The MailBag

December 2021

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

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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.
4836 Victor Street
Next Meeting: **December 19th**
Also join us by Zoom
https://us06web.zoom.us/j/94640600811
Meeting ID: 946 4060 0811
or call +1 301 715 8592 US

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: **TBA**

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

Seven Tips to Help Ostomates Survive the Holiday Season by Editorial Team OstomyConnection.com; via The Hartford (CT)

Ostomy Update The holidays are fast approaching and that means parties galore! Office get-togethers, family gatherings, and neighborhood celebrations are filling up the calendar now until New Year's Eve. As much fun as the holidays can be, it can also be a time of stress for ostomates. It's important to recognize that this can be a crazy time, and with so much going on it's sometimes easy to forget to take care of yourself and manage your ostomy. Here are seven tips to help ostomates enjoy the holiday season, from what to wear, to what to talk about and more:

1. Plan ahead and prepare for ordering challenges Do you have enough ostomy supplies on hand? If not, now's probably the best time to place an order. Online medical suppliers and shipping companies are extra busy during the holidays, so you may experience delays due to staff shortages or bad winter weather.

2. Let family rituals change If you're attending a family event, it doesn't mean you need to eat food you're not comfortable with just to please them. Consider updating holiday meals with some new recipes to go along with the familiar dishes; it's a great opportunity for everyone to try something new. Most holiday celebrations are potluck style anyway, so offering to bring something won't be too out of the ordinary. If you are the host, suggest that your guests bring a dish so that everyone can enjoy their favorite food.

3. Know what to say Relatives and friends who know about your ostomy understand and won't insist you eat everything being served. If you encounter a situation where people do not know you're an ostomate, there's no need to go into any long explanation at the dinner table. Saying "no thank you" should work if you're passed a dish that you prefer not to eat.

4. Drink plenty of water We know this is probably something you hear every time someone talks to you about an ostomy (especially an ileostomy or urostomy), but it's true that staying well hydrated can help. Water is essential for the proper circulation of nutrients in the body. Sometimes headaches can be caused by dehydration, so drinking water can prevent or alleviate the pain. Make a conscious effort to stay hydrated during the holidays!

5. Wear whatever feels right Loose clothing that is not too tight around your belly can help you feel more relaxed about your ostomy. Whether the party is casual or formal, don't stress over your outfit. Be comfortable and remember to pack extra ostomy supplies and clothes if you're taking a road trip somewhere far from home.

6. Slow down and eat for pleasure Eating slowly and chewing your food well is important to help prevent blockages when you have an ostomy. It may sound obvious, but enjoying the flavor of the food makes it a pleasurable experience. When you savor your food, you're less likely to overindulge which can cause unwanted digestive issues.

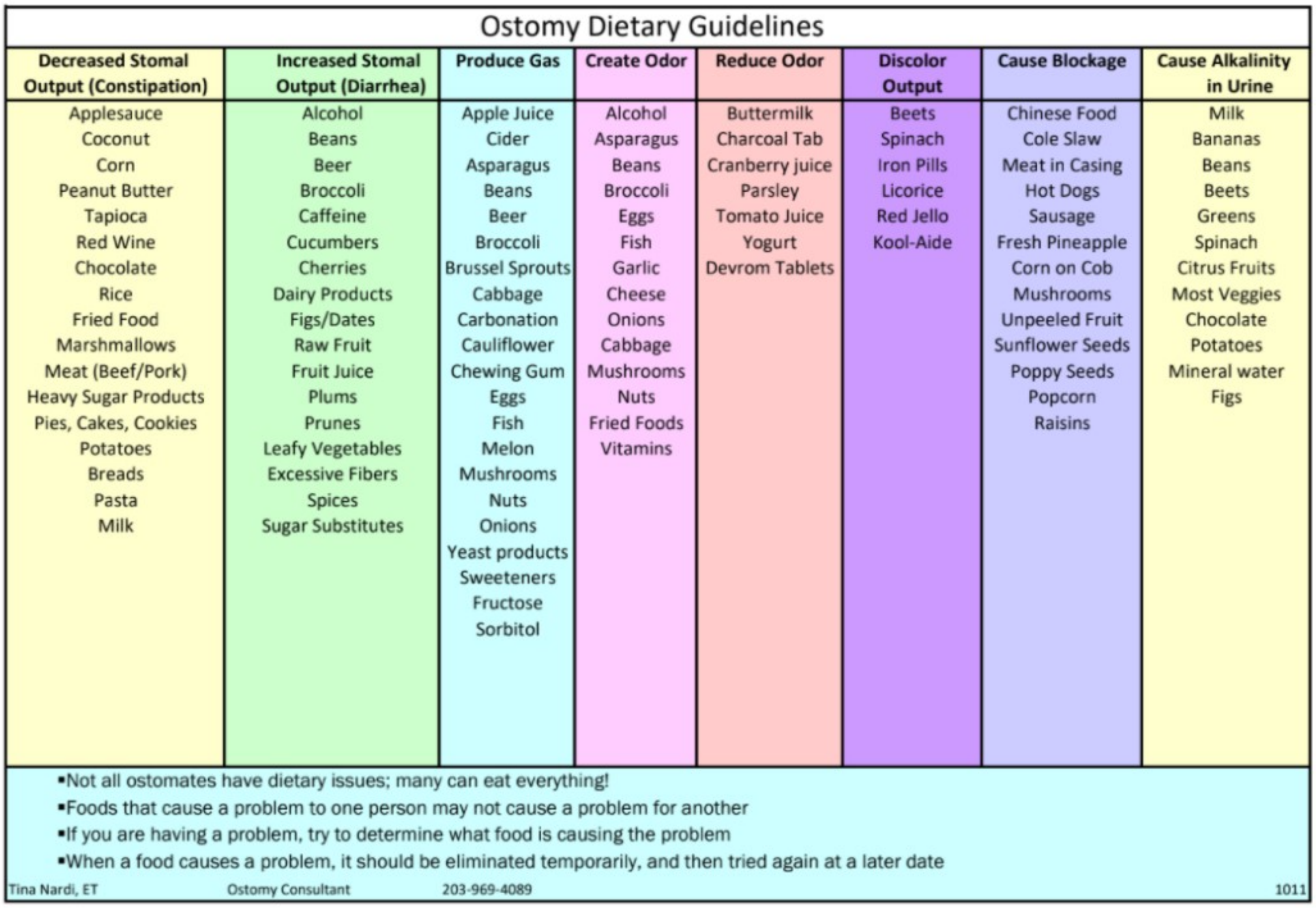
7. Make time to express gratitude Letting your family and friends know that you are grateful for their support during your ostomy surgery and recovery can actually make celebrations even better. If this is your first holiday with an ostomy, it might be an important thing to do. Sharing love and appreciation with others has such an uplifting effect.

Vegetarian and Vegan Diets for Ostomates www.colostomyuk.org from Ostomy Support Group of Northern Virginia, LLC

Consultant Dietitian Sophie Medlin has written some fantastic advice for vegetarian and vegan ostomates (and those looking to include more plants in their diet). It's national vegetarian week in the UK so it's a great time to talk about plant-based diets! Most people won't be surprised to hear that the number of people following vegetarian and vegan diets has risen by 40% in recent years. Adding more plants (fruit, vegetables, whole-grains, pulses/beans, nuts and seeds) is ideal for our overall health but can be challenging when you live with a stoma. It's also important to recognize that there is a significantly higher risk of nutritional deficiencies on vegan and vegetarian diets. This is because there are certain nutrients that we can't get from plants or that are only available in much lower quantities. In particular, plant based eaters need to be more careful not to become deficient in vitamin B12, vitamin D, zinc, iron and omega-3 fatty acids. There is an added complexity for vegetarians and vegans living with an ileostomy as the same nutrients that are lacking on a vegan diet are also more likely to be deficient. Research tells us that 17% of people with an ileostomy have iron deficiency anemia,31% of the ileostomy population are deficient in vitamin B12, 13% of the ileostomy population are vitamin D deficient and 8% of the ileostomy population are zinc deficient. Unfortunately, this work hasn't been done for people living with a urostomy or colostomy. This means that vegetarian or vegan people living with an ileostomy can be deficient in these nutrients because their stoma lowers absorption AND because their diet contains less which is double the risk. That doesn't mean that anyone with a stoma can't or shouldn't follow a plant based diet, it just means that more time and energy will need to be put into planning and supplementing the diet appropriately. Similarly, many people living with a stoma may struggle to increase their plant based foods in their diet due to the fiber content disrupting stoma function. As always, this does not mean we shouldn't be trying to increase these foods regardless of whether we choose to cut out animal products. Some tips for including more plant based foods in your diet include:

- Blending beans and pulses into dips (hummus) and pastes for added plant based protein.
- Ensuring you have at least two vegetables with lunch and your evening meal and a portion of fruit in the day.
- If you struggle with vegetables, try vegetable juices, smoothies or soups as an alternative.

As vegetarian and vegan products have become more available, it is a great time to experiment with some of the red meat alternatives, particularly if you have had bowel cancer in the past. Choosing soya or Quorn mince in place of beef mince will be a healthier option. Unfortunately, 'vegan' doesn't always mean healthy so we still need to be careful of highly processed vegan foods. Overall, if you're not vegetarian or vegan, remember, more plants in our diets is always a good thing so consider this week a nudge to have a think about where you can get more in! If you are on a plant based diet and you live with a stoma, be aware of those deficiencies and ask your stoma team or GP to screen your bloods for deficiencies. There are some great plant based supplements on offer to top up your diet and some excellent resources from the Vegan and Vegetarian Society to help you plan an optimal plant based diet. For good ideas and recipes, go to https://www.colostomyuk.org/vegetarian-and-vegan-diets-for-ostomates



Ostomy Dietary Guidelines

Decreased Stomal Output (Constipation)	Increased Stomal Output (Diarrhea)	Produce Gas	Create Odor	Reduce Odor	Discolor Output	Cause Blockage	Cause Alkalinity in Urine
Applesauce	Alcohol	Apple Juice	Alcohol	Buttermilk	Beets	Chinese Food	Milk
Coconut	Beans	Cider	Asparagus	Charcoal Tab	Spinach	Cole Slaw	Bananas
Corn	Beer	Asparagus	Beans	Cranberry juice	Iron Pills	Meat in Casing	Beans
Peanut Butter	Broccoli	Beans	Broccoli	Parsley	Licorice	Hot Dogs	Beets
Tapioca	Caffeine	Beer	Eggs	Tomato Juice	Red Jello	Sausage	Greens
Red Wine	Cucumbers	Broccoli	Fish	Yogurt	Kool-Aide	Fresh Pineapple	Spinach
Chocolate	Cherries	Brussel Sprouts	Garlic	Devrom Tablets		Corn on Cob	Citrus Fruits
Rice	Dairy Products	Cabbage	Cheese			Mushrooms	Most Veggies
Fried Food	Figs/Dates	Carbonation	Onions			Unpeeled Fruit	Chocolate
Marshmallows	Raw Fruit	Cauliflower	Cabbage			Sunflower Seeds	Potatoes
Meat (Beef/Pork)	Fruit Juice	Chewing Gum	Mushrooms			Poppy Seeds	Mineral water
Heavy Sugar Products	Plums	Eggs	Nuts			Popcorn	Figs
Pies, Cakes, Cookies	Prunes	Fish	Fried Foods			Raisins	
Potatoes	Leafy Vegetables	Melon	Vitamins				
Breads	Excessive Fibers	Mushrooms					
Pasta	Spices	Nuts					
Milk	Sugar Substitutes	Onions					
		Yeast products					
		Sweeteners					
		Fructose					
		Sorbitol					

- Not all ostomates have dietary issues; many can eat everything!
- Foods that cause a problem to one person may not cause a problem for another
- If you are having a problem, try to determine what food is causing the problem
- When a food causes a problem, it should be eliminated temporarily, and then tried again at a later date

Tina Nardi, ET Ostomy Consultant 203-969-4089 1011

Destigmatizing Life with an Ostomy

Borrowed from Ostomy Support Group of Northern Virginia, LLC THE POUCH October 2021

Tina Aswani Omprakash encourages people from diverse cultures to speak up about IBD and ostomy surgery Tina Aswani Omprakash is an advocate, blogger, speaker and thought leader. She is also a person with Crohn's disease and an ostomy. And she has dedicated her life to urging others with IBD and ostomies to own them fully, in order to lead happier, richer lives. "Give it a voice, because what knocks us down can make us stronger, fiercer, and more united if we let it," explains Tina, who learned this lesson firsthand. When meeting this motivated, confident woman, you would never imagine that she has experienced a myriad of health issues while continuing to support others. She encountered many roadblocks in her journey to where she is today.

A Misdiagnosis and Multiple Surgeries — Tina was born into a close-knit South Asian family in New York that taught her to aim high and achieve a successful career. So, she was elated when she landed a fast-paced job with an investment banking firm on Wall Street after college. Then, at age 22, inflammatory bowel disease (IBD) started causing her pain and fatigue, and she was uncomfortable telling others what she was going through. Tina was diagnosed with ulcerative colitis initially, and she underwent a series of surgeries resulting in temporary ostomies that her doctors were able to reverse. Alternative medicine is widespread in the Indian community, and practitioner after practitioner gave her remedies that made her ill. Though they meant well, they suggested that she had brought the illness on herself because of her diet and her stressful work life. She started blaming herself, but also knew deep down that she had no control over her disease.

Crohn's Disease and a Permanent Ostomy — Eventually, Tina's diagnosis changed from ulcerative colitis to Crohn's disease, and recurring bouts of fistulas (abnormal openings between two organs or vessels) forced her to decide whether or not to get a permanent ileostomy. Unfortunately, a decision to get an ostomy would clash with her culture's high standards for jobs, marriage, and health. "In Indian culture you hide your disease," explains Tina. "It was a tug of war between the possibility of having a full, healthy life and upholding the South Asian standards that I was brought up with." Tina was not the only one in her family who had faced pressure to live up to those cultural ideals. In fact, her father had struggled with Crohn's disease as a young man. When his doctor recommended an ostomy, he refused due to concerns around marriageability. When he finally underwent ostomy surgery 15 years later, it was too late. He passed away from colorectal cancer when Tina was eight years old. So, at 28 years old, Tina made the decision to take her life back and get a permanent ileostomy. Afterward, her life blossomed and she was finally able to travel, eat more of her favorite foods, go on long walks, and be a full partner in her marriage.

Becoming an Advocate — When Tina connected with various gastroenterologists and patient advocates on Twitter to learn more about her condition, she realized that she wanted to become an advocate herself. "We are suffering so much by delaying our treatment," Tina admits. "We cannot look at the ostomy as a last resort, but as a viable treatment option and potential solution." It took four years for Tina to decide to come out publicly as a person with an ostomy. Her illness had already derailed her career and any prospects for further education, and it had negatively affected her self-esteem. However, she wasn't going to let it stop her from speaking out on behalf of others in diverse communities. In 2016, when she was finally in remission from Crohn's, Tina wrote a few well-received articles and led a women's support group for the Crohn's & Colitis Foundation. Two years later, the Foundation named her a Take Steps Honored Hero for being an advocate in the Crohn's and colitis community and sharing her story to inspire others. Despite her fears, she accepted the award and spoke in front of 600+ people, and her story went viral on social media. There would be no hiding after that!

Supporting and Empowering Others — After the story came out, a flood of publications reached out to her. She also received speaking invitations and requests to advise healthcare companies. She created a private Facebook group for people who hesitate to identify as having a bowel illness, so they would feel comfortable asking questions and receiving support. Some of her followers have messaged her saying, "The ostomy option has been presented to me, but I want to do everything possible to not have one," or "I'm too young for that, and I don't have a cancer diagnosis." Tina finds this devastating. "People need to live proudly with Crohn's disease and own it every step of the way," she says. "Ostomy product technology has come such a long way; nobody will even know that you have a pouch. I can still wear a sari—I just tie it a little higher."

Tina empowers others to speak up through her website **Own Your Crohn's**, and her social media platforms on Facebook, Instagram and Twitter. She co-created **IBDesis**, a global initiative comprised of a team of South Asian, or "Desi," advocates with IBD and/or ostomies in order to help other promising voices in the South Asian community speak up and destigmatize IBD and life-saving ostomy surgery. IBDesis' mission is to create resources, education, and awareness for South Asians around the world living with IBD and/or stomas to minimize the cultural stigmas and normalize the diagnosis in addition to treatment and/or surgery. Tina also volunteers with **Girls With Guts**, a popular non-profit organization. She is the Diversity Chairperson for their Community Connection initiative. "Our aim is to grow the number of voices from diverse communities sharing how to live a fulfilling life with IBD and how an ostomy has improved their quality of life," says Tina. Though she feels very fulfilled, Tina still has days when she's susceptible to her illness. Yet, even at her most vulnerable, she manages to reach out to others and share her experiences. The support and prayers of her newfound friends help her pull through and continue her mission. Her advice to others with IBD and ostomies who want to do advocacy work is to hone in on what is empowering them. "Find what makes you whole and give it a voice," advises Tina. "To help eliminate stigmas, you have to feel comfortable with yourself first and be authentic about your struggles." The world has taken notice of how Tina is empowering others. **Her Own Your Crohn's** blog was named one of the **Best Crohn's Disease Blogs of 2020** by Healthline Media, and one of the 2019 Top IBD Blogs for Advocacy by MyTherapyApp.com. In addition Tina's advocacy work won the Healio Gastroenterology Disruptive Innovator Award for "The Patient Voice" in 2019. More recently in 2021, the Crohn's & Colitis Foundation recognized Tina for her phenomenal leadership and powerful impact on the IBD community with the Above & Beyond Volunteer Award. IBD knows no culture or standards—it can happen to anyone, and can change life for better or for worse. Tina chose to make something great out of it. "Diseases like IBD don't define us, but they do shape our perspectives; they help us develop the empathy and ability to provide support to others," concludes Tina. "I don't take life for granted anymore and that's the silver lining with this illness."

Note: Tina Aswani Omprakash is a health advocate for patients living with chronic illnesses and disabilities. Through her writing, social media presence, and public speaking engagements, she spearheads public health causes, including those creating awareness for IBD (Crohn's disease and ulcerative colitis), life-saving ostomy surgery, and initiatives supporting global women's and minorities' health. She is presently working on her Master's of Public Health at the Icahn School of Medicine at Mount Sinai. Tina lives in New York City with her husband, Anand. Financial Disclosure: Tina Aswani Omprakash received compensation from Hollister Incorporated for her contribution to this article.

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AUGUST 11, 2022 - AUGUST 13, 2022

2022 HOUSTON TEXAS

https://www.ostomy.org/event/uoaa-8th-national-conference/

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