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Diet & Digestive Health Twitter Chat IFFGD, Tina Aswani Omprakash and Dietitian Neha D. Shah, MPH, RD, CNSC, CHES Nutrition for Ileostomy: The Dietitian and Patient Perspective

Diet & Digestive Health Twitter chat series with the International Foundation for Gastrointestinal Disorders (IFFGD) co-host and patient advocate Tina Aswani Omprakash and lead dietitian Neha D. Shah, MPH, RD, CNSC, CHES. We are excited to work with you to educate patients, caregivers, and others about how they can use Nutritional for the Ileostomy: The Dietitian and Patient Perspective.

#### IFFGD - introductory tweets and remarks:

The views and experiences shared by our participant are their own and do not reflect the official positions of IFFGD. Each patient is different. Always consult with your health care provider or a registered dietitian (RD) on a diet treatment plan that is right for you. Information and resources shared during today's chat should not replace medical care that you are receiving. And reminder, be sure to include #DDHChat in each of your tweets.

# <u>IFFGD - welcomes everyone to the chat and introduces co-host Tina Aswani Omprakash and lead host dietitian Neha D. Shah, MPH, RD, CNSC, CHES:</u>

Welcome to our October #DDHChat on nutrition for the #ileostomy with co-host and patient advocate @ownyourcrohns (Tina Aswani Omprakash) and lead host @nehagastrord (Neha D. Shah). Each year people of all ages undergo #ileostomy surgery. The reasons that someone might have this surgery varies from person to person. One reason someone might have an #ileostomy surgery could be due to complications of other digestive diseases such as #IBD Crohn's or Ulcerative Colitis. Having #ileostomy surgery can be life changing and lifesaving as well!

We're joined today by #Gldietitan @nehagastrord to share her unique insights on nutritional support for people living with an #ostomy and by @ownyourcrohns to discuss the patient experience of navigating through the diet while having an ileostomy. #DDHChat

# <u>IFFGD, Tina Aswani Omprakash and lead host dietitian Neha D. Shah, MPH, RD, CNSC, CHES Q&A:</u>

### Q1: @nehagastrord how is diet initiated immediately after #ileostomy surgery? #DDHChat

Neha D. Shah, MPH, RD, CNSC, CHES: At a hospital I used to work at, we had two diet stages for the #ileostomy. Day 1: we would start with a Post-Surgical Step I diet that had mostly oatmeal, cream of rice/wheat, chicken noodle/tomato soup, and plant-based milks. Day 2: the Post-Surgical Step II diet, which allowed all foods except for high lactose dairy, bran, raw vegetables, fried foods and sugary foods/beverages. Then a low fiber diet was prescribed for the home for six weeks. The plan then was to reduce it down to two weeks, which was good to see to reduce excess restrictions. How the diet is

initiated after #ileostomy surgery varies within surgery teams. Some do restrictions to fiber and some do not. #DDHChat

Tina Aswani Omprakash: After my 2nd & 3rd #ileostomy surgeries, I always asked my surgeon's team for a nutritional consult inpatient to get the best sense of what I can eat post-op. I started slowly with the typical bananas, white bread, white rice, potatoes and of course, lots of water! I started very slowly eating small bites of softer foods & taking breaks in between morsels so that I could see & feel if my digestive system was faring ok. If I felt even the slightest bit of nausea or discomfort, I would report it to my nurse and/or surgeon's team. As I progressed in the hospital with my diet and was discharged, I continued the low-fiber diet at home so as to not irritate my insides while I healed. After my 1st post-op appt with my surgeon, he cleared me to expand my diet gradually. Once cleared to expand my diet, I started doing more soups with rice noodles, broths, pasta, mashed potatoes, smoothies and as a vegetarian, introduced some well-cooked lentils, squashes (without skin) and tofu in small amounts to see how I might fare. #DDHChat

Q2: @nehagastrord it can be scary to add new foods after having surgery for the #ileostomy. What are some strategies to try to expand and build trust with the diet overtime? #DDHChat

Neha D. Shah, MPH, RD, CNSC, CHES: So food avoidances that were in place before #ileostomy surgery may possibly continue after surgery. Know that it is not easy for patients just to let it go. Cannot build trust with diet overnight. I help my patients make a weekly schedule to try small portions in an environment that they trust; usually at home. It may start as adding a food of ½ cup portion to one meal 3x/week and then build from there to each meal based on tolerance and comfort. Pay attention to the particle size (e.g., ground, mashed, blended) of foods that is tolerated and not tolerated well. Make the foods into the particle size that does work well. It can be overwhelming to look at the diet as a "whole pot of foods". Know that the various food groups out there are the "building blocks" of a diet. It is ok to focus on a "building block" or two at a time to help build the diet again. #DDHChat

Tina Aswani Omprakash: I remember my body revolting after my 1st #ileostomy surgery (#colectomy) when it came to eating. I hadn't eaten for months & was receiving total parenteral nutrition (TPN). I had #PTSD w/ food (#ARFID) which we now know GI psychologists & dietitians can treat. I remember my surgeon and TPN doctor giving me appetite stimulants during this time & my TPN was continued for a few months & gradually weaned off as I began to eat again. One of the strategies we used was including oral nutrition to help me feel like eating again. After I started to put on some weight with the oral nutrition, I was advised to see a GI-focused dietitian who could slowly help me reintroduce foods w/ biweekly plans of how to do so. It was a gradual process & took me 4 months to feel comfortable trying new foods. As I started to try foods I used to eat again, I realized the food wasn't making me sick anymore and that I wasn't running to the bathroom. My confidence began to grow, and my weight/absorption really started to come back as I became more comfortable with food again. #DDHChat

Q3: @ownyourcrohns it can be difficult at times to tolerate fruits, vegetables and legumes with having an #ileostomy. What are some ways have you included these foods? @nehagastrord how do you recommend these foods to be eaten into the diet? #DDHChat



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Tina Aswani Omprakash: For me, adding these types of fiber back into my diet has been essential as a vegetarian. This is where particle size & removing skins becomes very important. Blending helps as does chopping veggies into small pieces that may be easier to break down and digest. Smoothies were actually how I began introducing greens. I would use small amounts of fruit w/ bananas to start and then add a pinch of green powder or fresh greens in a smoothie and drink a half cup to see if I could tolerate it. I usually hand-blend lentil & vegetable soups & add rice or potatoes to help with binding. And now when I want to eat spinach, I will usually add rice & potatoes to it or else paneer (Indian cheese) to help bulk up my stool. Another thing I do is mash vegetables. So, I usually cook lentils, beans & vegetables in my instant pot or pressure cooker & then mash or blend them to tolerate them better. I add lemon, a variety of spices (turmeric, cumin, ginger, etc.) for taste. e.g., mung beans are healthy, but the skin is harsh. I soak these overnight & blend them in the AM w/ veggies (spinach, onions, etc). I add spices & make a batter followed by a savory pancake on a pan. It's delicious, packed w/ protein/fiber & I don't run to the loo! #DDHChat

**Neha D. Shah, MPH, RD, CNSC, CHES:** For these foods with fiber, small portions and particle size (raw or cooked) are going to be the strategies to try here with an #ileostomy. I do not pay attention to grams of fiber as it is important to listen to the body for tolerance to help expand intake. e.g., if cooked whole mushrooms are not tolerated well, then try mushroom soup, or its sauce or a mushroom quiche where the mushrooms are mashed. #DDHChat

Q4: @nehagastrord at times, rapid transit is seen with an #ileostomy. What are some foods that could be potentially included in the diet to help slow transit? #DDHChat

Neha D. Shah, MPH, RD, CNSC, CHES: I find that adding a ½ cup of food with soluble fiber to each meal has been helpful, such as oatmeal, bananas, and potatoes without the skin. Pay attention to what part of the day the rapid transit occurs with the #ileostomy. What is going on there? Is it when you are having your bigger meal of the day? If so, downsize the meal by subtracting a few TBSP as a large meal may increase transit. Adding a TBSP of soluble fiber powder once in the morning and once in the evening has been helpful to thicken #ileostomy output in many of my patients. #DDHChat Tina Aswani Omprakash: Bananas & potatoes added to meals are great as @nehagastrord mentioned. I also tolerate rice cakes & pudding as well as tapioca in different forms to help slow down transit. Adding different types of grains very slowly also helps to bind my output. I've tried rice, amaranth, kamut, quinoa pastas & waffles to see how I fare and generally do okay w/ these bulking up my output. I also find that certain nut butters (peanut, blanched almond & sunflower seed butters) prevent rapid transit for me. #DDHChat

Q5: @ownyourcrohns if there is an issue with excess gas in the #ileostomy, causing the bag to balloon out, what are some foods to eat less of, or overall strategies that you have used to help reduce the gas in the bag? #DDHChat

**Tina Aswani Omprakash:** Since lentils, beans & cruciferous veggies (broccoli, cauliflower, etc.) produce lots of gas, either you can eat smaller quantities or else sometimes I prefer to chop finely, blend and/or add spices that might reduce

gas/bloating after eating. I generally avoid carbonated beverages as I find them too gassy & bloating plus the sugar content in soda doesn't usually sit well with my insides. When I know a food might be gassy, I will eat it earlier in the day, so I don't have issues sleeping at night.

I also add some spices like a pinch of ginger or a squeeze of lemon so the food can go down a bit easier and not cause as much gas/bloat. I eat small meals and believe in variety as far as diet goes. I will eat things like hummus (mashed chickpeas) or babaganoush that are cooked well, blended. They may be gassy & fibrous, but they go down more easily yet bulken output due to their thick consistency. I also make small quantities of well-cooked cauliflower rice (finely chopped) and add a bit of white rice, other vegetables & a protein (lean meat, tofu or seitan) as a very small meal in the middle of the day.

I'm also a firm believer in walking and/or doing light exercise especially after meals to prevent gas from building up and to ease digestion. The 1st time I had a blockage was a few months after #colectomy when I ate a small amount of raw broccoli. I started having a lot of pain, wretching, then vomiting multiple times & got very dehydrated. I never really ate raw the same way again. The 2nd time I was working late & starving & bought a pack of peanuts, thinking I was being healthy. Nope. Later that night, I was gagging, my #ileostomy output came to a screeching halt & I was rushed to the hospital to have an NG tube placed. #DDHChat

Q6: @ownyourcrohns with the #ileostomy, how did you know when you had a blockage and what did you do to get treatment? How do you prevent this going forward? @nehagastrord what are some strategies to try with the diet to reduce the risk of blockage? #DDHchat

**Tina Aswani Omprakash:** I've been very careful since & really believe in eating soft foods that are cooked well, rather than raw foods and nuts. However, because of my #gastroparesis & chronic #constipation, I have had issues with obstructions the last few years even eating softer foods. #DDHChat

**Neha D. Shah, MPH, RD, CNSC, CHES:** Often, fiber is restricted to reduce risk. It is ok to eat fiber, but I then focus on particle size, small portions and small meals to reduce risk of blockage. Chew well to mechanically break down the foods in your mouth to mush. Practice! It can be helpful to make a list of foods that were eaten before the blockage (or each) came about so we can track patterns to learn more. #DDHChat

Q7: @nehagastrord dehydration can be a concern due to fluid/electrolyte losses. What would you recommend to ensure that individuals living with an #ileostomy hydrate well? #DDHChat

Neha D. Shah, MPH, RD, CNSC, CHES: First, recognize symptoms of dehydration so you know when to intervene and call your medical team if persistent. Symptoms such as excess thirst, fatigue and dizziness can arise. If the #ileostomy output is over 1500 ml in a 24 hour period, then it would be helpful to sip on beverages called oral rehydration solutions (ORS). ORS are beverages that have a specific ratio of glucose (sugar), sodium and water. The absorption of sodium and water in the small bowel is more when absorbed with glucose in its ratios. ORS may help reduce sodium losses and risk of dehydration. Ready-made ORS can be bought at the store or online. ORS can also be made at home using everyday ingredients, like 1 cup of apple juice, 3 cups of water and 3/4 teaspoon salt. A sample schedule for close to 1 L/day could be to try one cup between



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9-12 PM, another cup between 12-3 PM, another cup between 3-6 PM and the last cup between 6-9 PM.#DDHChat

**Tina Aswani Omprakash:** I prefer to make my own home ORS solutions when at home but if I'm on the go, I will carry portable ORS options. I often use coconut water, Naked Juice & Rebbl protein shakes to stay hydrated with no additives or preservatives. I always carry a bottle of water with me and refill it wherever & whenever I can. It's easy to add ORS solutions to it. I also find smoothies for breakfast very hydrating, full of electrolytes & nutrients when starting the day. I do sometimes add some extra salt to food especially when I'm feeling a bit lightheaded. I also take a powdered magnesium supplement @NaturalCalmCA to help with hydration & drink coconut water to improve my potassium levels.

I have in the past needed IV hydration when I get too dehydrated from a #Crohns flare or feel very faint & lightheaded from too much output. If this is something you think you might need, you can speak to your GI doctor about this. But imo, avoiding needles is best! For additional tips & tricks to manage hydration with an #ostomy, feel free to check out my blog: https://ownyourcrohns.com/thehydrationchallenge/ #DDHChat

Q8: @nehagastrord for an individual traveling with an #ileostomy, what are some items that would be helpful to pack to ensure adequate nutrition and hydration? #DDHChat Neha D. Shah, MPH, RD, CNSC, CHES: Going back to reducing risk of dehydration. The most important item I will focus on is packing ORS powders that you can mix into bottled water while traveling to optimize hydration. #DDHChat

Tina Aswani Omprakash: As @nehagastrordsaid, hydration is everything when traveling especially in the summer. There are many good portable ORS brands; however, I really like to carry Clif Bloks & one I learned about recently @SOShydration. I always carry extra #ostomy supplies & underwear while traveling. Whether it's a day-trip or a 2-week international vacation, always have EXTRA supplies on you so you don't feel even more anxiety around leaks. Always be mindful of diet when traveling. I often make sure there are restaurants close to the hotel that I can eat at. I also carry probiotics (especially saccharomyces boulardii) because my GI said it's good to prevent travelers' diarrhea. Here's an article I wrote for @everydayhealth on traveling with #IBD & an #ostomy for additional tips. Click here for tips. #DDHChat

Q9: @ownyourcrohns for an individual living with an #ileostomy wanting to dine out at restaurants, what are some tips that you found helpful to navigate the menu? #DDHChat

**Tina Aswani Omprakash:** As I mentioned earlier, I'm quite the foodie haha! I usually check menus & call to speak to the restaurant staff beforehand to make sure the food can be made a certain way (not too spicy, not too greasy, etc.). If there are soups, rice, potatoes, dumplings, pastas & a protein on the menu (tofu, seitan, mashed beans), I opt for those options. I avoid salads due to roughage & rawness. I've had bad experiences w/ stomach viruses when eating cold food so I stick to hot foods.

The best thing to do is to pick restaurants with cuisine you know sits well with you and pick a dish based on that. If you're gluten-free or allergic to any ingredients, make that known on the phone and in person. I always suggest emptying the #ostomy pouch first before the meal & eating small amounts & slowly to see how the food suits you. Here is a good guide by @Coloplast\_US on how to dine out with an #ostomy. click here to view the guide #DDHChat

## Q10: @ownyourcrohns how do you navigate discussions around diet when visiting the homes of friends and family for meals? #DDHChat

**Tina Aswani Omprakash:** Discussing diet has not been easy for me in social settings as I'm of an ethnic background where eating spicy food w/ seeds & fiber is what's considered acceptable. And not eating the host's food may be perceived as rude. I have too many times eaten foods that don't suit me and paid the prices hours later. That said, it's very important to make our needs known. People can only know if we speak up & educate them politely, of course! I tell the host beforehand, "Please don't mind but I will have to carry my own food as I have many dietary restrictions." If they want to cater to my diet, I will gladly tell them of some foods & recipes I can tolerate. Many times the host appreciates my openness & honesty & just wants to make sure I feel well. It's important to advocate for ourselves in these situations & not end up with a blockage, flare-up or difficult situation. #DDHChat

# Q11: @nehagastrord how can one find a #Gldietitian to guide food choices to help make eating easier with an #ileostomy? #DDHChat

**Neha D. Shah, MPH, RD, CNSC, CHES:** The @CrohnsColitisFn and @IFFGD have dietitian resources as a start. Check with #IBD centers as well. Virtual visits are possible! #Gldietitians that know nutrition for the #ileostomy teach strategies to troubleshoot the diet to keep symptoms associated with the #ileostomy at bay. While at it, to also help repair the relationship with food. #DDHChat

**Tina Aswani Omprakash:** A resource that I've found very helpful in eating with an #ostomy is one the @UOAA developed click **here** to view. #DDHChat

#### Live Questions:

LQ1: #DDHChat Hi, I don't an ileostomy but I have a colostomy. However, I wish to know with the group, currently, I keep losing weight and having blood discharge every day. Related to blood discharge, any particular foods can I consume to ensure my body hemoglobin enough in my body.

**Tina Aswani Omprakash:** Definitely, foods rich in iron. I do smoothies and add spinach and dates. You could also add lean meats to your diet. Something I had to do was get regular iron infusions and B12 injections at my GI doctor's office. You may want to consult your GI about optimizing your meds too to reduce bloody output and prevent flare-ups to allow nutrition to improve your status. #DDHChat

**Neha D. Shah, MPH, RD, CNSC, CHES:** Hi! I am sorry to hear of the weight loss! A couple of tips, for one, increase bites of food by an extra two TBSP at each meal as a start. Hopefully it won't be too much of an increase in volume, but enough to add calories by the end of the day. #DDHChat

#### IFFGD- final tweets and remarks:

Remember to celebrate #OstomyAwarenessDay Saturday, October 3rd! To learn more about Nutrition for the Ileostomy, visit Tina's blog or follow her on FB/Instagram/Twitter:



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@ownyourcrohns. For any additional #GInutrition questions related to #ileostomy, please reach out to @nehagastrord at www.nehashahnutrition.com or email address at neha@nehashahnutrition.com #DDHChat