

UOASL 2018 MEETING SCHEDULE

www.uoaastl.org

FaceBook at United Ostomy Association of Greater St.Louis (UOAA-STL/UOASL)

- July 2 St. Luke's - Room 1 & 2
August 6 St. Luke's - Youth Rally Follow Up
*Sept 10 St. Luke's - Summer Wrap-up. Dinner provided by
UOASL -Breakout groups - Room 4 & 5
Oct 1 **Christian Hospital - Dietrick Building
Nov 5 Leonard Naeger Memorial Lectureship - Drugs &
Your Ostomy - St. Luke's Hospital Room 4 &5 -
Dec 3 Annual Banquet (Starts at 6:30PM)
Syberg's Restaurant, Dorsett Rd

**Any articles welcome for consideration:
personal experiences, health, obituaries, tested tips, etc.**

Publication Deadline May 25, 2018

Send articles to: Mary Beth Akers
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St. Charles, MO 63303
636/916-3201
marybethakers@excite.com

LIVE & LEARN By Email

Are you interested in getting this publication by email? Send an email to marybethakers@excite.com and let her know that.

Mailing Information Update

Please let Brenda Schulte know if your info changes. Her address is: 115 Pine St., Old Monroe, MO 63369.

Her phone number is: 636-661-5607.

Please let us know if you have any change in home address, email address, company address or contact person.

We would really like for you to keep getting the L&L's and postcards.

If you do not receive any of our information please let us know.



LIVE AND LEARN Summer 2018

President's Message

To All Members and Friends of UOASL,

We had a very short spring! But as always, St. Louis weather is still up and down. I hope you are able to enjoy the nice weather days and find a way to bear the heat and humidity on the others.

The Product Fair at Mercy in May had a wonderful turnout. We decided to do something a little different this year. We had many nurses and other professionals in attendance. We had different topics at each table to talk about diet and nutrition, hernias, travel, basic ostomy, etc. If you were able to attend, please let us know what you thought. We have included some of the information from handouts at some of the tables here in the newsletter. Information was shared with everyone about the UOAA website at www.ostomy.org. It is chock full of information, support, advocacy, and links to help ostomates. Check it out!

Thanks to all the professionals who gave their evening to help us pull it off and especially, Lisa Hezel, for organizing it! Thanks to Kay Gundy, RN, CWOCN, Eileen Fahey, RN, COCN, Sharla Fischer, RD, LD, CDE, Retta Sutterfield, RN, CWOCN, Linda Geurin, RN, WOCN, Betsy Naeger, RN, CWOCN, Carol DeBoard, RN, BSN, Alalia Kraft, RN, BSN, WCC, Laura Noel, RN, FNP, CWOCN, Rachel Basler, RN, BSN, CWON, Roxie Lupien, RN, CNL, CWOCN, CFCN, Rados Stoddard, BSN, RN, CWON, CFCN and Karen Kroger who also brought TSA agent, Debra Thomas!

We thank our exhibitors: Coloplast, Convatec, Safe n' Simple, Medical West Healthcare Center, McKesson, and B. Braun Medical. As always, we appreciated the chance to learn about new products.

Congratulations to our Raffle winners, Walter Bisch and Martha Weaver, and Jan Abrams who won the Google Home Mini donated by one of the vendors.

I look forward to seeing you at a meeting and please do not hesitate to e-mail me at marybethakers@excite.com or call 636-916-3201.

Mary Beth Akers, President, UOA St. Louis

FOUR STEPS IN DEALING WITH A FLUSH STOMA

By Wendy Lueder, Broward County, FL, The Broward Beacon

One of the more difficult challenges an ostomate may face is dealing with a stoma that either protrudes just a little bit or not at all. Some are even what I like to call “below the water line” or lie below skin level. After some unsuccessful surgery I have been dealing with this condition for a few years.

When your stoma is flush the output has difficulty being directed into your pouch; thus, leaks and pouch changes are more frequent and annoying.

For ileostomates or colostomates with a liquid output, changing your skin barrier wafer is not an option to be delayed, as the output contains digestive enzymes and bile salts which damage and irritate your skin. If you do have a flush stoma, here are four suggestions that might help make your life easier.

First, try using a skin barrier that has built in convexity. This means that the wafer doesn't lay flat on your skin but has a gentle curve toward your body that pushes the skin around your stoma down and away. But for some, this solution is insufficient to take care of the problem, and greater convexity is needed.

Second, you might try the ostomy products on the market that are the shape of flexible washers called barrier rings. You may know them as Eakin Cohesive Seals (distributed in North America by ConvaTec), or Adapt Barrier Rings by Hollister. There are also other generics on the market. Be careful. Quality does vary among these rings. If placed around the skin of your stoma underneath the barrier wafer, the rings add an extra depth of convexity thus helping to push the skin down around your stoma even farther. Remember, no other skin creams, preparations of any kind or stoma pastes should be used along with the barrier rings, as this will adversely affect the adhesion of the seal. Also make sure your skin is clean and dry before applying and use soap with no oils or creams. I use a hair dryer set on very low to make sure my skin is dry in humid South Florida.

The third hint is that you actually might need to use an ostomy appliance belt (not a hernia belt). ConvaTec makes a white one and Hollister a fleshtone one. Both can be used interchangeably and snap on to the sides of your pouch. I put a little pressure on with the belt, forcing my skin barrier closer to my body and thus pushing my stoma up. DO NOT use a belt without first consulting your Doctor or Ostomy Nurse as some conditions such as a hernia make wearing one a prohibited option.

As all of these options used together still didn't completely solve my problem, I've had to go to DEFCON level 4. I have to lose weight. Some extra pounds I really didn't need have given my tummy a little pooch which made my convexity options less effective. As I have been losing weight my tummy's gotten flatter and the convexity options one through three are more effective. When out to dinner with my honey husband, I hate this option as desserts are always calling me off the menu, but a functional ostomy system just happens to be more important.

All about Stoma Paste

UOAA Update 2011, further edited in 2018 by Judea Sy, RN, BSN, CWOCN

Most ostomates have tried stoma paste at one time or another and more than half use it on a regular basis as part of their pouching system. What is it? Technically, stoma pastes are skin barrier compounds manufactured by several companies that are applied around stomas or skin surface irregularities, to provide additional protection and a uniform sealing surface around the stoma and under the wafer/barrier. Stoma paste usually comes in a tube similar to toothpaste. It needs to be used sparingly (in a thin line). The name of the compound (i.e., PASTE) does not accurately describe its application and the manufacturers certainly could have found a better name to describe it. It is not (as the name implies to some) a glue that is used to adhere the wafer or barrier to the skin. What does it do? When applied correctly, stoma paste provides an additional degree of protection around the stoma and on any exposed skin between the base of the stoma and on the opening in the wafer/barrier. It can be used to fill in any irregularities, such as wrinkles, folds or suture scars on the skin underneath the wafer. This will provide a smooth skin surface, for better adhesion and less chance of leakage. The easiest way to think of how stoma paste works is to compare it to the caulking around your bathtub. It is used to fill in voids. **Thanks to News and Views, Pomona Valley Hospital Medical Center, Upland, CA**

Hydration Handouts from Product Fair

The summer months are here and, while it is a great time of year with lots of fun, frivolity and relaxation, there are also some important considerations for ostomates in staying healthy during this time. Different parts of the gastrointestinal tract perform different functions, with the small intestine mainly digesting and absorbing nutrients from the foods that are eaten, and the large intestine mainly absorbing water and electrolytes back into the body.

For colostomates who have only had a small part of the large intestine removed, their ability to absorb water may not have been affected very much and they may not need to compensate for reduced fluid absorption. However, for an ileostomate who has had all of their large bowel removed and perhaps some of the small intestine too, the need for additional fluids is greater. Over time, the small intestine will begin to compensate for the functions of the large intestine, but it takes time for this adaptation to occur. The requirement for extra fluid is also affected by the nature of the stomal output. If it is very liquid and resembles water, then it is imperative to replenish this fluid loss.

The first step for an ostomate in assessing fluid balance is to determine their level of output. How can you tell if you are dehydrated? Some of the most common symptoms are dry mouth, headaches, irritability, fatigue, poor concentration, constipation and dry skin. Low blood pressure and fainting spells can also be indicative that fluid levels in the body are low. (Cont.)

(Cont.) As we age the sensation of thirst starts to weaken, and it isn't triggered as often as it used to be. Therefore, as we get older, it is important not to rely on the sensation of thirst to tell us when to drink. Therefore, when it comes to replacing fluid in the body, water is best. For those who are not fond of the taste of water, adding some fresh lime or lemon juice, or a dash of apple, orange or pineapple juice can improve the taste. This can also help with absorption. Switching to herbal teas can also help to rehydrate the body. If having to get up to go to the toilet during the night is a problem, drink more fluid earlier in the day and less after 3.00 pm.

Getting the Right Fluids from the VeganOstomy

You're going to want to know what options are available, since water isn't the best option to use exclusively in our case (it contains no electrolytes).

Water content of various fruits and vegetables: Apple 84%, Celery 95%, Cucumber 96%, Lettuce (iceberg) 96%, Orange 87%, Peach 88%, Tomato 94%, Watermelon 92%

A basic salad of: 4 cups of romaine, 1 small tomato, 1 small cucumber, 1 medium celery, and 1 small carrot contains 500ml of water plus nutrients!

- Drink less caffeinated beverages and alcohol. If you find that caffeinated beverages cause your output to loosen considerably, then you may want to cut back. Alcohol acts as a diuretic for everyone, and can cause you to lose fluids because it causes increased urination.
- Herbal teas can be a nice option, as they usually offer antioxidant benefits, but be aware that some may still contain caffeine and others may be high in tannins, which may reduce iron absorption. If you are anemic, don't drink teas at the same time you take your iron supplements or with meals.

Tips

- Don't wait until you're thirsty before you start drinking; thirst is a sign that you are already becoming dehydrated.
- Fatigue may be a sign of dehydration.
- Headaches can also be a symptom of dehydration, so if you are prone to them, try upping your fluid intake.
- You may notice that if you don't drink enough, your output may slow down and you might get crampy; take that as a warning to drink more!
- Be aware that many fruit juices can cause diarrhea (especially prune juice), so dilute or limit them if your goal is rehydration.
- Experiment with drinking before, during or after meals. You may find that depending on when you drink, your output may loosen up or thicken up, and that'll have an impact on the amount lost throughout the day.
- Your urine frequency, amount, color and smell will give you a good idea as to how hydrated you are: aim to get your urine to be clear and as odorless as possible; dark and smelly urine is often a sign of dehydration.
- Get regular urine and blood tests to measure your electrolyte balance.
- Artificial sweeteners may cause diarrhea, so be mindful when using them.
- Sip drinks, instead of chugging them for better absorption.

The Most Inspirational Women in History Who Lived With an Ostomy

By OstomyConnection Editorial Team 3/8/2018 issue via Insights of OASNJ

March 8 was International Women's Day and March was Women's History Month, so Ostomy Connection celebrated five inspirational women who are all ostomates and achieved great things. They remind us that no matter what obstacles we face, we are capable of anything.

Athlete, Babe Didrikson Zaharias: Babe Didrikson Zaharias is widely regarded as one of the greatest female athletes of all time. She won two gold medals in track and field at the 1932 Summer Olympics before turning to professional golf and winning 10 LPGA major championships. In 1953, her career was put on hold after being diagnosed with colon cancer and undergoing colostomy surgery, but she made a comeback in 1954 winning her 10th and final major championship at the U.S. Women's Open. In 1955, her cancer resurfaced and she passed away at the age of 45.

Entertainer, Barbara Barrie: Barbara Barrie is an American actress of film, stage and television. She has been nominated for an Academy Award, a Tony Award and three Emmy Awards and is also an accomplished author. Barbara was diagnosed and successfully treated for cancer in 1994, enduring chemo and radiation treatments, and multiple surgeries including a colostomy. She has written two biographical books about her battle with colorectal cancer and living with a colostomy - *Second Act* (1997) and *Don't Die of Embarrassment* (1999) - in order to speak out about the importance of early detection. Barbara lives in New York and is 86-years-old.

Business Woman, Letitia Baldrige: Letitia Baldrige was an American etiquette expert, public relations executive and author who was most famous for serving as Jacqueline Kennedy's Social Secretary. In 1964, she founded her own PR business and wrote several successful books. Most of her career was spent as an entrepreneur, but she also did significant charity work with Jane Goodall to help fundraise for the preservation of habitats for wild chimpanzees. The Washington Post wrote that she was diagnosed with colon cancer in 1978, and the NYT mentioned that she lived with an ostomy. She died of cardiac complications in 2012 at age 86.

Nurse, Norma Gill: Norma Gill was born on June 26, 1920 and became the world's first Enterostomal Therapist (ET) nurse in 1958. She was diagnosed with chronic ulcerative colitis, yet found the strength to look beyond her own situation to recognize the needs of others in similar circumstances. Norma finally found relief from the illness after undergoing ileostomy surgery and then became interested in working with ostomy patients. She believed that ostomy surgery should be a stepping stone to an improved quality of life and devoted years to help revolutionize ostomy care.

(Continued)

(Cont.) **Activist, Linda King Aukett:** Linda King Aukett is recognized globally for her volunteer and advocacy work in the ostomy community. She had ileostomy surgery in 1970 because of ulcerative colitis. Linda and her husband Ken co-founded The United Ostomy Associations of America in 2005 and she was also involved as a member of the Youth Rally leadership team which convenes an annual summer camp for children with bowel and bladder diseases. Linda dedicated her life to helping ostomates by advocating for thousands who are underserved with national insurers. She passed away on March 1, 2013 at age 69 after battling thyroid cancer. Linda worked tirelessly and selflessly for all of us and her legacy will live on for many years to come.

FOR THOSE WHO USE FACEBOOK AND TWITTER

The National UOAA is on both!

To find us on Facebook, go to Facebook.com/UOAA Inc.

To follow us on Twitter, go to Twitter.com/UOAA, or while logged in, search for @UOAA.

UOAA also has a Social Blog! You can find our blog at blog.ostomy.org.

Basic Ostomy Skin Care

Found on UOAA website—ostomy.org

People who have a stoma often share many of the same questions and concerns. This best practice document provides answers to some of the common questions that people ask about the day-to-day care of the stoma and the surrounding skin. People with a stoma often worry that their skin may become irritated from the stool, urine, or pouching system. It is important to treat the skin gently, protect it from stool, urine, and chemicals, and use products correctly to decrease the chance for skin problems. The basic rule is to keep it simple. Understand the reasons for doing what you do. Follow your Wound, Ostomy, Contenance (WOC) nurse or health care provider's recommendations and the directions from the product manufacturers. When fewer products are used on the skin, there is a smaller chance for developing skin problems. If you have questions about the information in this document, problems with leakage, or skin problems around the stoma, contact your WOC nurse or your health care provider.

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Urostomy (Bladder Surgeries) Handout from Product Fair

The urinary system is a simple network with complex functions. It plays a role in fluid balance, electrolyte balance, acid-base balance and excretion of waste. To maintain healthy kidney function, drink sufficient fluids to keep the urine diluted. If urine color is darker than usual, it is an indication of concentrated urine which requires an increase in fluid Intake. Certain foods and drugs can discolor the urine or produce a strong odor.

Urine pH Balance

Urine pH is defined as the fluid's degree of acidity or alkalinity. When the food you eat is burned in the body, it yields a mineral residue called "ash." This ash can be either acidic or basic (alkaline) depending on whether the food that is "burned" contains mostly acidic or basic ions. Most fruits and vegetables actually give an alkalinized ash and tend to alkaline the urine. Meats and cereals will usually produce an acidic ash.

Acid Ash Foods- Most meats, breads & cereals, Cheese, Corn, Crackers, Cranberries, Eggs, Macaroni, Nuts, Pasta, Rice, Prunes, Plums, Fish, and Poultry

Alkaline Ash Foods - Milk, Bananas, Beans, Beets, Greens, Spinach, Most fruits (including citrus fruits), and Most vegetables

Neutral Foods – Butter, Coffee, Cream, Honey, Salad, oils, Syrups, Tapioca, and Tea

Unless otherwise indicated, the urine should be maintained in an acid state. To maintain an acid urine state, increase your daily fluid intake to eight to ten (8 oz.) glasses of water. Drink cranberry juice in place of orange juice or other citrus juices which tend to make the urine more alkaline, take vitamin C daily (if okayed by physician) and try to eat an acid ash diet (see above listing).

VISITING SERVICES

Upon request from you, a Doctor, a Nurse, or an Enterostomal Therapist (Wound Ostomy Contenance Nurse): A **VISITOR**, who has been specially aimed will be sent to visit an Ostomy patient, either Pre-Op or Post-Op. The visitor will be chosen according to the patient's age, sex and type of Ostomy. There is **NO CHARGE** for this service and **WE DO NOT GIVE ANY TYPE OF MEDICAL ADVICE**. We only show the patient that his/her operation is not the end of the world, but a **NEW** pain free beginning to life again. Call Mary Beth Akers 314/636-9201.

That Annoying Pancaking

via Vancouver (BC) Ostomy HighLife and No Central OK

What is pancaking? Pancaking is one of the most common problems that people with a colostomy will complain about. It is caused when output stays at the top of the pouch and does not slide down into the bottom. It can stick around the top of the pouch, causing a bulge. It's really annoying! What can you do to prevent this? • Make sure you are drinking enough fluids throughout the day, it is recommended to drink about 2 liters in 24 hours. This will help to soften stool. • Something else that has worked for some people with a colostomy would be to drink cool boiled water with a dash of lemon first thing in the morning. This can also help to soften stool. • Try increasing the amount of fiber you are eating— more veggies, fruits etc. • If none of the above work, try putting a small amount of lubricating agent into your pouch. Ostomy pouch lubricant made by Hollister, Coloplast and ConvaTec are best for this but you can also use vegetable oil, Pam spray or even Vaseline. (Note: household lubricants may add to odor.) Smear whatever lubricant you choose around the inside top of the pouch. • Before you put your new pouch on, put a little bit of tissue paper into the bottom so it's not causing a vacuum when you seal.

TSA Information from Product Fair

Passengers with ostomies: should inform the Transportation Security Officer of an ostomy and where it is located before screening; can be screened without exposing or emptying an ostomy; can conduct a self pat-down of the ostomy in most circumstances.

Medically Necessary liquids, gels, and aerosols are permitted in excess of the 3.4 ounces but must be declared and presented. See www.tsa.gov for the most up to date information.

You may contact TSA-STL-Debra Thomas (314)656-1160 or TSA Cares (855)787-2227, several days before travel with concerns or questions.

Prepare for Take Off - Pack These Tips and Advice When Traveling with an Ostomy

By Wil Walker, Manager, Clinical Education, Hollister Incorporated

(Article provided to UOAA, our national parent organization, by Hollister, which is a digital sponsor of UOAA. Sponsor support along with donations from readers like you help to maintain the website and free trusted resources of UOAA, a 501(c)(3) nonprofit organization.)

Traveling with an ostomy does not have to slow you down. Whether you're traveling by car or plane, here are some suggestions on how to make your trip worry free.

How many extra ostomy supplies should I pack when traveling?

When traveling, you should pack double the number of supplies you would normally need, to make sure you have plenty of pouches and supplies on hand. That way, you are ready for the unexpected, such as a delay in returning home, lost pouches, or changes in climate and environment that call for more pouch changes than usual. In the event that you do need additional supplies while traveling, most manufacturers have products available around the world. Before you leave home, check to see where you can purchase new supplies in the areas where you plan to travel.

Which supplies should I keep with me in my carry-on when I fly?

Your short-term items should go in carry-on luggage so they remain with you at all times and are within easy reach. It's advisable to keep these supplies in a separate, small travel kit to make visits to the toilet simple and discreet.

On long car trips, what should I do about emptying my ostomy pouch?

It could be very messy to attempt emptying an ostomy pouch during a car trip, especially on bumpy roads without the correct type of receptacle in which to empty it.

(Continued)

Get Ostomy Answers!

The Phoenix is the leading national magazine for ostomates, their families and caregivers. Each issue contains 72 pages of inspiration, education and information including new products, medical advice, management techniques, personal stories and more.

Subscriptions directly fund the nonprofit United Ostomy Associations of America – the only national organization providing vital information, resources, support and advocacy for ostomates.



The Phoenix



One-year subscription \$29.95 Two-years for \$49.95

Payable to: The Phoenix magazine, P.O. Box 3605, Mission Viejo, CA 92690

(Cont.)

Frequent restroom stops are recommended for the most hygienic emptying.

What should I expect when going through airport security?

Pack all of your ostomy supplies in a separate, small travel kit that can go through security independently from your other carry-on items. Your hand luggage will be inspected at the security baggage check before boarding an aircraft.

If you have any prescription drugs with you, have your healthcare professional prepare a card explaining that they are medical supplies. You may be searched before boarding the aircraft, so be prepared to explain about your stoma and ask to be searched in a private area for medical reasons.

I heard that I can get a special travel certificate explaining what I am bringing on the plane. What is this and how do I get one?

Travel certificates available through ostomy associations are available to help explain your need to carry ostomy pouches, skin barriers and medications. It is recommended to search online for travel certificates available for ostomy patients. Read: UOAA's Travel Communications Card.

What if I have to use the restroom when the "fasten seat belt" sign is on?

Government and airline restrictions could interfere with your access to the restroom during flight. Plan accordingly by emptying your pouch before takeoff. You may also want to consider a private conversation with the flight attendants to inform them that you require restroom trips throughout the flight, and ask them to help you plan accordingly based on your flight schedule.

Will the pressure in the cabin affect my pouch?

A change in cabin pressure on a plane could create a small amount of gas in the pouch. You may consider using a pouch that includes a filter while traveling to help deodorize and slowly release gas from the pouch.

Helpful Link: Hollister Travel with an Ostomy:

www.securestartservices.com/travel

Hollister Secure Start services provide ongoing support to people living with an ostomy. We are here to help! Call us today at 1.888.808.7456.

So, You Have a Colostomy

Metro Maryland via Indian River FL OA & Gr. Cincinnati Area

Veteran colostomates usually know the difference between colostomies, but what about the new colostomate? All this person knows preoperatively is the doctor is going to operate on his/her bowels. If the patient is lucky, a WOCN will visit and explain what is going to happen. Surgeons have one concern getting the diseased portion of the colon removed and if necessary, forming a stoma outside the body. The patient may have been told what and why this operation is needed. What about when the patient awakens after the surgery? **TERROR!** This is when a WOCN becomes a friend for life. She/He will visit (upon the doctor's orders) and explain the difference between having an anus and having a stoma.

Beginning with the rectum, if the colostomate has a left-sided stoma, then it's a sigmoid colostomy. The fecal output will eventually regulate itself (if the patient doesn't irrigate) and behave similar to anal evacuation. If you have a descending colostomy, usually it is located on the left also in the descending colon and the output is semi-formed. This occurs because much of the water has been absorbed as waste moves through the ascending and transverse colon on the way to the rectum and anus. On the other hand there is the transverse colostomy which is located within the transverse (crosswise) colon and the output is usually liquid to semi- formed because digestive enzyme content decrease as the stoma, usually on the right of the abdomen, is farther to the left of the transverse colon. There is also an ascending colostomy. As the word ascend describes, this part of the colon discharges a semi-liquid and fecal matter rich in digestive enzymes that may irritate the peristomal skin. The output may be closer to that of an ileostomate.

If you are confused, just picture your colon as an upside down "U"=Ω, when facing your abdomen. Start on the right with sigmoid colon and continue with the above descriptions across the abdominal cavity to the left. Of course, you can just say the heck with it all and go out and enjoy life.

HOW FIBER AFFECTS AN ILEOSTOMY

Kay L. Peck, Dietitian, Napa Valley, CA. via The Pouch & Ostomy Rambler

Whether or not to include fiber, and to what extent, should be based on the person's tolerance of foods. The small intestine has a remarkable capacity to adapt. 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 fiber is indigestible material from plants that acts like a sponge, soaking up water and increasing the bulk of the intestinal contents as they move through the system more quickly.

In a person with a colon, fiber is essential to preventing constipation and keeping the person "regular". This is the main function of fiber. Another theory about fiber is that it promotes mucosal growth, thus keeping intestines healthier, promoting gut function. Usually a person without a colon, i.e., with an ileostomy, doesn't have a problem with constipation. It is virtually impossible. They may have mostly watery stools.

Again, over time a person may adapt, especially if the last section of the small bowel—the ileum—is still intact. Consuming too much fiber or insoluble fiber may aggravate a person's diarrhea or watery stools. If this is the case for you, **LIMITING** insoluble fiber such as bran, popcorn hulls, seeds, nuts, skin, stringy membrane parts of fruits and vegetables may be helpful. However, another type of fiber—soluble—may be beneficial to someone with an ileostomy.

The function of soluble fiber is to make the intestinal contents thicker and can actually prevent diarrhea. This fiber is found in oatmeal, barley, dried beans, peas, Metamucil and in the pulp of some fruits and vegetables.

Just a side note—I worked with a woman years ago who had short bowel syndrome. All of her colon and a significant part of her small bowel had been removed. She found that adding pectin—Certo, which is used to make jam and jelly—to her daily diet helped her minimize diarrhea. She also added a little applesauce every day.

TOP 10 WAYS

PATIENTS SHOULD USE UOAA'S OSTOMY & CONTINENT DIVERSION PATIENT BILL OF RIGHTS (PBOR)

1. **Use the standards of care outlined in UOAA's Patient Bill of Rights as a basis for explaining the services you need with your health care providers, health insurance plan administrator, or while at the hospital or an outpatient clinic.** If you have questions or concerns, discuss them.
2. **Read UOAA's PBOR and compare it to your surgical experience.** Is there information you did not receive that you would like to know more about? Go to UOAA's website: ostomy.org for the many resources available. For example: Check out the ostomy information tab, request a New Ostomy Patient Guide or download the guide.
3. **Apply the standards to your current situation.** Do you have access to healthcare professionals who are knowledgeable about ostomies or continent diversions and who you can consult as an outpatient? Do you need to reevaluate your self care due to a change in a medical condition or a change in your ability to function?
4. **Make sure family members or friends who act as your advocate have a copy of UOAA's PBOR.** Have them provide a copy for healthcare professionals in medical facilities or long-term care.
5. **Self-advocate for your access to knowledgeable professional ostomy care, if, in your situation, it is limited or non-existent.** Include a copy of UOAA's PBOR when you contact your healthcare system, health insurer customer care or healthcare facility to inquire about how they can assist you by providing the needed care.
6. **Share UOAA's PBOR with your family and support system, anyone you meet with an ostomy or anyone who is considering ostomy surgery, and ALL your healthcare providers.** Ask your physicians to post UOAA's PBOR in their offices.
7. **Keep a copy of UOAA's PBOR in your wallet** with your list of ostomy supplies and medication list.
8. **Discuss the standards in the PBOR at your local UOAA Affiliated Support Group.** No local support group? Contact UOAA for assistance with starting one in your area. Check out online discussion groups at ostomy.org.
9. **Include a copy of UOAA's PBOR** in your information package when you are meeting with your legislators.
10. **Share your feedback with UOAA** after you use the PBOR by entering your experience at: <https://www.surveymonkey.com/r/UOAA-BillOfRights-Feedback-Form>

Advocates for a Positive Change www.ostomy.org 1.800.826.0826



You Matter! Know What to Expect and Know Your Rights Ostomy and Continent Diversion Patient Bill of Rights

The Ostomy and Continent Diversion Patient Bill of Rights is a tool for patients to advocate for their own care. It is meant to empower those who live with an ostomy (temporary or permanent) or a continent diversion. It identifies the needs and expectations for those needing this type of surgery and for the community of people who are currently living with an ostomy or continent diversion. In order to achieve a desirable quality of life, a person undergoing ostomy or continent diversion surgery must have access to high-quality care in all healthcare settings. Counseling and Care in the patient bill of rights should be provided by a trained medical professional such as a Certified Wound Ostomy Continence Nurse (WOCN), Ostomy Nurse, Ostomy Management Specialist (OMS), or Ostomy Care Associate (OCA). The patient shall be involved in all phases of the surgical experience except in emergent situations and shall:

Receive preoperative counseling that must include:

- Preoperative stoma site marked by a medical professional following Standards of Care (established by the Wound, Ostomy and Continence Nurses Society, American Society of Colon & Rectal Surgeons and American Urological Association position statement)
- Explanation of surgical procedure and the rationale for surgery
- Discussion of ostomy/continent diversion management
- Impact of surgery on activities of daily living such as physical adaptation, clothing choices, exercise, possible changes in sexual activity and treatment, and dietary needs
- The opportunity to talk with someone who has been through ostomy or continent diversion surgery
- The opportunity to discuss the emotional impact of surgery
- Counseling in a language and at a level of understanding that is comfortable for the patient

Receive during the operative phase:

- A stoma that can be fit with a quality functioning pouching system
- A stoma that is appropriately positioned for their unique body, needs and comfort (if medical condition allows)

Receive postoperative nursing care specific to ostomy/continent diversion type and include the patient as well as their designated advocate (if any). Preparation for discharge will include:

- Individual instruction in care of ostomy including demonstration of emptying and changing pouch
- Ways to troubleshoot difficulties with basic skin and stoma issues including blockage and hernias
- Dietary and fluid guidelines given both verbally and in a written format such as UOAA's Ostomy Nutrition Guide
- Information on the availability of a variety of supply and product choices
- Information about the supply ordering process
- Resources for obtaining supplies specific to patient circumstances (e.g., uninsured/underinsured)
- Concierge services through ostomy manufacturers
- Resources to organizations who support and advocate for patients living with an ostomy or continent diversion
- Educational materials (such as UOAA's New Ostomy Patient Guide)

Receive during the lifetime of the ostomy or continent diversion the patient/designated advocate will benefit from ongoing support and care to include:

- Access to healthcare professionals with knowledge specific to the care of an ostomy or continent diversion in the outpatient setting
- Recognition of the need for reevaluation of care with the changes caused by aging and change in medical status

If you believe your rights are not being met, speak up - be a force for change!

Advocates for a Positive Change

www.ostomy.org 1.800.826.0826



