Mount
Sinai

Icahn
School of
Medicine at
Mount
Sinai

How To Care For Yourself After Surgery:

Caring For An Ileal Conduit (Stoma)

Ileal Conduit

As a newly diagnosed patient, you should learn about your diagnosis and treatment options as much as you can. Learning about your treatment options will help you make the treatment decision that is right for you. One option for some patients who opt for surgery to remove the bladder (Cystectomy) is to have an **Ileal Conduit**. This booklet "*How to Care For Yourself After Surgery: Caring For An Ileal Conduit*" will help you learn more about the **Ileal Conduit** procedure, how to care for yourself after surgery, problems you might encounter after surgery, and some recommendations to help you cope with surgery and side effects.

This booklet contains the following topics:

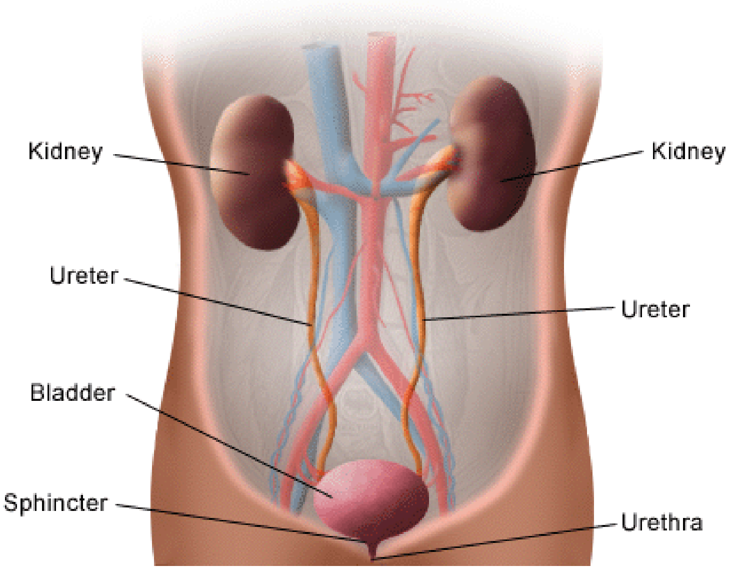
- Ileal Conduit Procedure
- Your Stoma
- Stoma Location
- Your Stoma Care
- Drainable One-Piece Collection System
- Drainable Two-Piece Collection System
- How To Empty Your Bag
- How To Change Your Bag
- How To Change Your Bag Step By Step
- The Night Drainage System

Ileal Conduit Procedure

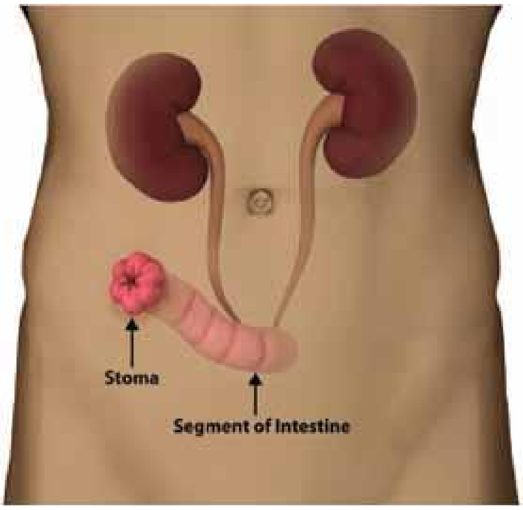
An ileal conduit is a type of **urinary diversion** which a surgeon creates using a piece of small intestine after removing the bladder. To do this, the surgeon takes a short segment of the small intestine and places it at an opening in the skin he has made on the surface of the abdomen to create **a stoma**. The **ureters**, which normally carry urine from the kidneys to the bladder, are then attached to the other end of the segment of intestine inside the abdomen. The urine now travels from the kidneys, passing through the ureters and the newly formed ileal conduit, to the stoma and out into a collecting bag known as a **stoma bag**. This bag is worn outside the body around the stoma 24 hours a day. Because the nerves and **blood supply** are preserved, the new conduit is able to propel the urine out of the body and into the bag constantly. The pictures below show the change in the **urinary tract** after ileal conduit procedure.

All **bold purple words** are included in the glossary at the end of this booklet.

Front View of Urinary Tract



Urinary Tract After Ileal Conduit



THINGS TO CONSIDER: The creation of an ileal conduit will mean several things to you in terms of care and what to expect after surgery. It is important to know and understand that it will take several weeks, perhaps even months, before you fully recover from your surgery. It will also take you some time to learn how to empty and change your stoma bag.

Learning how to empty or to change your stoma bag is very important to avoid urinary leakage and to maintain an active life style. A nurse will teach you how to empty and change your stoma bag after surgery and before you leave the hospital. This booklet provides some information that will help you learn about how to care for your ileal conduit.

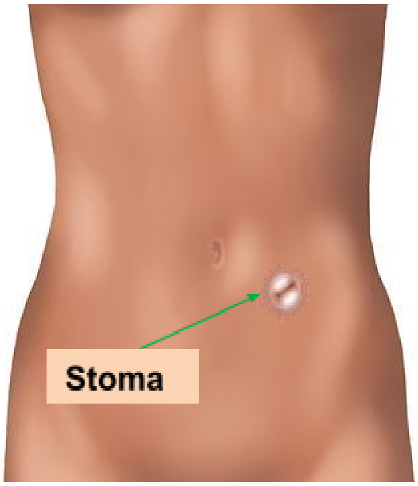
Your Stoma

A stoma is the end of the **small intestine** that can be seen sticking out of the **abdominal wall** like a rosebud. This is the part where urine will leave your body to be collected in the stoma bag. Having an ileal conduit means that you will not be able to control urine as it leaves your body.

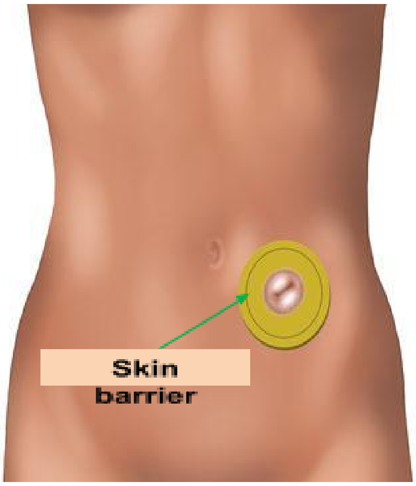
Stomas are different in size and shape. They are round or oval in shape and stick out of your abdomen an inch or less above your skin. They are red and moist (*similar to the inside of your mouth*) and have no feeling. Thus, you will not feel any pain touching your stoma or cleaning the skin around it. After surgery your stoma will be swollen; after a while it will shrink to a stable size. This means that you will need to adjust the opening of the stoma bag or the skin barrier that protects the skin around the stoma to the size of the stoma as it shrinks over time.

Stoma Location

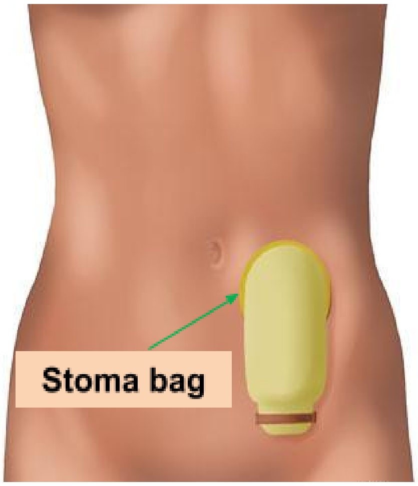
The ideal location of your stoma is usually above the waistline on a flat part of your abdomen lightly raised above the skin and away from deep body folds or scars or other problem areas. However, the size and location of the stoma might vary depending on your surgery and the shape of your abdomen. Stoma size and location might also change during major weight gain or loss. Most changes in stoma size take place within the first six months after surgery, but changes may occur at any time. It is very important that you discuss the stoma location and care with your physician and the **stoma nurse** before your surgery.



A stoma



A skin barrier



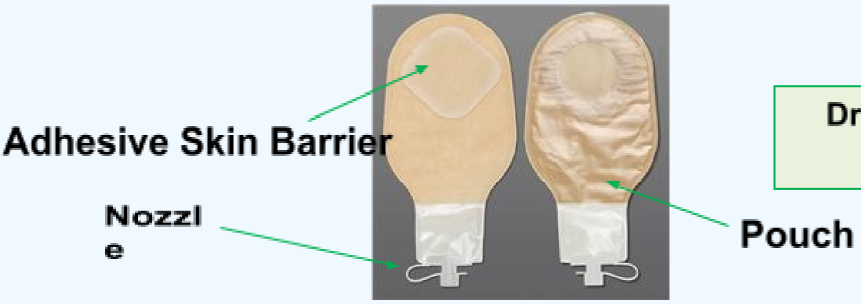
A stoma bag attached to a skin barrier

Your Stoma Care

Stomas require no special care. Stomas may be uncovered during showering or bathing, but should never be scrubbed and only patted gently with a soft towel. When bumped or rubbed, stomas may bleed slightly. Contact your physician immediately if the bleeding is substantial or persists for several hours or if you notice a change in color or a change in the general appearance of your stoma. The major function of the stoma bag is to collect urine. It also helps protect your stoma and the skin around it and keeps the odor contained inside the bag. There are different types of stoma bags but all of them are light weighted and lie flat against your skin. Stoma bags can be divided to two types; one-piece and two-piece systems.

Drainable One-Piece Collection System

This is a one piece collection system or bag that could be applied and removed as a single unit. The bag is connected to a skin barrier that will be attached to the skin around the stoma. This means that when you remove the bag, the skin barrier will also be removed. The one piece bag could also be drainable. The drainable bags could be emptied from the bottom without removing the bags. This will allow you to keep the bag for several days until you decide to change it.

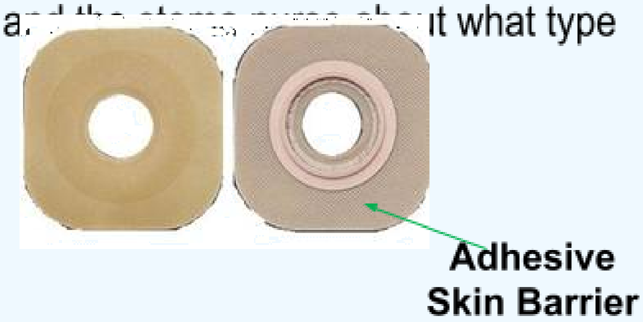


Drainable One-Piece Stoma Bag

Drainable Two-Piece Collection System

The bag is connected to a skin barrier. This will allow you to change the bag without removing the skin barrier. This facilitates frequent bag changes and cuts down substantially on changing time and effort. It also eliminates unnecessary wear and tear on the skin around the stoma when the faceplate is intact and only the bag needs to be changed. The two-piece bag can also be drainable. The drainable bag can be emptied from the bottom without removing the bag (see pictures below). This will allow you to keep the bag for several days until you decide to change it. Talk to your physician and the stoma nurse about what type of stoma b [illegible] you.

Drainable Two-Piece Stoma Bag



Skin Barriers (Pre-Sized)

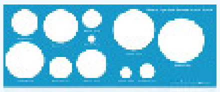
How To Empty Your Bag

This is the first task you will learn after your surgery. A stoma nurse will help you learn how to empty your stoma bag. It is recommended that you empty your bag when it is one-third to one-half full. If your bag is too full it will start to pull away from your skin. This will cause **urinary leakage**, skin irritation, and make you feel uncomfortable. To empty your bag, you will need to follow these steps:

1. Sit or sta oilet with the lowest ag pointing t n your legs.
2. Place a layer of toilet paper in the toilet bowl to splashing
3. Hold the bottom of the bag up. Open the bag by twisting **the nozzle** (see the picture below) or removing the nozzle plug. Before lowering the bag, pinch together the nozzle.
4. Slowly lower the nozzle toward the toilet.
5. Release your fingers and let the urine drain.
6. When empty, tap the nozzle to remove any last drops of urine.
7. Close the bag by twisting the nozzle into the "**CLOSED**" position or

How To Change Your Bag

A stoma nurse will help you learn how to remove and change your stoma bag after surgery while you are still in the hospital. You can change your bag every three to five days if you have no problem with leakage or itching skin. You will need the following equipments to change your stoma bag.



How To Change Your Stoma Bag Step By Step

Step 1: Remove the old stoma bag

- To remove the old stoma bag, begin by peeling away one corner of the wafer (skin barrier). With one hand pressing the skin and the other hand lifting the wafer, gently remove the wafer from the skin. You can use adhesive remover pads to help lift the wafer off of your skin. Many wafer contain alcohol and may be irritating the skin. Make sure to clean off the skin with soap and water. Place the old stoma bag in a plastic waste bag.

Step 2: Clean the area around your stoma and examine your stoma for discoloration

Look at your stoma. Your stoma should be red and moist.

If the color is blue, purple, or black this may be considered a medical emergency. Call your physician immediately.

Look at your skin around the stoma. Your skin around the stoma should look like the rest of the

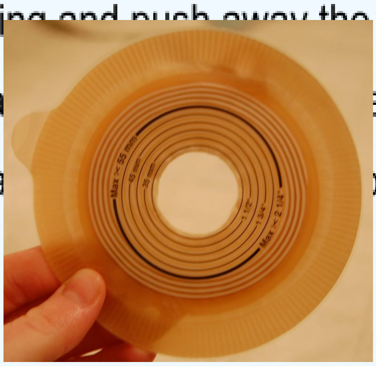
How To Change Your Stoma Bag Step By Step

Step 3: Measure the size of your stoma and fit the new skin barrier to the size of your stoma

1. Select the circle size on the measuring card that fits closest to the size of your stoma without touching it. Cover your stoma with a piece of tissue to catch any urine leakage while you are measuring your stoma.

- Trace the best circle size that fits your stoma onto the back of the paper on the wafer (skin barrier).
- Use the scissor to cut the wafer to this circle size.

4. Center the new opening over your stoma to make sure it fits along the stoma edge. If it does not fit, cut and adjust the opening until it fits.
5. If you are using a one-piece collection system (bag), place your finger into the small pre-cut openi bag before you start cutting to avoid damaging the ba ed, you cannot use it. In order to prevent odor, you ca dorant to the bag as well.



REMEMBER. The stoma size or shape may change during the first 3-4 weeks after surgery as the swelling goes down.

How To Change Your Stoma Bag Step By Step

Step 4: How to apply the new bag

- If you have a two-piece system (bag), attach the bag to the plastic ring on the wafer.

Peel the paper off of the back of the wafer.

Put stomahesive paste around the opening on the sticky side of the wafer.

Squeeze stomahesive paste around the hole on the wafer, the same thickness that you would squeeze toothpaste onto a toothbrush.

If the skin around the stoma becomes red or open, you may need to stop using Stomahesive Paste® and use an Eakin Seal a soft, flexible pectin ring. Mold the Eakin Seal on the skin around the stoma.

- Center the bag around the stoma and place it onto the skin. Firmly press the wafer to the skin near the stoma and hold for 30 to 60 second so that the wafer sticks to the skin.
- Make sure that the tap at the bottom of the pouch is turned to the "**CLOSED**" position.
- Wash your hands.

The Night Drainage System

A night drainage system can be attached to the stoma bag before you go to bed. This system then collects and stores urine. That way, you can sleep all night witho pty the stom bag.

One-piece container and tube

Tube

Container

Parts of a Night Drainage System

The parts of a night drainage system are shown above. Talk with your physician or the stoma nurse about what will work best for you.

Setting Up the Night Drainage System

There are several types of night drainage systems. Each night drainage system consists of several parts. Whichever type you chose, you will need to set up the system (connect parts) before connecting it to the stoma bag. Be sure to do the following:

- The tubing and the container can come as one piece. But they can also come as two pieces. If they do, put one end of the tubing into the lid of the container. Keep connected until the container must be replaced.
- Each night, connect the other end of the tubing to your stoma bag.

The Night Drainage System

At Night:

The stoma bag should be about one-fourth full when you attach the drainage system to it. This will help urine flow into the tubing from the stoma bag. To attach the system to your stoma bag:

- Place the night drainage container in a basin on the floor next to your bed.
- Connect the tubing to the stoma bag.
- Open the closure on the stoma bag drain. This way, urine can flow through the tubing.
- Use a leg strap to keep the tubing next to your thigh. This will help prevent the tubing or the stoma bag from twisting.

In the Morning:

To detach the night drainage system from the stoma bag each morning:

- Return the stoma bag drain to the "**CLOSED**" position to prevent leakage.
- Remove the lid from the night drainage container (but keep the tubing in place).
- Empty the night drainage container's contents into the toilet.
- Rinse out the tubing and container with cool water in the bathroom sink or tub. Let the tubing and container air-dry.

Cleaning the night drainage system

Clean the night drainage system every 2 to 3 days. Follow these steps:

- Set white vinegar, a measuring cup, and a funnel next to the bathroom sink or tub.
- Pour 1/4 cup vinegar through the tubing into the night drainage container

Problems You Might Experience Because Of Your Treatment

1. **Leaking:** Your stoma bag will leak if it is full or the bag is damaged. To avoid bag leakage you will need to empty your bag when it is one-third to one-half full.

2. **Irritability:** The skin around your stoma can become irritated and red when it comes in contact with urine from your stoma. This is normal. To avoid skin irritation, you will need to adjust the opening of the wafer (skin barrier) to the size of your stoma as described above. It is also recommended that you change the skin barrier every 3 or 5 days to avoid skin irritation if you are using a two-piece pouching system. You will also need to examine the skin barrier every now and then to look for exposed skin and urine leaking under the barrier. If you notice exposed skin or any leaking, you will need to change your bag. You may also need to use skin barrier past to fill any gaps between the barrier and the skin.

3. **Stoma size and shape:** After your surgery, your stoma will be swollen. However, the stoma size and shape will change during the first three months after your surgery. It is recommended that you keep measuring your stoma size every time you change your bag during this period and to keep track of this change. Avoid buying pre-cut skin barrier during this period until your stoma size becomes stable.

Problems You Might Experience Because Of Your Treatment

5. **Mucus in the urine.** Mucus in the urine is normal since the ileal conduit is built with part of the intestine.

6. **Occasional flecks of blood on your stoma.** You may see blood spots on your stoma because the stoma has good blood supply. You may also see blood spots when you are cleaning or changing the stoma bag. Contact your physician immediately if you see blood in your bag or if the bleeding continues.

7. **Stoma retraction:** This means the stoma is lower than the surrounding skin level. This might make your stoma bag seal difficult. If you have stoma retraction you might also experience urine leakage. You will need a good seal to solve this problem. Contact your physician or the stoma nurse if you have problems with persistent leaking.

8. **Urine is not coming out of the stoma.** Contact your physician immediately if urine stops coming out of your stoma. This might be a sign of blockage or internal changes that needs immediate medical attention.

9. **Leaking at night** at night often due to excessive drinking of liquid er 7-8 p.m. You can also use the nigh

Problems You Might Experience Because Of Your Treatment

10. **Sexual Function (Men)**. For men, the surgeon also removes the prostate together with the bladder. This can cause erectile dysfunction. It is common to suffer from some level of erectile dysfunction because of the surgery. You should discuss with your doctor your chances of having erectile dysfunction after surgery and possible treatment options. Some doctors will recommend the oral medicine with PDE5 inhibitors Viagra, Levitra or Cialis, Vacuum Erection Devices, Intracavernosal Injections, or Penile Implants for men with erectile dysfunction.

11. **Sexual Function (Women)**. For women, the uterus, cervix, fallopian tubes, and ovaries, are removed during surgery. This can cause some level discomfort and difficulty during sexual intercourse. Many women might feel nervous about resuming sexual function after surgery. However, remember, the vaginal tissue expands/stretches and will allow for sexual penetration. You may want to consider using a lubricant as many women note they do not have sufficient physiologic lubricant. You should discuss with your physician your chances of having sexual problems after surgery and possible solutions for these problems.

Recommendations

Your Medical Information:

It is recommended that you carry medical identification with you at all times. You can keep a card with information about your surgery “Ileal Conduit” with you all the time. Some patients recommended the following:

- Having a medical alert bracelet or necklace with the information engraved on it.
- Keeping a card with this info in the glove compartment of a car.
- Telling their family members what information to communicate in case of emergency.

You will also need to notify your physician if you experience some of the following problems:

- Wound or severe change in stoma color (dark purple color). Stoma discoloration could indicate a serious problem that needs immediate medical attention.

- Continuous bleeding from the stoma.
- Chills and/or fever.
- Persistent nausea and vomiting.
- Persistent abdominal pain.
- Blood in the urine.
- Severe skin breakdown that does not heal or

Recommendations

Activities after your Ileal Conduit surgery:

- You can shower when all the drains are removed. Tub baths are not to be taken until your incision is completely healed.
- No straining or lifting over 10 pounds for 4-6 weeks.
- You may drive after 4 weeks.
- Avoid contact sports for 4 to 6 weeks, or until your doctor tells you it is safe.
- Swimming is okay after 6 weeks.
- You may resume sexual activity when you are ready.
- Plan on being off work for 6-8 weeks.

Diet:

- Eat a regular diet as you are able. Some foods, such as spicy foods, asparagus, fish, eggs, medicines, and vitamins, can change the smell of your urine. You should drink at least 2-3 quarts of fluids per day. A high urine output will help reduce your risk of infection. High fluid intake also reduces the risk of stones.

Traveling:

- When you are travelling by plane, it is a good idea to carry the “Traveler’s Communication Card”.
- This card can help you to communicate with federal Transportation Security officers (TSO) and airline flight attendants easier. It is also your legal right to use this card when you wish or need to speak to them in a non-verbal way.
- Please note that this is **neither a “certificate” nor a “pass”** to help you

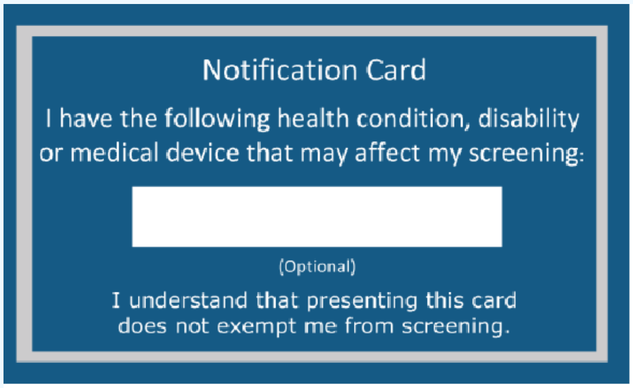
Traveler's Communication Card

To use during screening before boarding

This is intended for you to show the TSO before being patted-down or entering a full-body scanner.

Outside Left

Outside Right



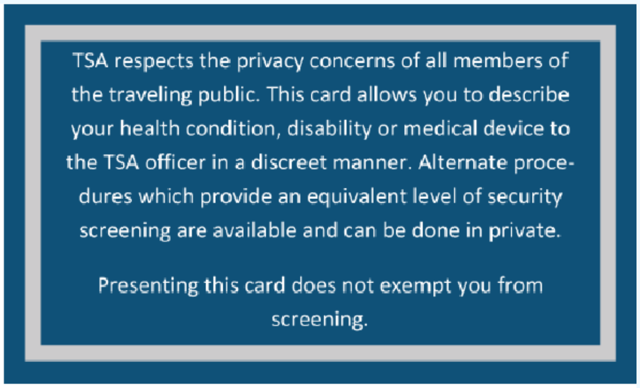
Notification Card

I have the following health condition, disability or medical device that may affect my screening:

(Optional)

I understand that presenting this card does not exempt me from screening.

FOLD LINE



TSA respects the privacy concerns of all members of the traveling public. This card allows you to describe your health condition, disability or medical device to the TSA officer in a discreet manner. Alternate procedures which provide an equivalent level of security screening are available and can be done in private.

Presenting this card does not exempt you from screening.

~ ~ GOTTA GO <u>NOW</u> ~ ~ RESTROOM ACCESS

The cardholder contains body waste in an <u>OSTOMY POUCH</u> (stool/urine) and/or carries pouches and related supplies and/or a catheter to manage personal hygiene. S/he needs access to the restroom <u>now</u> in order to empty the pouch — this is critical for the cardholder's well-being and for public sanitation.

TRAVELER'S COMMUNICATION CARD

Provided by the UOAA, a volunteer-based health organization dedicated to providing education, support and advocacy for people who have or will have intestinal or urinary diversions.

United Ostomy Associations of America
www.ostomy.org 1-800-826-0826

Inside Left

Inside Right

To use while in flight

This is to use when the pilot has chosen to limit restroom access or when you are supposed to be wearing seat belt during turbulence. You might also want to show it to a flight attendant during boarding and/or getting settled so he/she will be mindful of your situation.

Other Resources Available For Patients And Survivors

American Cancer Society (ACS)

ACS offers educational information for bladder cancer patients about treatment and side effects, nutrition and diet after treatment, and offers supportive care for cancer patients and survivors. ACS services include support groups for patients, survivors, and family members to discuss their concerns and receive support from others in the online community.

ACS support services: HYPERLINK "http://www.cancer.org/Treatment/SupportProgramsServices/index" http://www.cancer.org/Treatment/SupportProgramsServices/index

ACS CSN: HYPERLINK "http://csn.cancer.org/" http://csn.cancer.org/

The National Cancer Institute (NCI)

The NCI also offers educational information for bladder cancer patients about treatment and side effects and offers several booklets to help the patient and the family caregiver to cope with and adjust to cancer and treatment. HYPERLINK "http://cancercontrol.cancer.gov/ocs/ff_series.html" http://cancercontrol.cancer.gov/ocs/ff_series.html

Bladder Cancer Advocacy Network (BCAN)

BCAN—the Bladder Cancer Advocacy Network is the first national advocacy organization dedicated to increasing public awareness about bladder cancer; to advancing bladder cancer research; and to providing educational and support services for the bladder cancer community. BCAN's website provides information for newly diagnosed bladder cancer patients, patients with recurrent cancer, and support groups in the United States and Canada.

Other Resources Available
For Patients And Survivors

United Ostomy Associations of America (UOAA)

The UOAA is a national organization to provide support, information and advocacy to ostomates (a person with a stoma) and their caregivers. The web site includes a discussion board that provides access to online conversations related to living with a stoma, as well as a treatment fact sheet and care guide. HYPERLINK "http://www.uoaa.org" http://www.uoaa.org **/ or 1-800-826-0826**

Wound Ostomy and Continence Nurses Society (WOCN)

The WOCN is a professional nursing society of nurse experts who specialize in the care of people with wounds, ostomies and incontinence issues. Many of the nurse specialists provide care for patients with an ostomy and a search can be done to find a WOC nurse in various United States locations. HYPERLINK "http://www.wocn.org" www.wocn.org **or 1-888-224-9626**

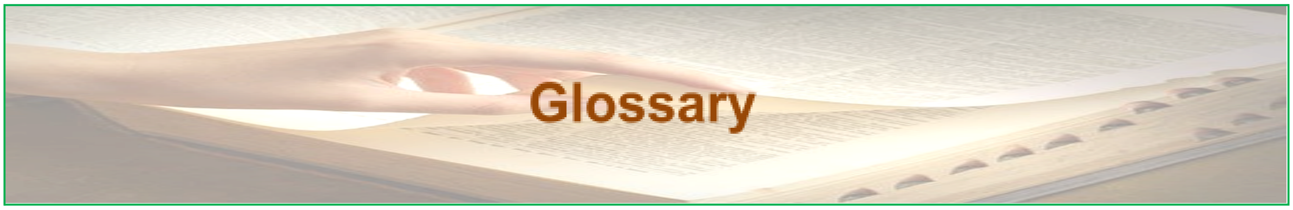
National Coalition for Cancer Survivorship (NCCS)

The NCCS is a cancer advocacy organization aims to empower cancer patients and survivors through cancer education. The NCCS offers the Cancer Survival Toolbox®. This award winning audio set is provided to survivors, caregivers and clinicians at no cost. **Call 1-888-650-9127 or visit the website at** HYPERLINK "http://www.canceradvocacy.org/" http://www.canceradvocacy.org/

Manufacturers of ostomy equipment

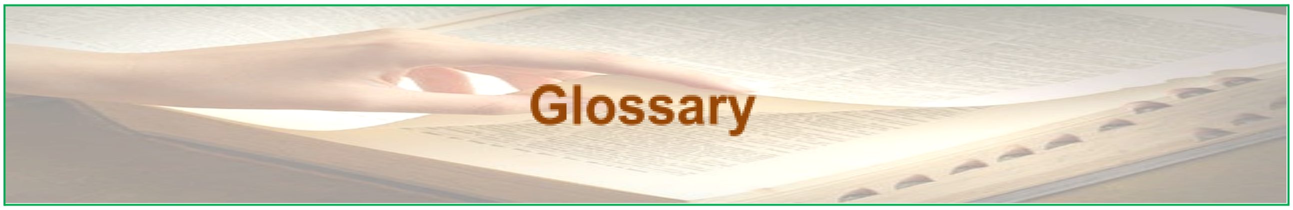
- **Coloplast:** On line interactive user guide, sample line. HYPERLINK

Abdominal wall	The area that represents the stomach boundaries of the stomach cavity.
Blood supply	The amount of blood that flowed into and supplied to an organ or part of the organs during a certain time period.
Catheter	A flexible tube. A urinary catheter is a tube that is put into the bladder or the continent urostomy to drain out the urine.
Cut-to-fit or moldable convex	This is a one-to- two piece pouching system allowing users to cut or mold the opening in the skin barrier to fit irregular shape stomas. These are especially recommended if the stoma is not round.
Ileal conduit	A urinary diversion operation which allows urine to pass from kidneys and ureters through a passageway made of a short piece of small intestine to the outside of the body.
Large intestine	It is the last part of your digestive system. It absorbs water and eliminates the residues (waste) of digestion.
Mucus	Fluid secreted from glands or cells. It lubricates membranes, including the inside of the digestive tract.
Nozzle	A nozzle is often a pipe or tube, and it can be used to direct or modify the flow of a fluid.
Ostomy	A surgically created opening in the belly (abdominal wall) through which the body gets rid of waste. This term refers to ileostomies, colostomies (both of which drain stool), and urostomies (which drain urine).
Stoma bag	It is a medical device that provides a holding place for the collection of waste from your body through the ostomy.



Stoma nurse	A registered nurse who takes care of and teaches ostomy patients. Special training is required for certification. This nurse may also be called a Wound, Ostomy and Continence nurse (WOC) or an Enterostomal Therapy (ET) nurse.
Pouch	The collecting bag for waste that comes out of a stoma.

Skin barrier	Any one of many substances used to cover and protect the skin around the stoma. Can be pliable sheets, pastes, powders, etc.
Stoma	A stoma is the actual end of the ureter (red color) or small or large bowel that can be seen protruding through the abdominal wall.
Ureter	The 2 tubes that drain urine from the kidneys, normally they go into the bladder, but in the case of a urostomy they drain urine out of a stoma
Urinate	Emptying your bladder of urine.
Urinary diversion	Any one of several surgical procedures to divert urine away from diseased or defective kidneys, ureters, bladder, or urethra. In many diversions, a new passageway for urine is formed through the belly (abdominal wall) to outside the body. This involves making a stoma or suturing a tube in place to drain urine. If a stoma is made, a pouch (bag) is usually worn. See urinary tract and stoma.
Urinary tract	A flexible tube. A urinary catheter is a tube that is put into the bladder or the continent urostomy to drain out the urine.



References

- Facing Bladder Cancer. Bladder Cancer Advocacy Network (BCAN). [2012]. Available under: HYPERLINK "http://www.bcan.org/facing-bladder-cancer/frequently-asked-questions/treating-bladder-cancer/ileal/" http://www.bcan.org/facing-bladder-cancer/frequently-asked-questions/treating-bladder-cancer/ileal/ [10/17/2013]
- Roni Olsen (1990). A Guide to Bladder Cancer, Urostomy, and Impotence. Highline Edition.
- Home Care Instructions for Changing an Ostomy Pouch. Children's Hospital Boston [2013]. Available under: HYPERLINK

Icahn
School of
Medicine at
Mount
Sinai

Mount
Sinai

ACKNOWLEDGEMENTS

The development of this booklet was made possible through a generous grant from the American Cancer Society (ACS) offered to Nihal E. Mohamed, PhD.

We would like to thank the ACS, the research team, colleagues, consultants, and patients and their family caregivers who contributed to this study. In particular, we would like to thank our colleagues at the following institution for their support of this study and their feedback that helped make this booklet better serve the needs of bladder cancer patients and survivors:

DEPARTMENT OF VETERANS AFFAIRS • UNITED STATES OF AMERICA

Supported by Mentored Research Scholar Grants from the American Cancer Society
(121193-MRSG-11-103-01-CPPB)