Edgepark Medical Supplies

888-394-5375

www.edgepark.com

Landauer Metropolitan

800-631-3031

www.landmetro.com

(Accepts Medicaid in New York State)

McKesson Medical-Surgical

800-453-5180

www.mckesson.com

You can also buy ostomy supplies at local pharmacies and medical supply stores. However, the prices may be higher due to a low volume of supplies or because they may not take your insurance.

Ostomy product manufacturers

Listed below are companies that make ostomy products such as skin barriers, pouches, and other ostomy accessories (such as pastes, powder, and rings). Many of these companies also have a WOC nurse on staff to answer questions. Feel free to call and ask for samples of products.

Coloplast Corporation

800-533-0464

www.coloplast.us

ConvaTec Professional Services

800-422-8811

www.convatec.com

Cymed

800-582-0707

www.cymed-ostomy.com

Hollister, Inc.

888-740-8999

www.hollister.com

Marlen Manufacturing & Development Company

216-292-7060

www.marlenmfg.com

Nu-Hope Laboratories, Inc.

800-899-5017

www.nu-hope.com

MSK Support Services

Resources for Life After Cancer (RLAC) Program

646-888-8106

At MSK, care doesn't end after active treatment. The RLAC Program is for patients and their families who have finished treatment. This program has many services, including seminars, workshops, support groups, counseling on life after treatment, and help with insurance and employment issues.

Social Work Department

212-639-7020

Social workers help patients and their families and friends deal with issues that are common for cancer patients. They provide individual counseling and support groups throughout the course of treatment, and can help you communicate with children and other family members. Our social workers can also refer you to community agencies and programs, as well as financial resources if you're eligible.

Sexual Health Program

For women: 646-888-5076

For men: 646-422-4359

MSK's Sexual Health Program helps patients address the sexual impact of their disease and treatment. You can meet with a specialist before, during, or after your treatment.

Resources

Books

100 Questions & Answers about Colorectal Cancer

Authors: David Bub, Susannah L. Rose, and W. Douglas Wong

Boston, MA: Jones and Bartlett Publishers; 2003

The Ostomy Book: Living Comfortably with Colostomies, Ileostomies, and Urostomies

Authors: Barbara Dorr Mullen and Kerry Anne McGinn

Boulder, CO: Bull Publishing; 2008

The Complete Financial, Legal, and Practical Guide for Living With Cancer, HIV, and

Other Life-Challenging Conditions

Author: David Landay

New York, NY: St. Martin's Press; 1998

Positive Options for Living with Your Ostomy: Self-Help and Treatment

Authors: Craig A. White and Robert W. Beart Jr.

Alameda, CA: Hunter House; 2002

The Human Side of Cancer: Living With Hope, Coping With Uncertainty

Authors: Jimmie Holland and Sheldon Lewis

New York, NY: Harper Collins Publishers; 2000

Organizations

CancerCare

800-813-HOPE (800-813-4673)

www.cancer.org

National nonprofit organization that provides free help to people with all cancers. Services include counseling, education, information, and financial assistance.

Caregiver Action Network

caregiveraction.org

Provides support to caregivers of those who are ill, elderly, or disabled. Works to provide caregivers with support, empowerment, education, and advocacy.

Colon Cancer Alliance (CCA)

877-422-2030 (toll-free helpline)

www.ccalliance.org

National nonprofit patient advocacy organization dedicated to screening, access, awareness, advocacy, and research related to colon cancer.

Crohn's and Colitis Foundation of America

800-932-2423

www.ccfa.org

Works to find a cure for and prevent Crohn's disease and ulcerative colitis. Aims to improve the quality of life for people living with these diseases through research, education, and support.

C3Life.com

www.c3life.com

Website dedicated to helping people with ostomies live their lives to the fullest. Online community includes a discussion forum, recipes, blogs, hints, and tips.

Gilda's Club New York City

195 West Houston St.

New York, NY 10014

212-647-9700

www.gildasclubnyc.org

Provides meeting places for people living with cancer and their family and friends. Gives people a place where they can meet others to build support systems. Offers free support and networking groups, lectures, workshops, and social events.

International Ostomy Association (IOA)

www.ostomyinternational.org

Works to improve the quality of life for people who have ostomies or related surgeries.

National Ovarian Cancer Coalition (NOCC)

888-682-7426

www.ovarian.org

Works to increase awareness of ovarian cancer and to improve the survival rate and quality of life for women with ovarian cancer.

NCI's Cancer Information Service

800-4 CANCER (800-422-6237)

www.cancer.gov/aboutnci/cis

A federally funded cancer education program that provide accurate, up-to-date, and reliable information on cancer that is easy to understand.

Ovarian Cancer National Alliance (OCNA)

866-399-6262 (toll free)

www.ovariancancer.org

Works to put ovarian cancer on the agenda of policy makers and women's health leaders.

United Ostomy Associations of America, Inc. (UOAA)

800-826-0826

www.ostomy.org

A volunteer-based health organization that supports people who have had or will have intestinal or urinary diversions. This includes providing education, information, support, and advocacy.

Women's Cancer Network

312-578-1439

www.wcn.org

Works to inform women around the world about gynecologic cancers. Provides a personalized risk assessment tool to assess risk for gynecologic and breast cancers.

Wound, Ostomy, Contenance Nurses Society

888-224-WOCN (888-224-9626)

www.wocn.org

Members are experts in the care of people with wounds, ostomies, and continence disorders.

If you have any questions, contact a member of your healthcare team directly. If you're a patient at MSK and you need to reach a provider after 5:00 PM, during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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