

C-M-E Ostomy Chapter
Jenna Kreke
Sarah Bush Lincoln
1000 Health Center Dr.
Mattoon, IL 61938



One of the **happiest**
moments ever is when
you find the **courage**
to **let go** of what you
can't change.



Charleston • Mattoon • Effingham Area Ostomy Chapter

Meetings

Meetings of our Ostomy Chapter are held the second Thursday of the following months:

- **April** - Lumpkin Family Center for Health Education at Sarah Bush Lincoln
- **July** - Effingham - location to be determined
- **September** - Lumpkin Family Center for Health Education at Sarah Bush Lincoln
- **December** - Mattoon- location to be determined

Special Invitation

A special invitation is being extended to all persons who have a colostomy, ileostomy or a urinary diversion (ileo bladder or ileo conduit) and all other interested persons who desire to participate in the organization. Our objectives are to help in the physical, emotional, and social rehabilitation of ostomy patients through mutual aid, information, and understanding.

For transportation, additional information, being added to the mailing list, please phone Linda Will, RN, Effingham, **(217) 342-6651**, or Ramona Tomshack, RN, CWOCN, Sarah Bush Lincoln, **(217) 348-2189**.

Individual Support

Upon request by a doctor or nurse, a specially trained person, will be sent to visit a person with an ostomy. The person will be chosen according to the patient, age, sex, and occupation. There is no charge for this service; and we do not give medical advice.

Please consult your own doctor or ostomy nurse for the medical advice that is best for you.

Chairperson

Paula Miller
1902 N. US Hwy 45
Mason, IL 62443
(618) 686-7975

Linda Will
511 N. Main St.
Effingham, IL 62401
(217) 342-6651

Sharyl King
3204 Walnut Ave
Mattoon, IL 61938
(217) 235-0269

Medical Advisors

Linda Will, RN

Ramona Tomshack, RN, CWOCN
(217) 258-2189

Debbie Murray, BSN, RN, CWOCN
(217) 238-4850

Jenna Kreke, BSN, RN, CWOCN
(217) 238-4804



December Christmas Party

6 pm • Thursday, December 13

The Airport Steakhouse, Mattoon
410 Airport Rd, Mattoon, IL 61938

We would like to welcome any ostomate and family to come to the ostomy Christmas party! This is a great meeting to go to; we socialize, eat some great food, and play some bingo! This year we are providing the group with pie from the Airport Steakhouse! Also, the Advanced Wound Center at Sarah Bush Lincoln is supplying the desserts for the party.

When you come, bring a \$5 Christmas gift (baked goods are a GREAT gift!!)

Notes from the September meeting

We had several new members at the meeting! It was great to meet you!
Steve from Convatec was there to give advice and show us all the latest and greatest products.

In case of inclement weather

If you think the meeting is possibly cancelled due to bad weather, you can call Ramona’s number 217-348-2189 after 3 pm, she will include the cancellation information in her voicemail.

Holiday Greetings

The Chairmen and Medical Advisors
would like to wish everyone a
Merry Christmas
and Happy New Year!!



Do you have questions? If you have a question, you are not alone!

Email me at dmurray@sblhs.org or send your question to:

Debbie Murray
1000 Health Center Drive, Suite 302
Mattoon, IL 61938

The questions will be anonymous but answered in the next newsletter!

Frequently Asked Questions



Does insurance cover the cost of my ostomy supplies?

Medicare Part B covers ostomy equipment. Medicare only allows a predetermined maximum quantity each month. Medicaid is the federal/state insurance of last resort for low-income persons. Check with the state Medicaid office for specifics.

Individual Health Insurance: most plans typically will pay a high percentage of the “reasonable and customary” costs after the deductible is met.

What should I do if I get hospitalized again?

Take your ostomy supplies with you since the hospital may not have your brand in supply. If you are in doubt about any procedure, ask to talk to your doctor.

Ask to have the following information listed on your chart: 1) type of ostomy or continent diversion, 2) whether or not your rectum is intact, 3) describe in detail your management routine and list the ostomy products used. For urinary stomas, 4) do not take a urine specimen from the urostomy pouch, use a catheter inserted into the stoma.

Got any tips on emptying the pouch?

Check the pouch occasionally to see if it needs emptying before it gets too full and causes a leakage problem. Always empty prior to going out of the house and away from a convenient toilet. Most people find the easiest way to empty the pouch is to sit on the toilet with the pouch between the legs. Hold the bottom of the pouch up and remove the clamp. Slowly unroll the tail of the pouch into the toilet. Clean the outside and inside of the pouch tail with toilet paper. Replace the clamp.

Ask A Nurse

The Phoenix Magazine - Fall 2018

Miralax Substitute

I have a colostomy and constipation. I have been taking Miralax since my doctor suggested it several months ago. The problem is I feel dehydrated and I think it's because of the Miralax. Is there something else I can take instead? - T.C.

Dear T.C.,
Yes, there are many different laxative you can take. Which laxative you and your doctor choose is really based upon the cause of your constipation. Most people are constipated due to a lack of water and fiber in their diet. Other patients need to take medications that slow transit-like narcotics, or certain heart medications and vitamin supplements.

Most laxatives work by drawing water into the intestine to make stools softer and easier to pass. Miralax (PEG solution) is an osmotic laxative; magnesium products are saline laxatives. Other medications like Amitiza (lubiprostone) increase fluid secretion and transit, while Linzess (linaclotide) increases the production of a chemical called cyclinc guanosine monophosphate; this increases fluid secretion into the intestine and reduces the sensitivity of pain-sensing nerves. If you use any of these laxatives that draw water into the bowel lumen, it is important to drink plenty of fluids to maintain hydration. Stimulant laxative like senna and phenophthalein are also available but are generally discouraged for long term use; they may be a reasonable solution for occasional bouts of constipation.

Blood in the Bag

I noticed some blood and I'm not sure where it's coming from. It's not a huge amount. I can't tell if it's coming from inside or outside the stoma. How much blood is a cause for concern? - B.L.

Dear B.L.,
The best way to tell where the blood is coming from is to remove the bag and closely observe the effluent - is the blood oozing from the edge of the ostomy, or coming out of the central aspect of the stoma? Your ostomy nurse may be a great resource in helping you sort this out. Remember if you have an ileostomy, the consumption of red foods may cause your output to look "bloody," when it is actually red food dye that you are seeing. Passing large clots or filling the bag with blood is cause for serious concern and immediate evaluation by your colorectal surgeon or gastroenterologist.

X-ray with Barium

I have an ileostomy due to ulcerative colitis. My doctor wants to use an upper gastrointestinal tract x-ray with barium to diagnose my difficulty swallowing. Will this procedure and the barium be OK for my ileostomy? I have high output and worry this will make me dehydrated. - D.L.

Dear D.L.,
It is OK to do a barium swallow to diagnose the cause of your swallowing difficulty, even if you have an ileostomy. Barium is an inert substance that will not increase your output. Other contrast agents like those used for CT scans can definitely increase your output since they are hyperosmolar, and will draw fluid into the bowel and increase volume of output.

Skin Issues & Solutions

Vancouver (BC) Ostomy HighLife March / April 2018

SKIN IRRITATION UNDER TAPE

Irritated skin that develops only under the tape of your skin barrier can occur for a variety of reasons. The skin may be itchy, blistered or open and weeping. This problem can develop at any time, even if you have worn the same type of product for months or years. In this case, you may be sensitive to an ingredient in the tape, or your skin may have become damaged when tape is removed.

RASH AROUND A STOMA

Sometimes a rash is caused by a skin infection or sensitivity, or even from leakage. The area may be red or red with bumps. Itching may also be a symptom. It is important to get assistance in determining the cause since the suggestions for treatment will vary.

LEAKAGES CAUSING IRRITATION

Stoma discharge can be irritating to your skin, causing redness that can lead to open raw skin that weeps or even bleeds. This type of irritation is often very painful. (People with ileostomies are at the highest risk for this kind of skin damage.) A change in the size or shape of your stoma or the shape of your abdomen can change the fit of your pouching system, leading to leakage.

What Are Some Solutions?

- Try a pouching system without tape. These products are adhesive but use a skin barrier instead of tape.
- Apply stoma powder to any open skin before applying your new pouching system.
- Contact a stoma care nurse if you are having difficulty keeping your skin barrier on.
- Change your pouch promptly if drainage is leaking under the skin barrier.
- Change your pouch on a regular schedule before it leaks.
- Contact your stoma care nurse if you are having difficulty keeping your skin barrier on.
- Consider using accessories (convex skin barriers, paste, rings/seals) to help prevent leakage under the skin barrier.

Ostomy News and Products

The Original Pink Tape / Hy-Tape

When applied to dry, nontreated skin, Hy-Tape provides a waterproof protective seal around the edges of the pouch. Those who experience reactions to adhesives often find that the latex free, zinc oxide based adhesive leave the skin healthy and intact.

I know some ostomates are using tape on their skin, this is a better alternative if you feel you need to use tape on your skin to keep the pouch on.

Request a Sample:

Would you like to experience Hy-Tape?
Call **1-800-248-0101** and we will send you a sample pack!



The Nu-Comfort Belt

Extra easy Velcro adjustment on left and right, 360° of extra support to entire wafer, extra support to the peristomal area including small peristomal hernias. Twice the width of standard ostomy belts, also can be used with 1 or 2 piece pouches.



That Annoying Pancaking

Vancouver (BC) Ostomy HighLife

Pancaking is one of the most common problems that people with a colostomy will complain about. It is caused when output stays at the top of the pouch and does not slide down into the bottom. It can stick around the top of the pouch, causing a bulge. It's really annoying!

What can you do to prevent this?

- Make sure you are drinking enough fluids throughout the day; it is recommended to drink about 2 liters in 24 hours. This will help to soften stool.
- Something else that has worked for some people with a colostomy would be to drink cool boiled water with a dash of lemon first thing in the morning. This can also help to soften stool.

- Try increasing the amount of fiber you are eating—more veggies, fruits etc.
- If none of the above work, try putting a small amount of lubricating agent into your pouch. Ostomy pouch lubricants made by Hollister, Coloplast, and ConvaTec are best for this but you can also use vegetable oil, Pam spray or even Vaseline. (Note: household lubricants may add to odor.) Smear whatever lubricant you choose around the inside top of the pouch.
- Before you put your new pouch on, put a little bit of tissue paper into the bottom so it's not causing a vacuum when you seal.

6 Things I Wish Someone Had Told Me About Ostomy Surgery

Laura Cox, Ostomy Lifestyle Specialist Shield Healthcare

You’re making the right decision

I remember being told I could have elective ostomy surgery within the next few months or that if I chose to keep my colon, it would probably be emergency surgery within the year. I was so sick and in a lot of pain, but there were so many unknowns about surgery. I decided it was best to remove my colon in a non-emergent way. I had a lot of worries about my decision and had a lot of “what ifs” in my mind. Six years after surgery, I believe I did make the best decision. Although life will never be the same as before surgery, the quality of my life has dramatically improved!

You will feel better, but it’s not a cure

I rationally knew that surgery was not a cure for Ulcerative Colitis, but I think part of me was expecting to have no symptoms of my autoimmune disease after my total colectomy. The truth is, I still get some extra intestinal-manifestations of my illness, like arthritic pain, canker sores, and fevers. Compared to my UC symptoms prior to surgery, these feel quite mild, but it is easy to tell my illness is still sometimes active.

It is different, but it is not devastating

Living with an ostomy is different than anything you’ve experienced, but you quickly learn that different isn’t bad. Sure, you miss some things about having a colon, like the ease of staying hydrated, but having an ostomy is completely doable and the longer you have it, the more living with an ostomy turns into your “new” normal.

It’s okay to be scared and sad, but you didn’t “lose”

I know sometimes people feel like they have to be brave, but the process of getting an ostomy can be scary, and there can be some sadness surrounding the change in lifestyle, but acknowledge those feelings, and then try to accept them while also learning all the beautiful things about having an ostomy too. I know it can feel as though you “lost” to your illness when it was time to get a total colectomy, but it was never a competition. My life certainly doesn’t feel like a “loss” 6 years post-op, and that feels like a victory.

You will be able to do all of the things you enjoy

Living with an ostomy has not taken anything that I hold dear to my heart away from me. During recovery you’ll have to take it slow, but as soon as you begin to come out of recover, you’ll be able to be active. Seven months post-op, I was able to hike, run, climb, swim, camp, and was even inspired to try new things like advocate, speak, and travel.

After the surgery, you will find a way to make meaning out of these experiences

Through the process of illness, pain, and surgery, you will find within you a growth that allows you to find meaningful ways to utilize the gifts that illness and surgery has given you. It is easier to practice gratitude when feeling well, it allows you to be empathetic to people who are hurting, it teaches self-compassion, and has shown you how resilient the human spirit can be. I believe Rumi said it best “The wound is the place where the light enters you.”

Ostomy Diet Guidelines After Surgery

Ostomy.org

Chances are you will be able to return to your normal diet not too long after your operation. It is good to keep in mind that foods that were good and healthy for your body before your operation are still good for you. A well-balanced diet is recommended for most individuals.

Although your ostomy nurse more than likely will give you tips and advise you on your health and diet, here are some alternative helpful suggestions for maintaining a proper diet after your surgery.

Follow the advice of your surgeon, dietitian, and/or WOC nurse regarding any dietary restrictions right after surgery or on a longterm basis.

Start Small

Ease your way back to proper nutrition with small quantities of food. It is recommended to eat 3 or more times per day in smaller quantities and portions. Try to eat these meals at the same time each day to help regulate bowel movements. Eating more frequently and in smaller quantities will help aid your body’s ability to process food and help with unnecessary gas. For the first several weeks after your surgery, eating simple and bland soft foods will be easier to digest. Keep in mind that chewing your food well also adds to the ease of digestion - the more broken up it is, the easier it will be to process. Take your time with introducing high-fiber foods back into your diet as these will be harder to digest and can cause blockages. Ileostomates are often encouraged to avoid high-fiber foods to prevent risk of obstruction. Always follow the advice of your surgeon, dietitian, and/or WOC nurse regarding any dietary restrictions right after surgery or on a long-term basis.

If you are trying new foods, it is advised to try them slowly and one at a time. This will help you to have a better understanding of how your body works with the new foods and if any will cause excess gas, constipation, strange odors, or diarrhea. Slowly incorporate them into your diet and make note of how your body responds to them. Remember that every body is different and what affects someone else may not affect you in the same way. This is why it can be helpful to keep a journal or diary of how your body responds to different foods.

Drink Lots of Liquids

It is important to drink lots of liquids with an ostomy. If you have an ileostomy, more specific ileostomy dietary guidelines will be helpful. Dehydration can happen as

you lose more fluids daily after an ileostomy, due to the fluid not being reabsorbed into the large intestine. Make sure to hydrate even more on hot and humid days or if you are participating in active sports. (Sports drinks and other high electrolyte drinks can help with this.)

Coffee and tea are fine to drink, but water and juices are still better sources of liquid, so be careful not to use coffee or tea as a substitute for water.

Can I Drink Alcohol With my Ostomy?

Alcohol is fine in moderation, you may want to try one drink (or even a half) and wait and see how it affects your body. Like other carbonated beverages, beer may cause extra gas and uncomfortable bloating but every body is different and what affects one person may not affect you in the same way.

Ostomy Problem Foods

Even though you can still enjoy most of the foods you loved before surgery, there are some foods to be aware of after your ostomy, specifically foods that are hard on digestion and can cause blockages. The following is a list of common foods that can cause problems, as they don’t break down easily:

- Nuts
- Seeds
- Popcorn
- Dried fruit
- Mushrooms
- Raw-crunchy vegetables

Eat these foods in small quantities and be sure to chew them well. If you think you have a food blockage, you should call your doctor or ostomy nurse. Having an ostomy certainly doesn’t mean you have to completely change your diet. By steering clear of a short list of problem foods and making sure to stay hydrated, you can get back to enjoying the foods you love.

To learn more about proper nutrition with an ostomy, visit Coloplast Care online.

Follow the advice of your surgeon, dietitian, and/or ostomy nurse regarding any dietary restrictions right after surgery or on a longterm basis.

