

Ostomies

What are ostomies?

The word ostomy means opening. An ostomy is a surgical opening from an organ inside the body to the outside of the body. It allows drainage from the body to the outside and can be created from different parts of the body. The opening on the surface of the body is called a "stoma," and many survivors with an ostomy refer to it as a "stoma."

The most common ostomies in cancer survivors are:

- **Colostomy:** (*colo* meaning colon and *ostomy* meaning opening) A surgical opening from the large bowel to the abdomen to allow fecal matter to pass to the outside of the body.
- **Ileostomy:** (*ileo* meaning ileum and *ostomy* meaning opening) An opening in the ileum, a part of the small bowel, to the abdomen. Small bowel contents can pass through to the outside of the body.
- **Urostomy:** (*uro* pertaining to urine and *ostomy* meaning opening) An opening in the urinary system where urine can pass to the outside.

Less common types of ostomies are:

- **Jejunostomy:** Opening into the jejunum, a part of the small bowel
- **Gastrostomy:** Opening from the stomach to the outside of the body
- **Tracheostomy:** Opening from the trachea
- **Internal ostomies:** A surgical opening between two internal organs rather than bringing one opening out to the surface of the body

This document will focus on colostomy, ileostomy and urostomy.

Do all survivors need ostomies?

All cancer survivors do not need an ostomy. In fact, very few survivors have to get an ostomy. Surgical advances have made it possible for some survivors to avoid ostomies. For example, surgeons now have surgical instruments that allow connection of the rectum back to the colon with less tissue than once was required for patients with rectal cancer. But for those who do require an ostomy, it is often a life-saving surgery.

Although about 100,000 ostomy surgeries are performed annually, many are for diseases not related to cancer. The number of ostomies performed on people with cancer is not known.

What types of survivors get ostomies?

Ostomy surgery may be performed on people of all ages. Even infants may require an ostomy. A small number of patients may require two ostomies, one into the bowel for passage of fecal matter and one in the urinary system for passage of urine.

The types of cancers where ostomies may (but not always) be performed are:

- Small bowel cancer or ovarian cancer that has spread to the small bowel (an ileostomy may be made)
- Rectal cancer (if the rectum is removed, a colostomy is made)
- Cervical cancer (because the cervix and the uterus are sandwiched between the bladder and the rectum, there may be a urostomy and/or colostomy)
- Bladder and urethra (if either of these need to be removed, a urostomy is formed)
- Small intestine (if there is cancer affecting the small bowel, an ileostomy may be formed)
- Colon (depending on the cancer's location in the colon, a colostomy may be required)
- Prostate (because the prostate lies just above the rectum, surgery or radiation to the area may require a colostomy)
- Uterus (the uterus lays below the bladder and above the rectum; sometimes surgery or radiation to the area may require a colostomy or a urostomy)
- Ovaries (cancer of the ovaries may spread in the abdominal cavity, obstructing either the small or large intestine and could require an ileostomy or colostomy)

An ostomy may be needed because of treatment side effects (radiation and/or surgery). For example, radiation to the prostate or cervix may cause a change in the bowel or bladder. This change can interfere with elimination.

You may also need an ostomy if your cancer spreads to your bladder or your rectum. This is more likely in cancers of body parts close to the bladder and rectum, such as cervical cancer and prostate cancer.

When will a survivor need an ostomy?

Most of the ostomies created for cancer survivors are done during the first stages of treatment to surgically remove the cancer. Some ostomies are done months or years after treatment when tissues that have been treated with radiation change in a way that requires an ostomy to bypass the damaged tissues. A survivor may also need an ostomy months or years after finishing active treatment if the disease has spread and is affecting the bowel or bladder. These could be a colostomy, a urostomy or in rare situations, both.

Examples of ostomies required later because of side effects from treatment include:

- Severe bladder or bowel irritation
- Chronic bleeding after radiation to the uterus, bowel or prostate gland
- Bowel obstruction after surgery

Examples of ostomies required because of spread of disease can include:

- Cancers of the lymph nodes that spread to the bowel
- Cancer of the cervix that spreads to the bladder

Are ostomies permanent?

Ostomies can be permanent or temporary. A temporary ostomy may be performed to allow healing to an area of the bowel or bladder below the ostomy. A permanent ostomy may be needed when the location of the cancer requires that the end of the colon (rectum), the entire colon, or the entire bladder be removed.

How will a cancer survivor's life change if s/he has an ostomy?

A person with an ostomy can lead a normal life. Much like the removal of a breast or an arm, this change in your body may cause grief. It may affect your body image or how you feel about your appearance. In addition, you may have to think or do some activities differently because of your ostomy.

Work: You can resume normal work activities. People with ostomies are professional athletes, teachers and lawyers.

Recreation: You can continue exercising, biking, swimming or hiking – basically doing the activities you enjoyed before your surgery.

Diet: Survivors with an ostomy quickly learn which foods cause discomfort or create problems passing through the ostomy.

- **Colostomy:** Some foods cause gas and/or odor. These foods are the same ones that gave you gas or odor before your ostomy. Some common causes are beans, onions, cabbage and spicy foods. Try to avoid those foods, especially if you are worried about odor.
- **Ileostomy:** Certain foods need to be chewed very well or avoided if they cause cramping or have difficulty passing through your ostomy. Such foods include corn, popcorn and nuts. With an ileostomy, a survivor needs to know which foods cause diarrhea. Because the drainage is liquid, diarrhea may cause an excessive loss of fluids and lead to dehydration. Make sure you get enough fluids when that happens.

Medications: Your pharmacist should be aware that you have an ostomy. Survivors with a colostomy or urostomy generally have some difficulties with medications.

- **Colostomy:** You can experience medication-induced constipation. Sedatives and pain medications are associated with constipation.

- **Urostomy:** Some medications cause urinary stones. If you are taking a fluid pill, be aware that your pouch will need to be emptied more frequently. Many survivors with a urostomy take vitamin C for odor control.
- **Ileostomy:** Because an ileostomy involves the small bowel and medicine is absorbed in the small bowel, ask your pharmacist about your medications. Tablets and capsules must dissolve before they are absorbed. A sustained release 12-hour medication may not work well if you have an ileostomy. The pill might be eliminated through the ileostomy without being properly absorbed. A liquid form of your medication may work better because it is absorbed faster. Also, antibiotics and antacids can cause diarrhea in a survivor with an ileostomy. Talk to your health care team about which medicines to take.

Clothing: Usually you can wear the same clothing as before surgery. You may feel more comfortable with loose clothing over your pouch. However, many survivors with an ostomy wear bathing suits or other close-fitting clothes without difficulty. Wear clothes that you feel comfortable in.

Bathing: You can bathe, shower and even swim. The ostomy is like the tissue in your mouth or your anus. Water will not hurt it. The skin around the ostomy should be cleansed and dried. If you experience redness or if special care is needed for the skin under the pouch, seek advice from your health care team.

Sexual activity: You may feel embarrassed and/or unattractive because of your ostomy or fear rejection from your partner. An open discussion with your partner may reveal that your partner is relieved to have you home and is not concerned about any changes in your appearance. Resuming sexual activities shows you are recovering, returning to your normal life and adjusting.

After surgery, you may want to begin gradually with cuddling, kissing and caressing. As you gain confidence and become more comfortable with your ostomy, you can enjoy your pre-surgery sexual activities. Remember, sexuality is about intimacy with your partner rather than about a single act of intercourse. No cancer treatment or ostomy can take away your sexuality. It is an important part of who you are.

Special considerations: Some cancer survivors with an ostomy require other cancer therapies along with the ostomy surgery.

- **Chemotherapy:** A survivor may realize that assistance is needed to care for the ostomy if s/he feels sick or tired after chemotherapy. Some chemotherapy medications may have side effects that affect the ostomy. Let your health care practitioner examine your ostomy during follow-up visits. Take an extra pouch so you can remove yours for the examination. If you have a colostomy and routinely irrigate it, stop irrigations when you have diarrhea.

- **Radiation:** Radiation is an integral part of cancer treatment for many survivors. If the ostomy is in the marked field of radiation, you may have to remove your pouch for each treatment. Carry a spare pouch with you for all medical visits because the office may not have a pouch that fits your ostomy. Radiation may cause skin changes around your ostomy. Make your radiotherapy health care team aware of any changes with your ostomy and/or your skin. If diarrhea occurs during radiation therapy and you have a colostomy or an ileostomy, alert your nurse. Always take your ostomy supplies with you to the hospital or clinic. Always alert your health practitioners that you have an ostomy and let them know how you generally care for your ostomy.

Even though having an ostomy can affect many different areas of your life, your value as a person has not changed. What has changed is the location and method of your elimination. Most people will be unaware of your ostomy unless you tell them. Many cancer survivors live a normal and fulfilling life with an ostomy. If you are having trouble dealing with your ostomy, either physically or emotionally, you can take steps to make living with an ostomy easier. For more information, see Suggestions.

Works Cited

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