



Ostomy & Colorectal Cancer

Colorectal cancer (CRC) forms in the colon or rectum. This cancer may be called colon cancer or rectal cancer, depending on where it starts. People with a CRC diagnosis may experience several challenges due to the cancer itself or treatment. Depending on the stage and severity of the cancer, CRC can cause different organs to stop working well. It may impact the colon, rectum, or bladder. If this occurs, you may need an ostomy. An

ostomy can be a life-changing procedure for many CRC patients. An ostomy can help you live longer and improve your quality of life overall. Some CRC patients may not need an ostomy at all. This resource uses information shared by people with CRC through Cancer Support Community's Cancer Experience Registry. It will provide an overview on ostomies and ways to cope if you do have the procedure.

CANCER EXPERIENCE REGISTRY

CSC's **Cancer Experience Registry (CER)** is an online research study. The CER aims to understand the emotional, physical, social, and financial impact of cancer. It is an opportunity for any adult impacted by cancer to share their experience. The annual CER Report describes general findings from the survey. This includes any unmet needs among patients, survivors, and caregivers. CSC uses these findings to identify and address gaps in cancer care. This helps us to better influence outcomes such as survival, quality of life, and health care cost. By gathering important insights from those affected by cancer, we can create better outcomes for patients and caregivers today, and for future generations.

To learn more or sign up for the CER, visit www.CancerSupportCommunity.org/Registry. You can also scan the QR code to learn more.

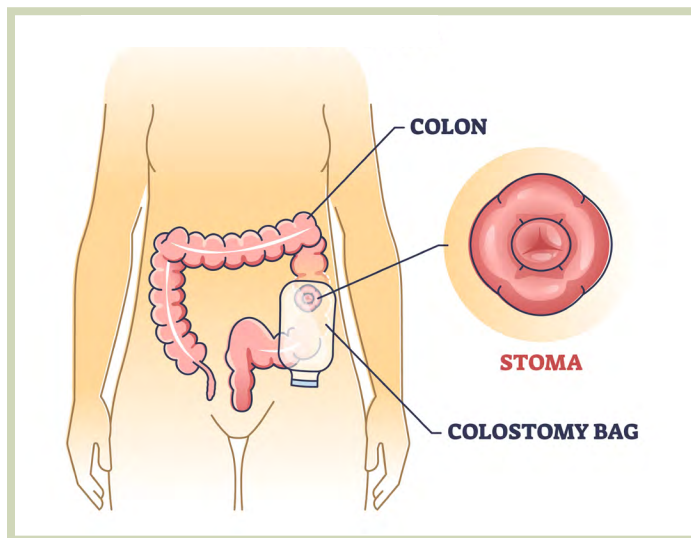


WHAT IS AN OSTOMY?

CRC can cause different organs in the body to stop working well. It may impact how the colon, rectum, bladder, or intestines function. If this occurs, your doctor may recommend an ostomy. An ostomy is a surgical procedure. It changes the way waste, like urine or stool, can exit the body. For most people with colorectal cancer, an ostomy is mainly used to help stool exit the body. During the ostomy surgery, an opening in the skin is created over the abdomen (belly). This opening is called a stoma. An external pouch is typically worn over the stoma to collect any waste.

Some CRC patients may not need an ostomy at all. If you do need an ostomy, it can help you live longer and improve your quality of life overall. For example, an ostomy can lead to better bowel function in the long term.

Some ostomies are temporary and only needed for a short period of time. This may be due to the side effects of a cancer treatment or a medical complication. A permanent ostomy is needed when any organs can no longer function or are removed.

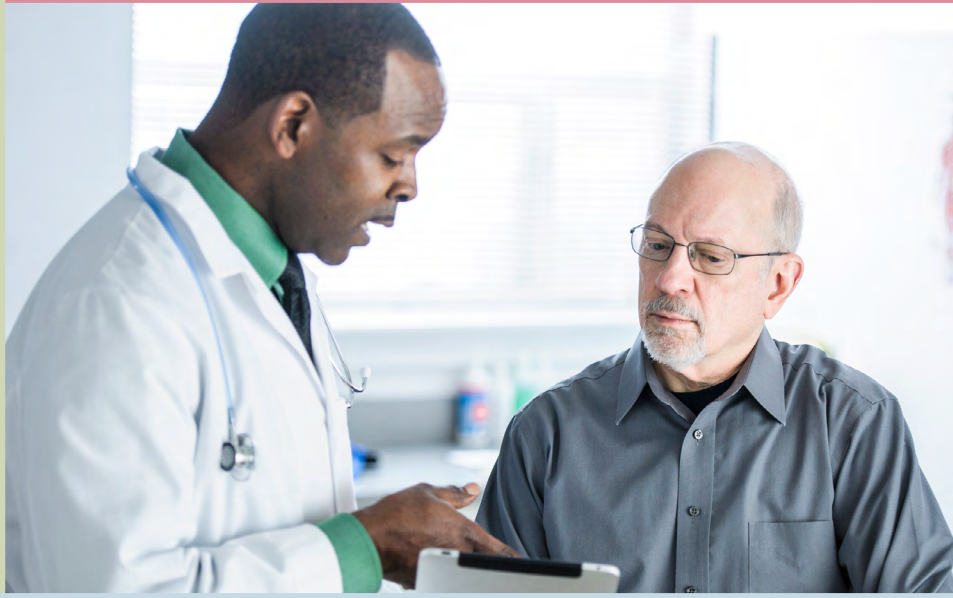


DIFFERENT TYPES OF OSTOMIES

Nearly 100,000 new ostomy surgeries occur in the United States each year. The most common types of ostomies include:

- **Colostomy:** This surgery occurs when a part of the colon or rectum is removed. An opening is created in the abdominal wall so that waste can exit the body. Colostomies may be temporary or permanent.
- **Urostomy:** A urostomy is typically permanent and cannot be reversed. When the bladder can no longer function, your doctor may recommend a urostomy. This surgery redirects urine so that it can pass from the kidneys to a pouch outside of the body. The most common urostomies are the Ileal or Cecal conduit procedures. During an ileal conduit surgery, a section of the small intestine (ileum) is removed. During a cecal conduit surgery, a section at the beginning of the large intestine (cecum) is removed.
- **Ileostomy:** This surgery may be temporary or permanent. An opening is created from the lowest part of the small intestine. The intestine is redirected to the abdominal wall. During an ileostomy, all or part of the colon may need to be removed.





YOUR HEALTH CARE TEAM

Before and after an ostomy surgery, you will work with a team of health care experts. The care team should work with you to make decisions that help you achieve your health goals. They should also teach you how to care for your ostomy. Some people you may work with include:

Gastroenterologist: A doctor trained in diagnosing and treating diseases of the digestive system. Often, you will first meet with a gastroenterologist for a colonoscopy.

Medical oncologist: A doctor who is trained to diagnose and treat cancer.

Colorectal surgeon: This doctor specializes in performing surgery in the colon and rectum. They will typically perform the ostomy procedure.

Wound, Ostomy, and Continence Nurse (WOCN): This person specializes in treating the skin and chronic wounds. They are trained to care for ostomies. WOC nurses will provide you with training on how to care for your ostomy. They should be available throughout your treatment to answer any questions.

Social workers: They are trained to assist with social and emotional needs. Social workers can help you and your family members find support groups and other psychosocial resources.

Patient or nurse navigator: Navigators help you manage your care. They help schedule appointments, get answers to your questions, and support you during your treatment.





PHYSICAL ACTIVITY & OSTOMY

Being physically active is important for your overall health. However, having an ostomy can make being active challenging. This was a primary concern for people with CRC in the Cancer Experience Registry (CER). In the CER, some CRC patients and survivors expressed that they avoided physical activity due to their ostomy. Over 30 percent of those surveyed said they avoided sports as well. If you have an ostomy, you may worry about what activities you can or cannot do.

Typically, you can go back to most activities after you heal from ostomy surgery. Talk with your doctor about the types of activities you want to do. They can advise you on how and when to do them safely. Your doctor may suggest staying away from contact sports. This can help avoid injuring the stoma. If you want to do contact sports, talk to your doctor or WOC nurse. They can recommend special products and things you can do for protection. If you lift weights,

ask your doctor when it is safe to start again. You can buy a special belt or binder to hold your ostomy bag in place. This can be helpful for running, swimming, or other athletic activities as well. It can prevent the ostomy bag from loosening and causing a leak.

BODY IMAGE

You are not alone if you have concerns about your body image. Surgery and other cancer treatments can change how a person views their own body. You may be shocked and/or embarrassed by the sounds, smells, and the amount/consistency of the output from your stoma. Clothing may even fit differently.

So, how do you cope with these body changes? First, take time to mourn your losses and know it's okay to feel sad, angry, and frustrated. Your feelings are real, and you have a right to grieve. Try to focus on the ways that coping with cancer has made you stronger, wiser, and more realistic.





Look for new ways to love your appearance. If you have any skin changes, ask your doctor about ways to care for it. A new haircut, hair color, makeup, or clothing may give you a lift as well. Build connections and community with other survivors. This can provide comfort, advice, and new ways to cope. Remember that while life changing, cancer treatments like an ostomy are lifesaving. They help improve your quality of life in the long run.

INTIMACY & SEXUAL HEALTH

How you feel about and perceive your body can impact your feelings around sex and intimacy as well. Changes to perceived body image can make intimacy tricky for all involved. More than half of the CRC patients and survivors in the CER expressed that their sexual life was negatively impacted by cancer and its treatment. The proportion was higher among those with an ostomy. Ostomies can be visible in intimate scenarios. Partners may be afraid they

will cause harm or affect the ostomy. The first step to intimacy during and after any treatment is patience and understanding. Talk openly and honestly with your partner about intimacy and how you are feeling. Seeking a specialist can help support this aspect of your life. It may help to talk with other people going through a similar situation as well. Talking with others can provide you with support and advice on how to communicate your needs in this area. Talk to your care team about being intimate with an ostomy. Bring up any aspects affecting your sexual health. For ostomies in the abdomen, it is recommended that you empty the external pouch before intimacy. Typically, contact with the ostomy will not cause harm. Be sure to let your doctor know if you do experience any pain or discomfort. Your care team may be able to give medicine or suggestions on how to reduce any discomfort.



Partners should allow time for their loved ones undergoing treatment to mourn any loss of physical confidence and changes to their body image. Those with cancer should be given the time to prepare themselves, find confidence in their bodies, and to communicate when ready. Openness and trust can ensure a healthy, comfortable, and intimate connection.

COPING, STIGMA, & EMOTIONAL WELLBEING

Navigating life with cancer can be difficult for the person who has it and those who care for them. Life after an ostomy procedure may require more physical and emotional energy. It can also require more time and money. You may not be able to do all the things you used to do right away. Some people in your life may respond in ways you dislike when they learn you have an ostomy or cancer. Concerns about how others may respond may worry you. You may feel reluctant to talk about your cancer experience with loved ones and others you interact with daily. Consider who already knows about your ostomy and who, if anyone, you would like to tell. You are the expert in making the best choice in this scenario.

While an ostomy can impact some areas of life more than others, people who have this procedure can live well. Prior to an ostomy, some people experienced pain and irregular bowels. After having ostomy surgery, many have less discomfort and feel more in control over their life. In the CER, nearly 30 percent of CRC patients and survivors with an ostomy said their ostomy did not impact their typical work schedule. Over 50 percent with an ostomy mentioned being open and

able to talk with others about their cancer experience.

As you navigate life with an ostomy, it is important to take care of yourself. This may mean putting your needs above other people's. It may also mean advocating for yourself — when you are uncomfortable or in pain — to get the support you need.

Be sure to **take care of your overall health.**

This includes eating well, getting enough sleep, and trying to stay active. Limit any use of substances, like smoking, alcohol, and even caffeine. Try not to judge yourself harshly if these changes don't happen right away.

Do the things you enjoy to take care of your mental health. Finding things to look forward to, no matter how small, can bring a sense of joy. This can include spending time with a friend, watching your favorite show, or trying something new.

Try to stay connected to others. It is important to share your feelings with people you are comfortable with and who are important to you. Talking with a counselor or therapist can help you cope with distress, anxiety, and depression. Share any concerns with a health care professional you trust.

MYLIFELINE® is CSC's private, online community. It allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. You can sign up at www.MyLifeLine.org.

To learn more about coping with an ostomy, visit www.CancerSupportCommunity.org/Colorectal-Cancer.



FINDING SUPPORT

It helps to have support, especially after your ostomy procedure. Reach out to your health care facility to see if you can get connected to a patient or nurse navigator. It can also be helpful to stay in contact with a WOC nurse. Almost 40 percent of people with CRC in the CER stated they rarely used their WOC nurse for support. These specialists can be a key resource if you are having trouble coping with the ostomy long after surgery.

There are many places to turn to for emotional support in your community as well. This can include connecting with

therapists and spiritual/faith leaders. Talking with other people going through a similar situation can also help. Over 50 percent of CRC patients and survivors in the CER said that they never used an ostomy support group or peer mentor. These resources are available to assist you through your cancer experience. It might take a couple of tries to find the right person or group. Ask your care team if they can recommend online or in-person support groups. Seek out patient advocacy groups. Look for groups that work with people diagnosed with CRC or with those who have an ostomy. They can provide a variety of support and resources as well.

CANCER SUPPORT HELPLINE®

If you need help finding resources or want help getting information about cancer, call CSC's toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m.- 8:00 p.m. ET and Friday 11:00 a.m.- 6:00 p.m. ET.

OSTOMY RESOURCES

Wound, Ostomy, and Continence Nurses Society · 1-888-224-9626 · www.WOCN.org

United Ostomy Associations of America, Inc. (UOAA) · 1-800-826-0826 · www.Ostomy.org

COLORECTAL CANCER RESOURCES

Cancer Support Community · 1-888-793-9355 · www.CancerSupportCommunity.org

Colorectal Cancer Alliance · 1-877-422-2030 · www.CCAlliance.org

American Cancer Society · 800-227-2345 · www.Cancer.org

American Cancer Society Colorectal Page · 800-227-2345 · www.Cancer.org/Cancer/Colon-Rectal-Cancer

Fight Colorectal Cancer · 1-877-427-2111 · www.FightColorectalCancer.org

Patient Empowerment Network · www.PowerfulPatients.org/Colon



CANCER SUPPORT COMMUNITY RESOURCES

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 190 locations, CSC and Gilda's Club network partners provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Become-Advocate.

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The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/Colorectal-Cancer. For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

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Colorectal Cancer Program Partner



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