

C-M-E Ostomy Chapter

Jenna Kreke
Sarah Bush Lincoln
1000 Health Center Dr.
Mattoon, IL 61938



Charleston • Mattoon • Effingham Area Ostomy Chapter

Meetings

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

- **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 of 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.
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(217) 342-6651

Medical Advisors

Linda Will, RN

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

Debbie Murray, BSN, RN, CWOCN
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Jenna Kreke, BSN, RN, CWOCN
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Amber Wenthe, BSN, RN, CWOCN
(217) 994-3385



September Meeting

6 pm • Thursday, September 12

Lumpkin Family Center for Health Education
Sarah Bush Lincoln Health Center, Mattoon, IL

We will be having Tom a representative from Hollister as a guest at the support group. He will be there to show new products, sign you up for samples, and answer any questions you may have. We would like to invite anyone to come to the support group meeting! The more the merrier!

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 hope you have had a safe and enjoyable summer!



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!

Happy Fall Y'all!!



Pumpkin Bread

Ingredients:

- 3 1/3 cups of all purpose flour
- 3 cups of sugar
- 2 tsp baking soda
- 1 1/2 tsp salt
- 1 tsp ground cinnamon
- 1 tsp ground nutmeg
- 1 15 ounce can pumpkin
- 1 cup vegetable oil
- 4 eggs
- 2/3 cup water

Instructions:

1. Preheat oven to 350 degrees. Prepare two 5x9x3 inch loaf pans with non-stick spray, set aside.
2. In a large mixing bowl combine pumpkin, oil, eggs and water. Mix in dry ingredients. Mix until combined. Spoon into loaf pans.
3. Bake for 60-65 minutes or until a toothpick inserted near the center comes out clean.
4. Cool for 10 minutes and remove from pan to wire rack.



10 Things I Wish I Could Tell Myself Before My Ostomy

Amy Oestreicher, featured on ostomyconnection.com

When I first got my ostomy, I felt very alone. I felt self-conscious of the smell and sound, and sometimes I longed for my old body. When I couldn't take self-loathing anymore, I decided to make friends with it. I reached out. I inquired about support groups in my area and realized there are many people like me. I realized my ostomy is a beautiful thing and has enabled me to do all the things I've been able to accomplish over the years. It is my uniqueness. These are 10 things I would have liked to tell myself when I first had an ostomy - 10 things I didn't know but eventually learned, which I am so grateful for today:

1. What it was:

I had no idea what an ostomy was before I had one. But I have a confession: I didn't realize exactly what it was until a year later! Coming out of multiple surgeries, I had so many bags and new anatomical surprises to think about that a little pink bulge on my belly seemed to be the least of my problems! I've learned things in the past 10 years that have shocked, scared and relieved me, such as: you can't actually feel your stoma - no nerve endings! I've had three ostomies and four ileostomies over the years. I didn't realize how different they were. Once I learned about the differences and functions of each, I was better able to take care of them.

2. What my limits were

When I saw that I'd have to live life with a bag stuck to my side, I assumed I'd be "fragile" for the rest of my life. But believe it or not, there are so many active ostomates out there! Swimming, karate, ballet, yoga - I've done everything I did before my ostomy and more.

3. There are so many strong ostomates

I was privileged to be the Eastern regional recipient of the Great Comebacks® award and meet five other amazing ostomates doing incredible things. There is a huge, supportive ostomy community. Did you know Great Comebacks® was founded by former NFL linebacker Rolf Benirschke?

4. Ostomates excel at innovation and inventiveness

It turned out I was able to do all those things I thought I couldn't - but that didn't mean it was easy. Some of the best things in life take work, and that makes you appreciate it even more. Let's just say that ostomy wraps, stoma guards and pouch covers have become good friends of mine, all products that were created by ostomates. I've also created a workshop for ostomy patients and healthcare professionals!

5. How Amazing My Body Is

I have a new respect for my body and the way it can function now.

6. Judgment Hurts, But Fear Hurts More

Stay informed and know the facts. The more I actually understood how an ostomy worked, the more I realized how wonderful it was. After that, I took it as my responsibility to educate others. Instead of wondering if I was being "judged" by others, I took it as a privilege to inform them.

7. Everything Is Connected

Take care of your full self: emotional, spiritual, mental and physical. If you're stressed, you might be bloated or feel pain or discomfort. Remember to take deep breaths in difficult times.

8. The People Who Love You, Love You

If you're just getting comfortable with your ostomy, remember that your support system loves you for who you are. You are more than your ostomy. Reach out when you feel alone and never forget how loved you are.

9. Eat Fresh

You are what you eat, so eat whole and nourishing foods. Your ostomy will thank you, and so will you!

10. Life Can Go On

Throughout the years, I've been strong, determined and willing to do whatever it took to stay alive. I've dealt with tubes, bags, poles, you name it. And if this ostomy is all that I'm left with after everything, then I am truly grateful. More than that, I thank my ostomy for enabling me to live life to the fullest, to my fullest. I call it my Harry Potter thunderbolt scar: a symbol of strength, courage, individuality and life. There are a few things I didn't know before my ostomy. But what I look forward to most is everything left to learn. Thank you, ostomy, for making the world a wide open door once again.



Common Ostomy Problems and Possible Solutions

UOAA STL. Winter 2018 • Excerpt from an article in the Huntsville, Alabama "Re-Route"

Food Blockages

Symptoms may include no output from the stoma for more than 4 hours, cramping in the abdomen, nausea or vomiting and high watery output.

Solution: Drink hot tea and increase your fluid input. Take a warm bath or shower and massage your abdomen. Have a glass of wine. This will help relax your abdominal muscles. Get down on all fours with your backside in the air. An undignified position, but it does help some people move a blockage. If the blockage persists for more than a few hours, seek medical advice from your nearest hospital.

Mucous and bleeding from the rectum

Solution: This is completely normal if your rectum is still intact, although annoying, since the mucosal lining of the rectum is still working. Try wearing a sanitary napkin to save soiling your underwear. If the bleeding is profuse, see your doctor.

Odor

Solution: Simple solutions that work for some ostomates are to place mint tic tacs or mint mouthwash into your bag. Deodorants, either taken orally or placed in your bag, are available from your ostomy supplier. DO NOT place aspirin in your bag in an attempt to eliminate odor—doing so can cause damage to your stoma.

Bleeding

Solution: First, determine if the bleeding is coming from the surface of the stoma or from internally. If it is internally, then it's wise to seek medical advice. If the bleeding is from the surface of the stoma, it should stop quite quickly. Stomas are made from the same type of skin as the inside of your cheeks and you know how easily they bleed. Even the slightest little nick can cause it to bleed. If bleeding is profuse or doesn't stop quickly, seek medical help. Cuts to the stoma can also be caused by the wafer riding off center. Try "picture framing" the wafer with some tape to stop it from moving.



Phantom rectal pain

ie: you get the urge to go to the toilet-the old way- even though you know you can't

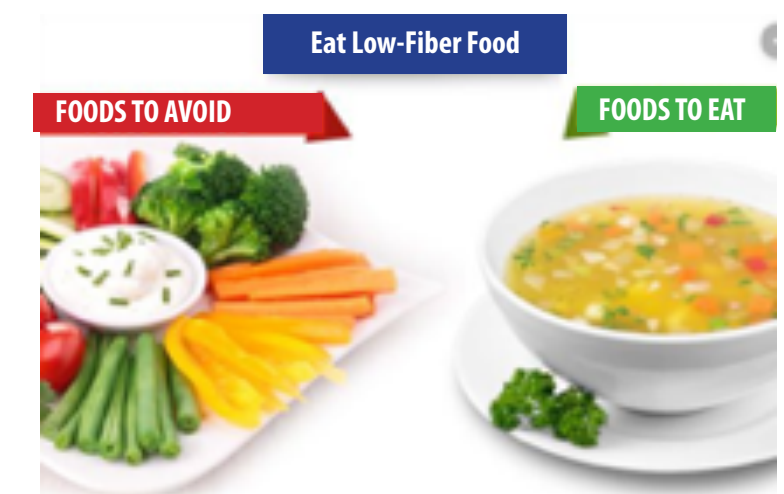
Solution: This pain is because your body needs time to adjust to its new plumbing and still thinks it needs to go to the toilet in the old way. Try going and sitting on the toilet anyway, even though you know it's pointless. A lot of people find this alleviates the pain. The good news is that over time, phantom rectal pains become less frequent and eventually disappear altogether.

Stoma is placed on or above the beltline

Solution: This is more common in men than women for some reason. DO NOT let them site your stoma on or above the belt line if at all possible. Belts will stop the stool from flowing into the pouch so try wearing trousers a size bigger than you would normally wear and wear braces or suspenders to keep them up rather than a belt.

Stoma shows through a tight dress

Solution: Try wearing bike pants or similar lycra pants under your outfit that will smooth out the line of the bag. Empty frequently.



Arthur The Stoma

A guide to Living with a Stoma

Arthur was born one Sunday night
Due to the surgeon's knife.
I didn't quite expect him, but
He helped to save my life.

To try and gain a pain-free life
That was my only goal.
I woke to find that things had changed.
I'd gained an extra hole.

He doesn't look offensive,
He's a rose that's still in bud.
Mainly he stays quite.
But he's not always so good.

Six thirty every morning,
He thinks it's time to wake.
He rustles up my breakfast
with a steaming hot pancake.

He then relaxes for a while.
I can forget he's there.
Generally he's pretty good
But sometimes he's a mare.

You can't relax with him around
Because all of sudden,
The thunder starts to rumble,
He can fart just like a good 'un

Sometimes he is docile
And you hear nothing for hours.
The next he's filling up the bags,
like he has super powers.

He can be really smelly
and gives out quite a reek.
And when he is mischevious,
He can cause your bag to leak.

I've told you all the bad things,
But he really is my friend.
'Cause ever since I've had him,
I've been slowly on the mend.

So raise a glass to Arthur.
He will probably stay forever.
And we can make it through this life
As long as we're together.

Ask a nurse

The Phoenix Magazine - Summer 2019

Blood with Urostomy

I recently had my bladder removed and have a urinary stoma. Right after surgery, my urine was a little bloody, but then it cleared up. It is a little bloody again and has a bunch of cloudy stuff floating in it. I feel fine. Is this normal?

~ K.R.

Dear K.R.

It is normal for the urine to be slightly bloody after surgery for an ileal conduit. As you have stated, it will clear in a few days. Some people have blood-tinged urine a little longer, if they still have small, temporary catheters (called stents) inserted during the surgery that protrude from the stoma. The surgeon will remove these days or weeks later depending on their preference. It is also expected that you will see mucus "shreds" in the urine when a piece of the intestine is used to create the ileal conduit.

Without seeing your urine however, I am concerned that it was clearer and now is "a little bloody with increased cloudiness." You need to call your physician to report these observations. It appears as though you have a urinary tract infection. Often, a urine culture will be ordered by the physician before an antibiotic is initiated to select the appropriate medication for treatment. If a medication is ordered at the same visit, you should have the culture done before you start the antibiotic and then follow physician directions. Some doctors prefer to initiate antibiotics before the culture results are available, since it may take 48 hours or more for a result to be obtained. Remember that urine for a culture should never be taken from the pouch or night drainage system and should always be a clean specimen to be as accurate as possible.

Other symptoms of a urinary tract infection are fever, chills, loss of appetite, abdominal or back pain, especially associated with bloody, cloudy or foul-smelling urine. In conclusion, call your doctor to follow up. This might be an infection.

Social Adjustment

I have noticed that since my ostomy surgery, I am not as social as I used to be. I was active on Facebook and shared jokes with friends. I no longer do that. Is this normal?
~ B.T..

Dear B.T.

Even though you may have mastered managing your ostomy and pouching system, it may take up to a year or so to psychologically adjust to having an ostomy. Depending on your history or the reason you needed to have an ostomy created, there may have been other health threats or concerns that contributed to your state of mind.

There are trained Ostomy Visitors, accessible through the UOAA (United Ostomy Association of America), that can call or even visit with you to share what they have learned from their own experience as ostomates. You may also find it beneficial to attend an ostomy support group to help alleviate any fears you may have about returning to your social life.

If these resources do not seem to address your concerns and you remain less social, you may wish to speak with your doctor about your feelings to get some professional assistance with coping strategies and other recommendations.

Nature Still Calling

My rectum was totally removed and I have a new colostomy. I still feel like I need to have bowel movements as I did before the operation, but I know that's not possible now that I have been "sewn shut." Is this normal? Will the urge go away eventually?
~ E.L.

Dear E.L.

The sensation of having a full rectum and needing to have a bowel movement after the removal of the rectum can be a common experience. The surgical disruption of the pelvic floor and nerve supply and subsequent scar tissue formation can result in this phenomenon, referred to as a phantom rectum. The sensations can be uncomfortable but not usually painful and decrease over time. The sensations can vary for different patients but usually resolve in about six months.