



JOHNS HOPKINS
MEDICINE



LIVING WITH AN OSTOMY

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Objectives

- Know how to access ostomy nurse care before and after surgery
- Be aware of multi-faceted challenges after ostomy surgery
- Be familiar with strategies to optimize pouch security
- Learn about peer support options
 - UOAA (online and local community Affiliated Support Groups)
 - Social media and internet resources

Role of the ostomy nurse



“It remains the most important function of the WOC nurse to provide instructions for self-care and encouragement and support to the person having ostomy surgery.”

“Patients should be provided with information on support services to facilitate their adaptation to a new ostomy including how to access ostomy support groups...(Level of Evidence: High)”

Nutrition and Hydration

- Drink 8-10 glasses of fluids daily, preferably isotonic
- Sip don't gulp
- Do not control output by limiting your drinks
- Chew thoroughly
- Low-residue diet
- Slow output with Loperamide
- For more information, request a copy of the free book for your patient, "A Patient's Guide to Managing a Short Bowel" at <https://www.shortbowelsyndrome.com/sign-up>

Eating with an Ostomy; Foods and Their Effects Food Reference Chart for People with an Ostomy

Listed below are general guidelines for individuals who have a colostomy or ileostomy. It is important to know the effects that various foods will have on stool output. The effects may differ for each person depending on surgery type and length/ function of the remaining bowel. To determine individual tolerance to foods, try new foods in small quantities. Remember to always chew thoroughly.

Disclaimer: This document contains information developed by United Ostomy Association of America. This information does not replace medical advice from your healthcare provider. You are a unique individual and your experiences may differ from that of other patients. Talk to your health care provider if you have any questions about this document, your condition, or your treatment plan.



GAS PRODUCING:	*ODOR PRODUCING:	MAY CAUSE LOOSE STOOLS; DIARRHEA:	** STOMA BLOCKAGE:
ALCOHOL (BEER) BROCCOLI BRUSSELS SPROUT CABBAGE CARBONATED BEVERAGES CAULIFLOWER CHEWING GUM CUCUMBERS DAIRY (e.g., MILK) EGGS LEGUMES (e.g., BAKED BEANS, LENTILS, PEAS) MELONS NUTS ONION PICKLES RADISH SOY PRODUCTS SPICY FOODS	ASPARAGUS BROCCOLI BRUSSELS SPROUT CABBAGE CAULIFLOWER EGGS FATTY FOODS GARLIC LEGUMES (e.g., BAKED BEANS, LENTILS, PEAS) ONION SMOKED FOODS STRONG CHEESE SOME MEDICATIONS SOME VITAMINS	ALCOHOLIC BEVERAGES APPLE AND PRUNE JUICES BAKED BEANS CHOCOLATE FRESH/RAW FRUIT FRESH/RAW VEGETABLES FRIED OR SPICY FOODS HIGH SUGARED BEVERAGES LEAFY GREEN VEGETABLES MILK/CHEESE (LACTOSE INTOLERANCE)	BAMBOO SHOOTS BOK CHOY BROCCOLI (RAW) CABBAGE (FRESH/RAW/ALL TYPES) CAULIFLOWER (RAW) CELERY COCONUT COLESLAW CORN (WHOLE KERNEL) DRIED FRUITS FRESH/RAW PINEAPPLE MUSHROOMS (ALL TYPES) NUTS, SEEDS PITH FROM CITRUS (e.g., ORANGES) POPCORN SKIN OF FRESH FRUITS (e.g., APPLE PEELS, GRAPES)
COLOR CHANGES:	*ODOR CONTROL:	***CONSTIPATION PREVENTION/RELIEF:	THICKENS STOOL for Diarrhea and High Output
ASPARAGUS BEETS FOOD COLORING (RED DYES FROM KOOL AID AND PUNCH) IRON PILLS LICORICE RED JELL-O TOMATO SAUCE	CONSUME PROBIOTICS (e.g., YOGURT, AIDS IN DIGESTION) EAT SMALLER/ MORE FREQUENT MEALS, AIDS IN DIGESTION FRUITS AND VEGETABLES; HELPS KEEP THE COLON CLEAN STAY WELL HYDRATED AND AVOID CONSTIPATION ODOR ELIMINATORS (DROPS, GELS, SPRAYS, TABLETS, SACHETS THAT CAN BE PLACED INTO AN OSTOMY POUCH)	BRAN PRODUCTS FRUIT JUICES FRUIT (FRESH/RAW OR COOKED) OATMEAL PRUNES RAISINS VEGETABLES (FRESH/RAW OR COOKED) WATER (STAY HYDRATED) WARM BEVERAGES WARM SOUPS WHOLE GRAINS	APPLE SAUCE BANANAS BOILED WHITE RICE OR NOODLES CREAMY PEANUT BUTTER HOT CEREALS (OATMEAL, CREAM OF WHEAT, RICE) MARSHMALLOWS PEELED POTATOES TAPIOCA PUDDING UNSEASONED CRACKERS WHITE BREAD, TOAST YOGURT

C Applies to people with a colostomy **i** Applies to people with an ileostomy

*Odor from diet will differ for each person. If you have concerns, discuss with your doctor. Odor eliminators may be purchased from distributors of ostomy products. **People with an ileostomy are at greater risk for stoma blockage/obstruction. These food types should be eaten with caution and not introduced into the diet until 4-6 weeks after surgery. Introduce them slowly, one at a time, and chew well. ***Increasing the amount of fiber in your diet will help you avoid becoming constipated. Discuss options with your MD.



HOW TO TREAT ILEOSTOMY BLOCKAGE



What You May Experience (Symptoms)

- Thin, clear liquid output with foul odor; can progress to no output.
- Cramping pain in the abdomen (belly); may be near the stoma or the entire abdomen.
- Decrease in urine output; urine may be dark in color. This may happen from dehydration due to not wanting to drink fluids because you don't feel well.
- Swelling of the abdomen and stoma.

If you suspect a blockage that may be due to food particles collecting inside your stoma (stoma blockage), follow step one.

If you are vomiting, or have abdominal pain, or have additional concerns, call your doctor or go to the ER before trying these steps.

STEP 1

Call your health care provider's office to let them know about any change in function lasting more than 2-4 hours even if there is no pain or vomiting.

- If your stoma starts to swell, replace your pouching system. Cut the opening of your wafer a little larger than normal to accommodate the swelling.
- If there is no output from your stoma, and you are not nauseated or vomiting, stop eating solid food and only consume liquids such as juices, warm broth or tea.
- Take a warm bath or shower to relax the abdominal muscles.
- A heating pad placed on a low setting may be helpful to relax the abdominal muscles.
- If possible, take a short walk or just walk slowly around your house, as long as it's not too painful.
- Try several different body positions, such as a knee-chest position, or lie on the side of your stoma with knees bent, as it might help move the blockage forward.
- Massage the abdominal area and the area around your stoma. Most food blockages occur just below the stoma and this may help dislodge the blockage.

If you do not have any output for several hours, have abdominal pain and/or you are vomiting, your abdomen is distended (swollen), and the symptoms continue, or your stoma is edematous (swollen) or the color of the stoma has significantly darkened; follow step two.

STEP 2

- Stop eating and drinking.
- Call your doctor.
- If you are unable to reach your doctor, go to the emergency room (ER) immediately.
- Take your pouching supplies with you to the ER as they may not have your particular products.
- Take this card to the ER with you and give it to the admission nurse or medical professional caring for you.

Note: After abdominal surgery, a blockage of the small bowel can happen for many reasons including from scar tissue (adhesions). If stool is not coming out of your stoma, it is best to call your doctor or go to the emergency room (ER) immediately to determine if you have a stoma blockage related to food, or a small bowel obstruction.



For tips to help prevent blockages, see UOAA's **Eating with an Ostomy – A Comprehensive Nutrition Guide for Those Living with an Ostomy**

How To Treat Ileostomy Blockage

Give this card to the emergency room medical professional caring for you



Instructions for Medical Personnel

- Check for local blockage (food particles, peristomal hernia or stoma stenosis) via digital manipulation of the stoma lumen. This can be done by lubricating the index finger and gently passing it into the ileostomy opening/lumen. You should gently pass the finger to below the level of the abdominal wall fascia. You should feel the tight edge of the fascia as you pass your finger through the lumen. If you cannot easily pass your finger, you should abandon the effort. The patient may experience cramping and discomfort during this maneuver which is normal.
- An abdominal X-ray or CT scan may be indicated to determine causes of obstruction and remove the volvulus portion.
- Begin IV hydration, check electrolytes, and provide pain management measures.

If an ileostomy lavage is ordered for a determined food blockage, it should preferably be performed by a surgeon or certified ostomy nurse using the following guidelines:

- Gently insert a lubricated, gloved finger into the lumen of the stoma. If a blockage from food particles is palpated, attempt to gently break it up with your finger.
- Remove the patient's entire pouching system and administer lavage through stoma.
- Insert a lubricated soft catheter #14-#16 into the lumen of the stoma until the blockage is reached. Do not force the catheter.
- **See Side Note**
- If food blockage is seen/felt - proceed with lavage. Slowly instill 30-50cc NS into the catheter using a bulb syringe. Remove the catheter and allow for returns.
- Repeat this procedure instilling 30-50ccs at a time until the blockage is resolved. This can take 1-2 hours.

Do not give laxatives or bowel prep - these can cause severe fluid and electrolyte imbalance and dehydration.



Note: If unable to easily insert the catheter, notify surgery.



If these measures are unsuccessful, order a surgical consultation.

This document contains information developed by United Ostomy Associations of America. The document is provided for informational purposes only and cannot be considered medical advice. Referring to this document does not create a doctor/patient relationship. The information is solely for the purposes of assisting you in being informed when speaking to your doctor. This information does not replace medical advice from your healthcare provider. You should always speak to your healthcare provider to obtain advice about your medical condition. You are a unique individual and your experiences may differ from that of other patients. Talk to your health care provider if you have any questions about this document, your condition, or your treatment plan.

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Reference: Jane Carmel, J.C. (2015). Wound, Ostomy and Continence Nurses Society® Core Curriculum: Ostomy Management. Philadelphia: Lippincott, Williams & Wilkins.



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OSTOMY POUCH SELECTION

(more complicated than you'd think!)

- *Wafer formulation: Standard or Extended wear*
 - *Flat versus Convex (Standard, Deep, Firm, Soft)*
 - *Adhesive sensitivity: Tape, Acrylic, Hydrocolloid, Silicone*
 - *One-piece or Two-piece? Mechanical or adhesive coupling, floating/accordion flange*
 - *Pre-cut or Cut-to-fit or Moldable*
 - *Pouches: Drainable (tail clip or Velcro?) or closed, opaque or transparent*
 - *Options: Belt, Paste ring/strip/tube, Barrier extenders, Deodorizers, etc.*
-

REQUESTING SAMPLES OR INFO

COLOPLAST CARE

Monday-Friday 8:00am-6:00pm CT 877.858.2656 or email care-us@coloplast.com

<https://www.coloplast.us/about-us/contact-us/>

<https://www.coloplast.us/global/Ostomy/ostomy-self-assessment-tools/>

CONVATEC ME PLUS

800.422.8811

<https://meplus.convatec.com/>

<https://www.convatec.com/product-selector-home/ostomy-product-selector/system-type/>

HOLLISTER SECURE START

Monday–Friday from 7:30am to 12pm, and 1pm to 5pm CT 888.808.7456

<https://www.hollister.com/en/Products/Ostomy-Care-Products>

REQUESTING SAMPLES OR INFO

CYMED

800.582.0707

<https://cymedostomy.com/samples.html>

NUHOPE

800.899.5017 or 818.899.7711

<https://www.nu-hope.com/contact-us/>

<https://www.nu-hope.com/request-samples/>

MARLEN MANUFACTURING

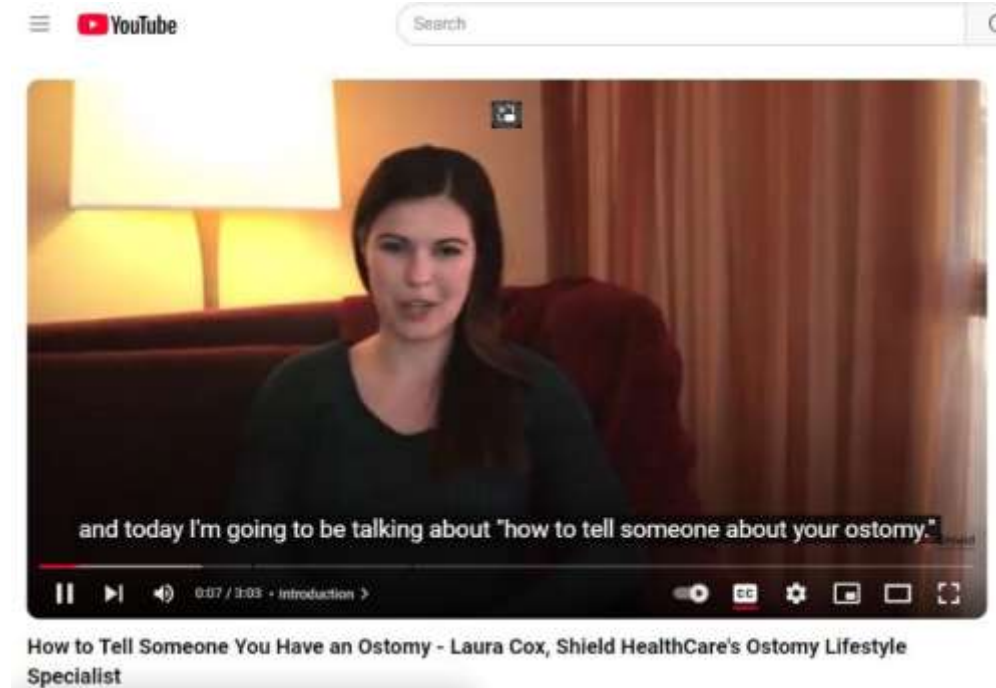
216.292.7060

Email: info@marlenmfg.com

<https://www.marlenmfg.com/request-a-sample/>

Get comfortable with telling people about the ostomy

- Shift perspective from embarrassment to gratitude
- Develop a script that includes:
 1. Why I have an ostomy...
 2. How it came to be...
 3. Explain what an ostomy means
- Does the other person seem comfortable enough for more details or do they seem to really hope that the conversation would move to something else?



[How to Tell Someone You Have an Ostomy - Laura Cox, Shield HealthCare's Ostomy Lifestyle Specialist - YouTube](#)



Mission:

The United Ostomy Associations of America, Inc., promotes quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration.

- 501(c)(3) nonprofit organization
- 300+ Affiliated Support Groups
- Member of the International Ostomy Association
- Your local ASG is the Greater Baltimore Ostomy Association

What does UOAA offer its members?

- Online resource
- New patient guides
- Phoenix magazine
- Moderated online discussion boards
- Ostomy Friends program
- Local support groups / Virtual support groups
- Regional and national conferences
- Political advocacy

"Because none of us is as loud as all of us."

Nearly half of all patients with inflammatory bowel disease (IBD) use the Internet as a source of information for their disease

Social Media

- Wide variation in quality of information
- Most not written by health care professionals
- Trust/quality control
- Consequences for confidentiality and privacy
- Risk that information may not be correctly applied
- Information overload AND incomplete information
- May deter patient from seeking care
- **No correlation between quality of information and mean number of YouTube views**
- **<https://www.veganostomy.ca/busting-ibd-misinformation/>**

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TAKE AWAYS

- Assess where your patient is now as far as self-care knowledge (don't assume)
- Help your patient establish care with an ostomy nurse
- Provide high-quality internet resources
- Introduce the UOAA and its mission and how to utilize its services
- Offer to be a guest speaker for your local ASG

THANK YOU!