The MailBag

April 2021

The Ostomy Support Newsletter Of Jacksonville, Ocala, Amelia Island, Citrus County, Gainesville, & The Villages

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Find all the past issues of the MailBag at http://ostomymcp.com/id6.html

Jacksonville
Contact Information:
Patti Langenbach
(800) 741-0110
(904) 733-8500
patti@ostomymcp.com
Support group meets the 3rd Sunday of each month 3 p.m.
Next Meeting: **via Zoom**

Gainesville Support Group
Contact info:
JoAnne Bell at 352-284-4214
Meets the 1st Sunday of each month (except Holidays)
at Hope Lodge2121 SW 16th St
Gainesville, FL
Next meeting: **TBA**

Ocala Support Contact info:
Karen Franco 352-304-1309
Meets the 2nd Sunday of each month (except July & Aug) at 2 p.m. at the Sheriff's Station 3260 SE 80th Street between Ocala and Belleview.
Next Meeting: **April 11th**

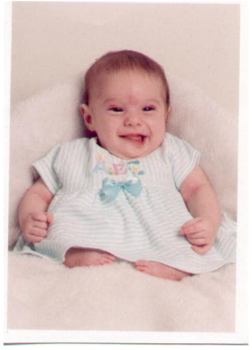
Citrus County Support Group
Meets third Sunday of each month at 2:00 PM in the Seven Rivers Regional Medical Center, 6201 N. Suncoast Blvd., Crystal River, FL 34428, in the Community Room of the Medical Office Building
Next Meeting: **TBA**

Amelia Island Area
Ostomy Support Group
(904) 310-9054
Meets second Monday of each month at 6:30pm
Next Meeting: **TBA**

The Villages Ostomy Support
We meet on the 2nd Tuesday evening of each month at 6:00 PM at (except July & August
Linda Manson
tvostomy@gmail.com
865-335-6330
Next Meeting: **via Zoom**
Contact Linda tvostomy@gmail.com

Samantha Carpenter's Ostomy Journey

My name is Samantha Carpenter. I am 24 years old. I live in Crawfordville, FL which is a little town right outside Tallahassee, FL. I have an amazing mom, dad, and little sister. Also, I have many amazing friends and one of those friends even granted me the blessing of being a god-momma. I love bowling, shopping with friends, swimming, drawing, working on crafts, taking road trips, and reading. I am a senior at Florida Agriculture & Mechanical University pursuing a Bachelor's in Biology/Pre-Med. Following that degree, I will be pursuing a Doctor of Pharmacy degree there as well. A life accomplishment I was very proud of is being able to drive my own vehicle, because I gained so much independence and freedom and it has been a huge blessing. My disability does not slow me down one bit and I always have an "I can" mentality.



I was born with a spinal condition called Sacral Agenesis/Caudal Regression Syndrome, means I was born missing the lower portion of my spine. My condition resulted in the malformation and immobility of my legs. Around the age of 5, my parents came to the decision to have my legs amputated at the knee, which was the best decision they made in my life because amputating gave me the ability to have options for mobility. I can crawl around places easier, able to get around in my wheelchair, and was able to give prosthetics a chance. The prosthetics put a lot of strain on my back, so I stuck to using my wheelchair as my means of getting around, which I would much rather prefer. Also, my medical condition affected the way I use the bathroom due to where my spine stops at. I use a colostomy for my bowel needs and I have had my colostomy since I was born. I used to despise the thing, because I did not like the thought of this bag being on my belly and people noticing it. Now as I have gotten older, I have learned to be more appreciative of it. One, when I'm gassy it doesn't smell because it gases in the bag, unlike those who don't have one. Another reason I have grown to appreciate it is I do not have to run to the bathroom every time I have a bowel movement. I can just change the bag when it gets full. I do have bad days with it though, like when I have an upset belly, but on those days I know just to have extra supplies on hand and to also try to not let my nerves get the best of me and cause a bigger mess to clean up.

A big success story with my colostomy was learning to be able to change the whole thing on my own. My mom was a huge person I depended on taking care of my medical needs, but as I got older I realized I am eventually going to be on my own and need to learn how to do this myself. Once that realization hit me, I had to figure out the way I was going to change my colostomy. Everyone has different ways of doing tasks, and I found out the easiest way for me to change my colostomy was by laying down and using my legs to hold a hand mirror in place and angled to see my colostomy. That way I can see what I am doing and not make a huge mess. Once I found out this technique, I became a pro at changing my own colostomy and I felt proud. I have run into bad days too though, but my advice is to always have a backup plan and utilize help from your people who support you. For example, one day I was last minute babysitting my god-babies and forgot to bring my mirror with me. Well, that day ended up being a sour belly day and when I rushed to the bathroom to fix my colostomy my oldest god-baby, mind you she is only three years old, asked me if she could help. She was right by my side and since I did not have my mirror I was trying to use my phone and it was smaller so I couldn't hold and see what I was doing. She noticed and took the phone from my hands and held it for me so that I was able to change my colostomy and still be able to see. Her being there and being my eyes by holding the phone so I can see was the most selfless and heartwarming moment I ever experienced. So, my advice is to not see the negative side of situations you are put through but find a new approach and be aware of the people who are there that will help and love on you during those times because they are important people and love you just the way you are.

Five Tips for Sleeping with an Ostomy Bag

via Vancouver Ostomy HighLife March/April 2021, From The Insider newsletter, Winter 2021 Amber from “Ostomy Diaries”, https://www.ostomydiaries.com/

“Sleeping with an Ostomy Bag” is just one of many informational videos produced by Amber that can be accessed on her website Ostomy Diaries. Amber was diagnosed with Crohn’s Disease at age 9 in 2008 and had a complete colectomy to become an ileostomate in 2016. She now teaches high school sciences – chemistry and physical sciences – and is pursuing a master’s degree in secondary education. Through her struggles with IBD and many hospitalizations, Amber also became a serious advocate for ostomates and those suffering from intestinal diseases such as IBD. To that end, she created and maintains the “Ostomy Diaries YouTube Channel” and reaches out through other social media platforms.

To view the video, just go to YouTube and type “Sleeping with an Ostomy Bag” in the search bar. For those of you that cannot access the video, following are the five (5) tips Amber recommends for sleeping with an ostomy pouch. These tips are especially valuable for new ostomates who are still adjusting to their new normal.

AMBER’S FIVE TIPS

1. Schedule your food intake to avoid having too much stool or urine passing through your system.

2. Empty your pouch just before going to bed. You can also set an alarm in case you are concerned about too much intestinal or urinary activity while you are sleeping.

3. Wear an ostomy belt. This can stabilize your pouch and offer you an increased sense of security.

4. Be careful with your pajamas. Make sure that your night clothes don’t constrict flow into your pouch.

5. Sleep with pillows on both sides. Consider using pillows to help you avoid sleeping on your stomach.

ABDOMINAL NOISES

from UOAA Update Via Triangle, Pittsburgh Ostomy Society Newsletter &
The Bud, Chippewa Valley Ostomy Association

Abdominal noises happen! As ostomates, we wonder why and we are embarrassed.
Any of the following may be the cause:

- You are hungry. Peristalsis goes on whether there is anything to move through or not. Empty guts growl. Eat a snack between meals, or consider four small meals a day.
- You are nervous, so peristalsis is increased. Try to slow down. Try to eliminate some stress (especially at meal times).
- Coffee and tea, cola and beer all stimulate peristalsis. Beverages consumed on an empty stomach will produce gurgles. Add a little bit of food with your beverages. Try some crackers or bread.
- Eating a high-fiber diet produces gas, so rumbles increase. Mix with other foods. Reduce amount of insoluble fiber. Switch to more soluble fiber.
- Intestines do not digest starches and sugars as easily as proteins and fats. Reduce the amount of carbohydrates that cause you trouble. Mix with proteins and fats.

UOAA COVID-19 UPDATES

UOAA will update this blog post with any information that may affect our community.

https://www.ostomy.org/coronavirus-effects-on-the-ostomy-community/

Soluble vs. Insoluble Fibre: What's the Difference?

If you have an ileostomy, should you eat fibre? How much? What kinds are safest? The intestine has a remarkable capacity to adapt. Matter (digested food) in the small intestine is quite watery, and after it moves into the large intestine, a good portion of the water is reabsorbed into the body.

Most fibre is indigestible material from plants. The fibre acts like a sponge, soaking up water, increasing the bulk of the intestinal contents, and making matter move through the system more quickly. In a person with an intact colon, fibre is essential to preventing constipation and keeping a person "regular". This is the main function of fibre. A person without a large intestine (ileostomy) doesn't have a problem with constipation, and will have loose or watery stool.

Some ileostomates report that over time, their stool becomes less watery as the small bowel adapts and 'makes up' for the loss of the large intestine. This is especially possible if the last section of the small bowel (ileum) is still intact.

However, consuming too much "insoluble" fibre may cause a blockage. Avoid or limit your intake of insoluble fibre such as bran, popcorn, seeds, nuts, skin/ seeds/stringy membrane parts of the fruits and vegetables.

However, another type of fibre (soluble) may be beneficial to the ileostomate. It may seem like a contradiction, but the function of soluble fibre is to make intestinal contents "thicker" and can actually help prevent diarrhea. This fibre is found in oatmeal, barley, dried beans, peas, Metamucil and in the pulp of fruits and vegetables.

Most foods have a combination of both types of fibre, but the above examples showthe differences. Adding pectin (Certo, used to make jam and jelly) to one's diet can help to minimize diarrhea. Add it to applesauce.

How much of any of this stuff the individual ileostomate can safely eat is, unfortunately, often determined by trial and error (and sometimes, despite knowing better, having just o-n-e more taste of those nuts!)

Pay attention to how much and how fast, you are eating any kind of fibre. It might seem silly to measure one's intake of certain things by the bite, but it's best to be ultra-cautious as you resume eating after surgery.

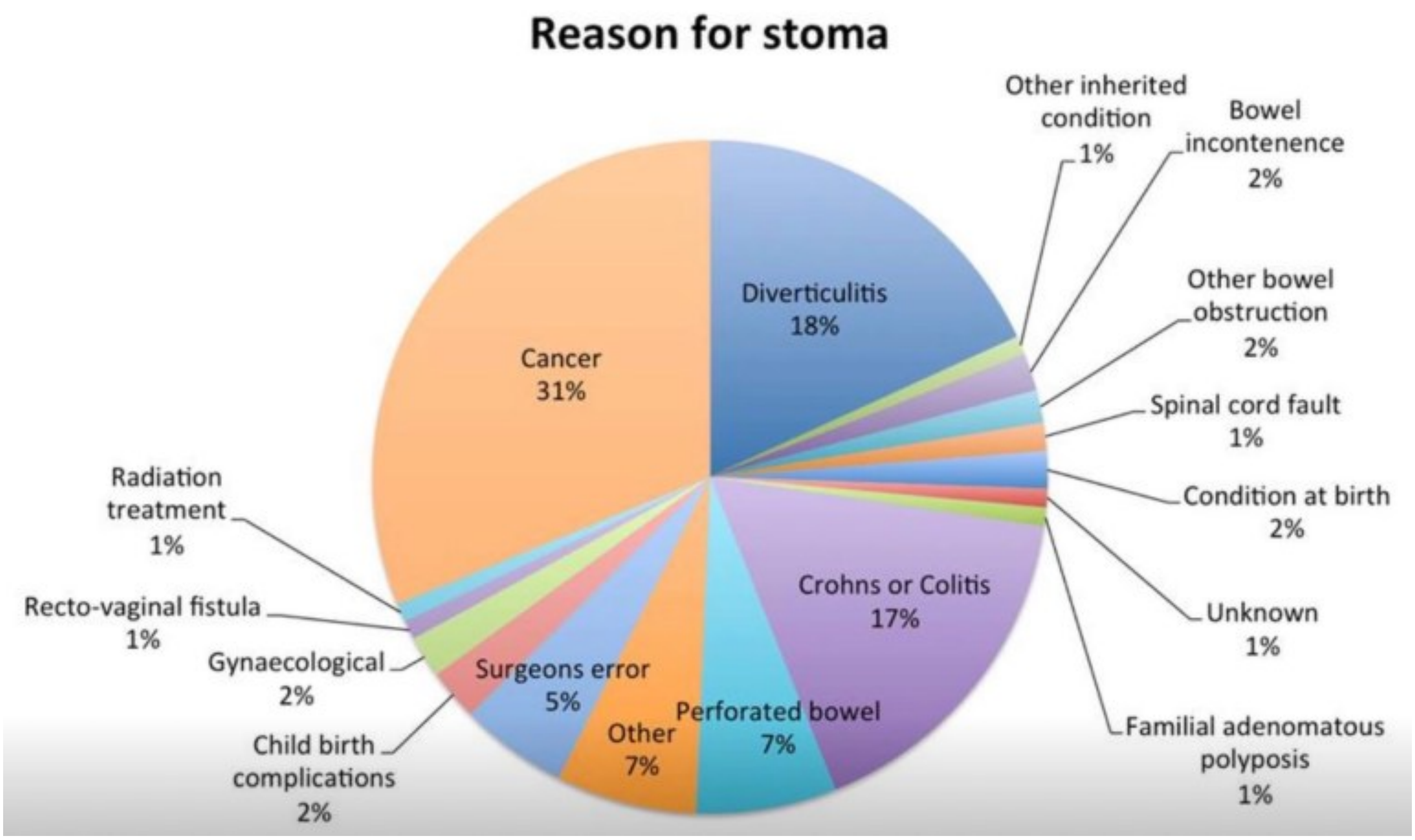
Add vegetables and fruits in very small amounts. Chew your chow carefully and thoroughly. Try not to learn your limits the hard way!

Source: via Winnepeg Ostomy Association February 2021 Newsletter, via Vancouver Ostomy HighLife May/June 2012 Reprinted from WOA's INSIDE/OUT February 2013.

UOAA's 8th National Conference-Canceled

AUGUST 5 - AUGUST 7

Due to the continued uncertainty with COVID-19, UOAA has made the decision to cancel our 2021 National Conference. We will revisit the situation next year to determine if one can be held in 2022. Thank you.



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http://psag-consumer.wocn.org/#home

UOAA Discussion Board
https://www.uoaa.org/forum/index.php

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