



Meeting Notice For February 13th at the Villages Ostomy Support

Patti Langenbach of **Medical Care Products** will be the guest speaker at the **6pm meeting**. Come out and say hello! She will be there to talk about current events in the Ostomy market and be available for questions.

Jacksonville Contact Information:

Patti Langenbach
(800) 741-0110
(904) 733-8500

mcp@ostomymcp.com

Support group meets the 3rd Sunday of each month 3 p.m.

4836 Victor Street

Next Meeting: **February 18th**

Also join us by Zoom

[https://us06web.zoom.us/j/](https://us06web.zoom.us/j/94640600811)

94640600811

Meeting ID: 946 4060 0811

or call +1 301 715 8592 US

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 **February 13th @ 6 pm**
Saddlebrook Rec Center (near Polo Field)

Masks Required

Contact Linda tvostomy@gmail.com

Visit the Peristomal Skin Assessment Guide for Consumers

<http://psag-consumer.wocn.org/#home>

UOAA Discussion Board

<https://www.uoaa.org/forum/index.php>

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>

Medical Care Products, Inc.

(904) 733-8500

(800) 741-0110

Get Ostomy Answers!

The Phoenix magazine provides answers to the many challenges of living with an ostomy. From skin care to nutrition to intimacy, in-depth articles are written by medical professionals, ostomy experts and experienced ostomates. Subscriptions directly fund the services of the United Ostomy Associations of America.

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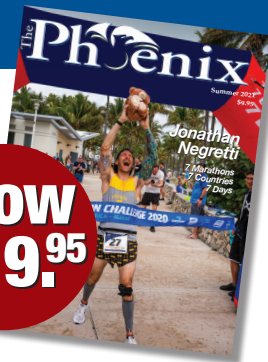
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8 myths about ostomies debunked

<https://www.crohnscolitisfoundation.org/>

Approximately 1 in 500 Americans live with an ostomy, a surgically created opening in the body for the discharge of body waste. Whether it's because of cancer, an inflammatory bowel disease (IBD) like Crohn's disease or ulcerative colitis, diverticulitis, or incontinence, an ostomy can give people with debilitating illnesses a new lease on life — one with fewer hospitalizations and. Despite the fact that having an ostomy can be life-saving, ostomies are often stigmatized. People sometimes equate having an ostomy with disability and a sub-par life. Case in point — seven years ago the Cincinnati Police Department launched a public education campaign to try and deter teens from entering a life of violence. While the ultimate goal of the campaign was admirable, they attempted to accomplish it by showing pictures of people with colostomies, declaring that a gunshot could lead to an ostomy for life.

“You're not killed, but you're walking around with a colostomy bag and that's just not the way to get a girl's attention,” said Lieutenant Joe Richardson in 2013.

This is just one example of a negative public campaign perpetuating the ostomy stigma. Unfortunately, these characterizations alienate ostomates around the country and worldwide.

MYTH: An ostomy is a death sentence.

This couldn't be farther from the truth. For many facing ostomy surgery, they are extremely ill, and the alternative to having surgery is facing fatal complications. Many patients will say that getting an ostomy gave them their life back.

Stephanie, a Crohn's disease patient who had ostomy surgery in 2012, said:

“Having an ostomy has given me back my life and I am able to do all of things that I've always wanted to do, but had been held back before by Crohn's disease.”

Stephanie

MYTH: Only cancer patients have ostomies.

Most people hear about patients with cancer having ostomies. However, patients with common diseases, like [Crohn's disease](#), [ulcerative colitis](#), diverticulitis, familial polyposis, neurogenic bladder disease, and birth defects, may require ostomy surgery at some point in their life.

MYTH: Ostomies are permanent for everyone.

For some patients, an ostomy is permanent. However, for many, an ostomy is performed to [allow part of the intestines to heal](#) from scarring, inflammation, infection, abscesses, and fistulas before the procedure is reversed to create an internal pouch.

MYTH: People with ostomies stink.

Most ostomy products are built with air filters in them that use charcoal, which neutralizes potential odors. Unless the individual has an ostomy leak, you won't be able to smell anything.

Take Aria — diagnosed with ulcerative colitis when she was in kindergarten, Aria was seven years old when she had a [proctocolectomy](#) (removal of her colon and rectum). Following the surgery, she lived with an ileostomy for two months while her j-pouch healed. She is just one example of the many young people who live with ostomies.

MYTH: Everyone can see if you have an ostomy.

Not if you don't want them to. Ostomies are designed to be hidden easily under most clothing. The person with the ostomy may be concerned about the visibility of their ostomy, but to the average person, it is typically unnoticeable.

MYTH: You can't dress regularly if you have an ostomy.

If you have an ostomy, you can wear the same clothing you wore before your surgery with very few exceptions. To provide peace of mind and additional support, some ostomates may wear special accessories to help keep the ostomy in place and prevent it from showing.

[According to the United Ostomy Associations of America](#), “many pouching systems are made today that are unnoticeable even when wearing the most stylish, form fitting clothing for men and women.”

MYTH: You can't be physically active if you have an ostomy.

This is also wrong. Many people with ostomies are physically active and participate in sports of all types. Rolf Benirschke played as a placekicker for the San Diego Chargers while living with an ostomy. Al Geigberger played professional golf with an ileostomy. Ostomates have completed half marathons, triathlons, and IRONMAN® competitions, like Elise Baum:

“I am so happy to have my life back. I feel great and don't have any restrictions on what I can do. Before the surgery, I was a prisoner. Now I am free.”

Elise

Every year, [approximately 100,000 people](#) in America undergo life-saving ostomy surgery. Let's take the time to educate ourselves about the different kinds of ostomies and begin to raise greater awareness and acceptance of ostomies to combat the misinformation and stigma that exists in our society.

A version of this article originally appeared on [The Huffington Post](#) and [Medium](#).

Michael Osso is President & CEO of the Crohn's & Colitis Foundation.

Finding a Doctor with Experience Treating Short Bowel Syndrome (SBS) Can Be Challenging

Short bowel syndrome (SBS) is a rare condition and as a result, the number of healthcare providers experienced in treating the disease is limited. It's important to advocate for oneself and find a provider who understands what you are going through. Healthcare providers can include a range of doctors, clinicians, and specialists.

So what resources are available to help you find an experienced healthcare provider? One resource tailored to providers experienced in treating short bowel syndrome is the SBS Healthcare Provider Locator. Patients and their caregivers have the option to enter search criteria such as zip code, mile radius, or state to generate search results. Any decisions related to contacting a healthcare provider identified in the search results is left to the patient or their caregiver.

SBS management may involve a multidisciplinary approach. The SBS Healthcare Provider Locator was developed to include a range of different providers, including gastroenterologists, surgeons, dietitians, and more.

Overall, finding a doctor with experience treating SBS can be challenging. By doing your research and utilizing available resources, you can prepare for your healthcare journey.

Start your search with the SBS Healthcare Provider Locator: www.SBSLocatorTool.com

Ostomy Benefits

By Dan McCoy dmccoy@dgmccoy.com Placerville, CA Ostomy Support Group

Early into my ostomy journey a close friend once asked if there are any benefits to having an ostomy. Off the top of my head I couldn't think of any. However, upon reflection a couple of benefits come to mind (in addition to the obvious benefit of being alive), plus a couple of other thoughts. Obvious benefits include: stool samples are MUCH easier with a colostomy compared to sitting on a "hat", plus chemo induced diarrhea is much easier to deal with when you don't have to rush to the bathroom every five minutes.

Beyond that are benefits that don't show up in an ostomy pouch.

Suppose someone had told me six years ago: this is your future - you will have lots of cancers and then will pee and poop out of your abdomen and back for the rest of your life (and occasionally leak all over yourself). I would have thought - "What a terrible way to live", and that ostomies must be on the person's mind all the time. I could not have been more mistaken. You can live a great life with ostomies, just a bit differently.

Of course, ostomates develop a different relationship with their waste, but living with ostomies quickly becomes just another way of dealing with life. I was initially struck by the idea that it's fairly easy to change when I have no choice. Now my ostomies are just "there" - like wallpaper - just a part of my daily reality. The old way of peeing and pooping didn't work anymore - like flipping a switch. My ostomies are so much a part of me and my daily life that I don't really think about them very much - 95% of the time.

Ostomies are so much a normal part of my life that I occasionally forget how much I have learned about ostomies and myself over the past five + years. Last week I had the opportunity to have an extensive conversation with a man scheduled for urostomy surgery in three weeks. First, I was impressed by how he had already received training to prepare for surgery at UCSF, and life after surgery. As our conversation continued, it brought an awareness of all of the lessons I learned, and taught myself over the last five years. Passing on those lessons came naturally and was much appreciated.

The larger benefit is a special awareness that illness brings - an intangible certainly, but best expressed as gratitude at a level I have rarely experienced before. Daily activities take on a special significance. We've all had thrilling times (however you define them), but thrilling times never last. What lasts is - normalcy. Day-to-day life. We spend the vast majority of our time on normal, everyday activities. Those small moments are to be treasured for the marvels that they are: many times a day the simplest observation can trigger...wonder. Doesn't last long...perhaps a few seconds to a minute of awe - watching my dog walk across the yard, noticing one flower among many, feeling raindrops on my face - a short reminder of the treasure I have at my fingertips.

Proper Care & Storage of Ostomy Supplies

from an article by Teresa Murphy-Stowers, Fort Worth, TX; via Dallas (TX) Ostomatic News

Ostomy supplies are not inexpensive, to say the least. So, it is important to understand how to apply them properly with the fewest errors possible and equally important to know how to take care of and store supplies until use. Proper care may avert the need to discard unused supplies and thus be as economical as possible.

- Be sure to read carefully the instruction sheet included in the box or guidelines on the container for specific recommendations for a given product.

- Generally, all ostomy supplies should be stored in a cool, dry location. Too much heat can melt or weaken many of the materials used in ostomy wafers, pouches, and accessory items. Avoid leaving supplies in a hot car or in direct sunlight.
- Review instructions periodically to refresh your memory and to see if any recommendations have changed over time.
- Keep supplies such as wafers and pouches in their original box. By doing so, you save the brand name, product identification number, and the lot and date information for those items. Perhaps you will never need this information, but in the event you do, the box you have saved will provide the information you (or someone helping you) will need for reorder or to report any quality control problems.
- Some ostomy supplies do have a “shelf life.” Be sure to check for dates that may be recorded on their containers. If you find you have a box with an expired date, check with the manufacturer, your local supplier, or an Ostomy nurse for advice on usage.
- While you do want to keep a “stock” of supplies so you are always prepared to change out your system, avoid the practice of stockpiling too much so your reserve will be as fresh as possible. This, of course, depends on factors such as the availability, proximity to a local supply house, or shipping issues.
- Purchase supplies from a trusted vendor—one you know will provide good service as well as stock/ship current stock.

Reporting Defective supplies

- If you determine your supplies are defective in spite of proper use and storage, contact the manufacturer at their toll free number to report the problem and receive product replacement or adjustment.
- Let your supply source know of your report to the manufacturer. They need to be aware of problems; however, the complaint needs to be directed to the manufacturer to ensure the defect can be addressed.

Keeping Your Pouch Odor Proof

by Victor Alterescu, RNET; via Quad City (IL) Newsletter and S. Brevard (FL) Newsletter

Rinsing a pouch out each time it is emptied is primarily a waste of time. For one thing, it takes longer to empty the pouch and you need more materials around you. You also leave more odor in the room since the pouch is kept open longer. The water, especially if it is warm, may open the pores of the pouch material and encourage odor permeation. Also, rinsing can affect the seal of your adhesive.

Rinsing a pouch after each emptying serves only an aesthetic purpose; the interior of the pouch may be clean but it does not serve a functional purpose. Frankly, it does not matter whether the interior of your pouch is clean any more than it matters if the interior of your colon is clean. The pouch is replacing an organ of storage, the colon and/or rectum.

The most important portion of the pouch that should be cleansed very thoroughly is the tip of the drainable pouch. Rinsing the interior can only increase permeation but cleaning the exterior neck will avoid any odor that may be present as a result of having fecal residue on the end of the pouch. Therefore, I often recommend that a person carry an alcohol wipe (individually wrapped in foil) to clean the tip of the pouch. The pouch is emptied, the toilet flushed immediately, and the lower portion of the exterior pouch cleansed with toilet tissue and alcohol.

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To: