



---

## 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, like the inside of your mouth. Your stoma will be swollen right after surgery, but the size will decrease in 6 to 8 weeks. You usually don't feel pain or pressure within your stoma. Your stoma does not have the nerve endings and cannot feel sensations of heat or cold.

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 most of 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, pasty, 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, pasty, 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

- Created 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 drains left over stool (poop) 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 (bag) or dressing is placed over the mucous fistula. The pouch may need to be emptied throughout the day. Once the drainage decreases, the mucus fistula can be covered with gauze and tape, band aid, or a special mucus fistula bandage.

## **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 case manager in the hospital will also arrange for a visiting nurse to come to your home after you're discharged from the hospital. They will reinforce the information on how to care for your stoma and adjust to being home. If you have any questions or problems once you're home, call your healthcare provider to contact your WOC nurse.

## **Pouching (bag) systems**

After your surgery, you'll wear a pouching (bag) system over your ostomy. All pouching systems are waterproof and odor-proof. 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 stool and gas. The skin barrier protects the skin around your stoma from possible stool leakage.

Your WOC nurse will help you find the best pouching (bag) 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 or waterproof bed pads to place over the mattress and bed sheets to use after surgery at home. This protects the bed in case the pouch accidentally leaks during the night.

## **Emptying your pouch (bag)**

Empty your pouch (bag) when it's  $\frac{1}{3}$  to  $\frac{1}{2}$  full. The pouch shouldn't become overly full. A full pouch will be more difficult to empty and could cause leakage. Your WOC nurse and the staff nurse will teach you how to empty your pouch.

Liquid stool empties easily out from the bottom of the pouch (bag). Pasty or thick stool may not drop to the bottom of the pouch as easily. You may squeeze the stool out from the pouch or add water to make it more liquid, and then empty the stool into the toilet. When emptying your pouch, do not squeeze all the air out of the pouch because the sides will stick together, and this could slow stool from dropping to the bottom. There are lubricants to help keep this from happening. This is more of an issue if your stool is thicker. If your stool is 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 (bag) system**

Your WOC nurse will teach you how to change your pouching (bag) 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 stool leakage. If you have any leakage or irritation that has lasted for a few days, call your healthcare provider's office to get in touch with 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 better health. 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 new ostomy 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 healthcare provider 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 at least 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.
- Contact your healthcare provider if you're experiencing abdominal pain or symptoms of dehydration. Symptoms include:
  - 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
- Foods that upset your stomach before your surgery may 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.
  - 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.
  - Make sure you cover your filter with the provided waterproof sticker when showering or bathing, if suggested by the manufacturer.
- 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.
- Contact your healthcare provider's office to discuss options for stool softeners.

**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 or in a lower portion of the intestines. 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 healthcare provider if you're taking these types of medications. If you see a tablet in your pouch (bag) that isn't absorbed, call your healthcare provider.

Don't crush pills unless your healthcare provider or pharmacist says you can do so. Taking crushed pills change the absorption of the medication and can cause problems with digestion.

## Exercise

Talk with your healthcare provider 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 6 to 8 weeks after your surgery. This includes housework such as

vacuuming or mowing the lawn. If this will be a problem for you, talk with your healthcare provider.

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) through your incision or around your ostomy. Speak with your WOC nurse after your surgery and during your postop visit to learn more about how to prevent a hernia around your stoma.

## **Odor control**

Pouching (bag) 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 healthcare provider 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.

## **Sexuality**

Sexuality is a part of relationships and life. After ostomy surgery it's common to feel insecure or concerned about your sexuality with a new stoma. Most people with new ostomies experience changes in how they feel about their bodies and worry about sexual activities. Talk with your healthcare provider about difficulties or fears that you may have.



## Sexual activity

Talk with your healthcare provider 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 (opening).

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 (bag) 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.

You may also plan your sexual activity for times when you're less likely to have a bowel movement. Some people with a permanent colostomy, irrigate (give themselves an enema through the stoma) to try to control their bowel movements. For more information about irrigation, see the section titled "Frequently asked questions about ostomy care".

Talk with your healthcare provider if surgery or radiation therapy caused changes that make it hard to have sex. Examples are erectile dysfunction (difficulty getting or keeping an erection) or vaginal dryness, pain, or tightness. 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. You can contact our Sexual Health Programs at the numbers listed below or have your healthcare provider's office place a referral.

Female Sexual Medicine and Women's Health Program: 646-888-5076

Male Sexual and Reproductive Medicine Program: 646-888-6024

The United Ostomy Associations of America, Inc. ([www.ostomy.org](http://www.ostomy.org) or 800-

826-0826) has information on sex for people 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.

- *Sex and the Adult Male With Cancer*: [www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html](http://www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html)
- *Sex and the Adult Female With Cancer*: [www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer.html](http://www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer.html)

## Showering, bathing, and swimming

You can shower with your pouching (bag) 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 or strips around the edges of the wafer to keep it from getting wet.

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 or two-piece swimsuits.

## Work

You can go back to work as soon as you feel ready and your healthcare provider 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'll probably be able to wear most of the same clothes you wore before your surgery.

## Travel

Bring extra pouching (bag) systems with you wherever you go, even if it's only a short trip or a healthcare provider'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'll 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 healthcare provider 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](http://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.ostomy.org/traveling-with-an-ostomy](http://www.ostomy.org/traveling-with-an-ostomy)) has information and helpful 'travel tips' that can be printed and used.

# Call your healthcare provider 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?

A colostomy irrigation is a type of enema that helps control when you have bowel movements. This means you wouldn't have any bowel movements between the irrigations. Irrigating may also reduce gas. Some people who irrigate their stoma are able to wear a stoma cap over their stoma instead of using a pouching system. 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 can't irrigate:

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

Ask your healthcare provider 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 healthcare provider immediately.

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

Your stoma has many blood vessels, so it may bleed easily with touch or irrigation. 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 healthcare provider. If you notice blood in your bowel movements or coming from the inside of your stoma, call your healthcare provider 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 healthcare provider or WOC nurse. You may have a stomal hernia (parastomal hernia). This happens because the abdominal wall muscle may be weak and the intestines bulge through the weak area. Your healthcare provider or WOC nurse will examine you to see if you have a stomal hernia.

People with a stomal hernia don't initially feel 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 healthcare provider:

- 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 try to prevent it from getting bigger by giving it support. A light panty 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 (bag) 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 healthcare provider 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 (bag) system?**

This is a personal choice. There is no risk of infection from changing your pouching (bag) 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 product (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

To learn how to change your ostomy appliance, watch *How to Change Your Ostomy Appliance* ([www.mskcc.org/pe/change\\_ostomy](http://www.mskcc.org/pe/change_ostomy)).

To learn how to empty your velcro end closure pouch, watch *How to Empty Your Velcro End Closure Pouch* ([www.mskcc.org/pe/empty\\_pouch](http://www.mskcc.org/pe/empty_pouch)).

To learn how to care for irritated skin around your stoma, watch *How To Care for Irritated Skin Around Your Stoma* ([www.mskcc.org/pe/skin-stoma](http://www.mskcc.org/pe/skin-stoma)).

## Support groups

You may find it helpful to join our ostomy group for patients with different types of ostomies. This is a live, confidential, 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 monthly on the 3<sup>rd</sup> Thursday of the month from 4:00 p.m. to 5:00 p.m. Visit [www.mskcc.org/event/ostomy-support-group](http://www.mskcc.org/event/ostomy-support-group) to learn more or register.

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](http://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. Most of the supply companies accept Medicare and other types of insurance. Call the company directly to ask if they take your insurance. If they don't accept your insurance, call your insurance company to get a list of suppliers that do. These companies will mail the supplies to you every month. After you reach out to the company for your supplies, they will work with your healthcare provider's office to get an order for the supplies. The supply companies are familiar with the insurance companies' coverage and can let you know the amount of supplies covered by your insurance company, and if you have a co-pay.

### Byram Healthcare

877-902-9726

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

### CCS Medical

800-260-8193

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

### Edgepark Medical Supplies

800-321-0591

[www.edgepark.com](http://www.edgepark.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

800-533-0464

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

**Convatec**

800-422-8811

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

**Cymed**

800-582-0707

[www.cymed-ostomy.com](http://www.cymed-ostomy.com)

**Hollister, Inc.**

888-808-7456

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

**Marlen**

216-292-7060

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

**Nu-Hope Laboratories, Inc.**

800-899-5017

[www.nu-hope.com](http://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 Programs

Female Sexual Medicine and Women's Health Program: 646-888-5076

Male Sexual and Reproductive Medicine Program: 646-888-6024

MSK's Sexual Health Programs help people 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

*Be Prepared: 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.cancercare.org](http://www.cancercare.org)

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

## Caregiver Action Network

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

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

## Colorectal Cancer Alliance

877-422-2030 (toll-free helpline)

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

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

## Crohn's and Colitis Foundation

800-932-2423

[www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.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.

## Foundation for Women's Cancer

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

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

## International Ostomy Association (IOA)

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

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

## **NCI's Cancer Information Service**

800-4 CANCER (800-422-6237)

[www.cancer.gov/contact](http://www.cancer.gov/contact)

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

## **Ovarian Cancer Research Alliance (OCRA)**

866-399-6262 (toll free)

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

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

## **Red Door Community (formerly known as Gilda's Club)**

195 West Houston St.

New York, NY 10014

212-647-9700

[www.reddoorcommunity.org](http://www.reddoorcommunity.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. Red Door Community used to be called Gilda's Club.

## **United Ostomy Associations of America, Inc. (UOAA)**

800-826-0826

[www.ostomy.org](http://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.

## **Wound, Ostomy, and Continence Nurses Society**

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

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

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

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

Caring for Your Ileostomy or Colostomy - Last updated on August 15, 2022

All rights owned and reserved by Memorial Sloan Kettering Cancer Center