

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





*The Phoenix* magazine shows you how to live with a colostomy, ileostomy, urostomy or continent diversion (j-pouch, kock pouch, etc.). From preventing leaks to ordering ostomy supplies to dating and intimacy, in-depth articles written by medical professionals, authors and ostomates show you what works and what doesn't to lead a full and rewarding life after ostomy surgery.



*The Phoenix* magazine is the official publication of the <u>United Ostomy Associations of</u> <u>America</u>. Subscriptions are a major source of funding for the UOAA to help improve the quality of life of people who have, or will have, an intestinal or urinary diversion. It has been published continuously since Winter 2005 by Ian Settlemire.

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https://phoenixuoaa.org/subscribe/

## **Topics in each 80-page issue include**

- Advice from medical professionals
- New ostomy products
- Skin care and treatment
- Odor control
- Sex and intimacy
- Emotional and psychological issues
- Diet and exercise
- Surgery techniques and advancements
- Personal stories of recovery

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#### Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/?ref=aymt\_homepage\_panel 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: March 14th

#### **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



## **Foods That Heal**

Via Phoenix Risings, 2/2021; Via Southern New Jersey and Live and Learn, St. Louis, MO and Springfield Family Ostomy Support Group



**Headache?** Eat Fish! Eat plenty of fish - fish oil helps prevent headaches; so does ginger, which reduces inflammation and pain.

**Hay fever?** Eat Yogurt! Eat lots of yogurt before pollen season; also-eat honey from your area (local region) daily.

**To Prevent Stroke,** Drink Tea! Prevent buildup of fatty deposits on artery walls with regular doses of tea. In some people tea suppresses the appetite and keeps the pounds from invading. Green tea is great for our immune system!

**Insomnia (Can't Sleep?)** Honey! Use honey as a tranquilizer and sedative.

**Asthma?** Eat Onions! Eating onions helps ease constriction of bronchial tubes. Onion packs placed on the chest are known to help respiratory ailments aiding breathing.

Arthritis? Eat Fish! Salmon, tuna, mackerel and sardines actually prevent arthritis. Fish has omega oils, good for our immune system.

**Memory Problems?** Eat Oysters! Oysters help improve your mental functioning by supplying much-needed zinc.

Colds? Eat Garlic! Clear up that stuffy head with garlic. Remember, garlic lowers cholesterol, too.

**Coughing?** Use Red Peppers! A substance similar to that found in the cough syrups is found in hot red pepper. Use red (cayenne) pepper with caution-it can irritate your tummy.

Breast Cancer? Eat Wheat, Bran & Cabbage! Helps to maintain estrogen at healthy levels.

**Lung Cancer?** Eat Dark Greens and Orange Veggies! A good antidote is beta carotene, a form of Vitamin A found in dark green and orange vegetables.

Ulcers? Eat Cabbage! Cabbage contains chemicals that help heal both gastric and duodenal ulcers.

Diarrhea? Eat Apples! Grate an apple, let it turn brown and eat it to cure this condition. Bananas are also good.

## **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/





*Entertainer Barbara Barrie* American actress of film, stage and television, nominated for an Academy Award, a Tony Award and three Emmy Awards, was TV wife of Barney Miller, 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."

Last fall I read her excellent book, *Don't Die of Embarrassment*. I felt compelled to write to her because she was one of the major stars in a favorite movie of mine,

Breaking Away. A few days before Christmas, I received a hand written note from her thanking me for my letter and offering me encouragement as an ostomate.

Thank you, Ms. Barrie. I so appreciate you. Alexis Wasson Secretary/Editor The Tulsa Ostomy Association

### **Does Anyone Else Know How to Care for Your Ostomy?**

Via Metro Maryland Ostomy Association, Inc, July-August, 2020 Previously Vancouver BC Ostomy High-Life and OA of N. Central OK Ostomy Outlook, via Tri-State Ostomate, IA AND ?

Many of us have been looking after our ostomies for years and have the routine down pat. Even if our ostomy requires some extra effort (seals, patching, powder, skin prep and so on) after enough practice we perform even a complicated change without difficulty. But what if we suddenly could not do this for ourselves? There are a myriad of injuries or conditions that could suddenly prevent us from performing our usual ostomy routines. What if we suddenly did not have the use of our arms or hands? What if we were unable to speak?

In most cases, our families and friends have little or no idea what we are doing in the bathroom. It would be a wise precaution to have a detailed list prepared in case of sudden emergencies.

Some points to include:

- 1.) Brand name and product number of preferred barrier and pouch.
- 2,) Specific instructions on how to remove and apply the barrier whether one or two piece.
- 3.) Step-by-step instructions how to prepare the skin for application of the barrier.
- 4.) Proper closure of the drainable pouch.
- 5.) How often should things be emptied.
- 6.) How to hook up a night drainage system (Urostomy).
- 7.) How to tell if the system is leaking.
- 8.) Where your supplies are kept.
- 9.) Where you can buy these supplies if they run out.
- 10.) Insurance information, including plan numbers.
- 11.) Can you be placed on your abdomen if necessary, for an extended period of time?





## Despite all the Positives, Some Ostomates Still Have an Extremely Difficult Time with Acceptance

Article credit: Life's A Polyp, by Jenny Jones: Jenny has a master's degree in social work and advocates for FAP on her

blog, Life's a Polyp

2019 marks 24 years since my first ostomy surgery. The surgery that resulted in an ileostomy for six years, and thirteen years since my reversal. I tend to forget the anniversary date but occasionally my mind will reminisce about the amount of time that has passed.

When I had my surgery, I was told the stoma would only be temporary and that after three months of healing I would have a j-pouch. Well, that didn't quite go according to plan. Due to complications, I ended up with an ileostomy and the surgeons told me there was not enough healthy rectum remaining to reattach my small intestine. However, my rectal stump was kept in place and thankfully I never had any pain or issues with it, so I'm glad it wasn't removed.

I experienced a lot of anger and denial with my ostomy, especially when the complications started. I hated my doctors, surgeons, hospital, and even my parents. I wanted them to all pay for what they had done to me. I was consumed by rage and even became suicidal for several years after that initial surgery. I never accepted my stoma because deep down inside I knew I wasn't meant to live with it for the rest of my life. I believed it fervently, I hoped for a miracle obsessively.

Then six years later, I went in for a routine colonoscopy and out of nowhere my doctor tells me there might be enough rectum to attempt a straight pull-thru procedure. He referred me to a colorectal surgeon. I could hardly contain myself at the consultation. It was a long shot, but I had to take it.

I knew my life was about to change with this reversal but I was also terrified that I'd wake up after surgery to find out it failed. My parents agreed to give me a thumbs up or thumbs down as soon as I opened my eyes from anesthesia, so I would know the result right away. I wasn't sure how I'd react if it was thumbs down and feared that I'd break down immediately. Fortunately, it was a thumbs up and I was able to relax and drift back into a drug-induced sleep.

The honest truth is that most of us do not cope well, and don't talk about our feelings for fear of criticism. Don't get me wrong, it's a lifesaving surgery and it can greatly improve your quality of life. Ostomies are nothing to be ashamed of. Not to mention, improvements to ostomy products over the years have been amazing. But despite all of the positives, some of us still have an extremely difficult time with acceptance — I was one of those people.

Fortunately for me, I was able to have my ostomy successfully reversed. That's what I personally needed because I was fixated and trapped in a world of rage. Looking back, had it been a thumbs down, I hope that I'd eventually be able to find self-acceptance and love my life with dignity, just like so many ostomates I know and admire.

## 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.



### Swim Confidently with an Ostomy Modified from UOAA Articles to Share, Summer 2016, by Ed Pfueller

Yes, you can safely go swimming with your ostomy! After healing from surgery people of all ages and types of ostomies can and do enjoy swimming in community pools, athletic clubs, aquatic centers, oceans, and water parks. They also surf, swim and scuba dive\* in open water, and relax in a hot tub. But we understand the hesitation that some living with an ostomy may have. From worry of leaks to the reaction of fellow swimmers, the anxiety can be enough to keep some people out of the pool. There are no ostomy-specific restrictions to swimming in public places. Just follow all the normal pool rules, such as rinsing off before entering, just like everybody else. Let's get you feeling confident in the water whether it is in your own backyard pool, the beach, or on a cruise. Here are some solutions to common concerns:

I'm afraid that my pouch will leak or my wafer will loosen while I'm in the water. If this is your number one concern, you are not alone. Remember, your pouching system is resistant to water and with a proper fit it is designed not to leak. If you have output concerns eat a few hours before swimming. A good practice is to empty your pouch before taking a dip. If you are hesitant about how your wafer will hold, take a practice soak in your own bathtub. It is best to avoid applying a new wafer or flange and pouching system right before swimming. The WOCN Society recommends allowing 12 hours for proper adhesion. Using waterproof tape or water-specific barrier strips are not necessary for most, but can provide peace of mind. Be aware that some may have skin sensitivities to the adhesives in these products. There are a wide variety of ostomy supplies on the market for swimming, and you should be able to find a solution that works best for you. Discover the optimal amount of time for you to stay in the water. Lynn Wolfson, a triathlete with Ostomy United suggests: "I limit myself to half an hour, forty minutes at most for maintaining the best adhesion." Others find they can swim longer with no issues while some notice the need for an appliance change in a few hours or the next day after a swim. If your pouch has a vent, another consideration is to make sure to use the provided sticker over the air hole so that the filter remains effective. When you have confidence with your ostomy pouch fit out of the water, you'll feel more confident in the water. Remember, travel with your emergency kit of supplies wherever you go.

What can I wear or do to help conceal my pouch and keep it secure? Whatever your bathing suit style, wearing a patterned or darker color is less transparent than a light colored swim garment. One-piece options for women include using a patterned design with a boy-leg bottom. For a two-piece suit consider a mix and match of tankini tops, high-waisted bottoms or boy shorts. You can also look for a suit with a concealing ruffle or skirt. The type of bathing suit depends on how many ostomies you have, where they are located on your abdomen, and what type of water activity you are doing. Men often favor a higher cut waist for trunks, or suits with longer legs. Stretch fabric undergarments and swim or surf shirts also provide support. Also, consider using an ostomy band or wrap under your swim suit to hold the bag more firmly in place.

Visit the Peristomal Skin Assessment Guide for Consumers



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

Medical Care Products, Inc PO Box 10239 Jacksonville, FL 32247-0239

To: