The MailBag

January 2024

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

Subject: Koolostomy
Date: Fri, 15 Dec 2023 14:22:36 -0500
From: Verna Griffin
To: Medical Care Products

I want you ***THANK YOU*** for including my business card in the newsletter.

It has been a wonderful 22 years of making pouch covers for fellow ostomates. The time has come to close the machines and dissolve my internet store.

The new year will bring new endeavors to enjoy... more time on my boat, more pickleball games to play, and more travel to experience.

Once again, thank you for your support of Koolostomy.

Verna Griffin

Jacksonville
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Support group meets the 3rd Sunday of each month 3 p.m.
4836 Victor Street
Next Meeting: **January 21st**
Also join us by Zoom
https://us06web.zoom.us/j/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 **January 9th** @ 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

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Naming Our Stomas

by Ellyn Mantell, morethanmyostomy.com

When I was in high school, a close uncle had a double amputation of his legs. He suffered from a rare situation that caused him to have the "arteries of a 90-year-old man" despite the fact he was only in his 30s. His two young daughters were terrified of his new anatomy, as well as all of the changes in their lives that were necessary. The social worker from his rehabilitation center suggested having the girls name his stumps, giving them the ability to feel closer to their dad, hoping to ameliorate their fear. I do not remember both names, just Shapey, and remember wondering what was in Laurie's and Shari's minds as they chose that name. In fact, that time in my life was so impactful that I chose my first career, speech therapy, because of the time I spent visiting my uncle in rehab. I was incredibly impressed with the work I saw being done in physical, occupational and speech therapy, and knew that was my future.

All of these years later, I am in the position of recommending naming our stomas in order to become more comfortable with, and able to, embrace our new anatomy. In reality, according to the Food and Drug Administration, an ostomy is considered an amputation. That is because our stoma actually replaces the function of an organ that no longer functions, such as the colon or bladder.

As many of you know, I call my stoma Lily, since my mother was Lillian, and she gave me my first life. Lily has given me my second life, and my gratitude is enormous. Each time I meet a new ostomate, I am very aware that they may have a while, perhaps a long while, to go before they feel gratitude. But eventually, I believe they will be grateful. Our stomas save our lives!

The first phone call or visit I have with new ostomates allows me to listen to what has brought them to this new anatomy. All of us have the same thing in common…we are survivors, having been through so much. Whether it is an intestinal blockage, cancer of the colon or bladder, an accident, a perforation, a disease process such as Ulcerative Colitis or Crohn's Disease, or pathological dysmotility, the outcome is pretty much the same. There must be an adjustment period, and I try my best to support them in that process. The key, I believe, is to point out how strong and determined they are to have survived, and they will use that determination to find their best lives in the future.

I also recommend joining an ostomy support group, since there are so many questions they will have, and to make the United Ostomy Associations of America website part of their recovery. I am always amazed at the amount of information available for the patient and their caregiver.

Lastly, I want to remind all who are adjusting to a new situation to have grace with themselves. We are much stronger than we ever thought possible, but even the mightiest of warriors needs to take time to assess their goals and the path to achieve them. And that may include reaching out to another. Please let me know if you need my support, from one thriver to another!

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.

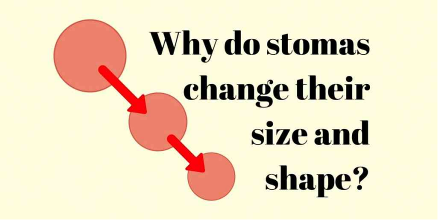
Beyond that are benefits that don't show up in an ostomy pouch.

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.



https://www.veganostomy.ca/

Anyone with an ostomy will tell you that sometimes their stoma will often act as if it has a mind of its own! In this article, I'll be explaining why stomas move, shrink, and grow!

What's Going On?!

It can be alarming to some and amusing to others, but there are several reasons why your stoma might move around and change size. Some of these reasons are totally natural and should not worry you, and others may need surgical intervention to correct.

Reduction in Swelling After Surgery

Surgery is traumatic for the body, and it's completely normal to have a swollen stoma soon after surgery.
If you **measure your stoma,** you may notice that it shrinks for the first 6 weeks or so after your surgery (with the most noticeable change happening in the first week). This is completely expected, and it's the main reason why patients are asked to measure their stoma before each appliance change for the first little while post-op.
At the same time, it's often not wise to keep your appliance on for more than a few days in the month following your surgery, as it may lead to **leaks** and **skin irritation** as the hole becomes too large for your changing stoma. This happened to me when I tried pushing my wear time to a week while my stoma size was still in transition – it was a painful lesson that I hope nobody repeats. There is no exact time frame for when your stoma will reach a consistent

size, and you may find yourself having to measure your stoma months or years after your surgery (like I do) because of various factors.

Peristalsis

One of the most common reasons why your stoma would change size and shape is peristalsis.

Peristalsis is a natural, wave-like movement of your intestines caused by muscle contractions in your gut. It serves an incredibly useful function of getting stool through your system and without normal peristalsis you may develop motility issues. It's important to realize that peristalsis is not something you can control; it's like a heartbeat, so your body will know exactly when it should happen (unless you have a motility disorder).

Because a stoma is part of your intestine sticking out of your body, you might be able to see peristalsis in action whenever a bowel movement happens. This is actually one of the reasons why I like wearing clear ostomy bags – it's interesting to see it in action! Sometimes, it'll look like your stoma is getting bigger, while other times your stoma may appear as if it's retracting or getting smaller. Either case is normal, however, I tend to notice that my stoma will retract more with peristalsis when I have a partial blockage (you may notice this, too). When cutting a hole for your appliance, always remember to make the hole slightly larger (only by a few millimeters) to account for peristalsis making your stoma larger. While peristalsis on its own does not (and should not) cause you pain, you may notice sharp pains coming in waves around your stoma if your wafer is cut too small. Likewise, you may also feel waves of pain caused by peristalsis if you have a blockage.

Weight Loss / Weight Gain

Whether you're experiencing intentional weight gain/loss or if it came about due to illness or other factors, it can still cause your stoma to change size or shape. Many of us experience dramatic changes in our weight after surgery, so it goes without saying that we may also find our stomas changing with the rest of our body. If you use pre-cut wafers and are planning to go on a diet, be sure to keep this in mind as the hole in your wafer may no longer fit your stoma properly. Along with our stoma changing size, weight loss/gain may also cause our skin to stretch our develop folds which can cause our wafers to no longer give us a good seal. Always keep these things in mind so you can plan for them.

Flush or Retracted Stoma

Most normal stomas stick out a little bit, but some people may have what's called a "flush" or "retracted stoma". In the case of a flush stoma, there is very little or no bump and the stoma is flat with the skin.
For a retracted stoma, the stoma actually points inwards, and this can be an ongoing problem for some ostomates. The cause of a permanent or chronically retracted stoma is often linked back to **poor stoma placement**. Both a flush and retracted stoma can cause issues like leaks or poor appliance adhesion, and in some cases, a surgical revision needs to be made to correct it. For me, **having a blockage** (whether it's a partial or complete obstruction) causes my stoma to shrink and retract. In fact, it's one of the red flags I use to warn me of blockages-in-progress, and it may be something you notice too.

Prolapsed Stoma

The opposite of a retracted stoma is a prolapsed stoma. There are two types of stoma prolapse, one that is "fixed" and one that is "sliding". A fixed prolapse is usually caused by the stoma not being created properly while the sliding type can happen for various reasons. Seeing a prolapsed stoma can be alarming and some extend out over 6″, which can cause problems fitting an appliance and can reduce a patients quality of life.

Someone who has a prolapsed stoma may experience it at random times, and this can make measuring the stoma more challenging. Unless a prolapsed stoma is causing dangerous complications (like bowel strangulation), the surgical correction is often planned and not urgent.

Hernias

Parastomal hernias are caused when a part of your bowel pushes through the muscle wall of your abdomen and can affect a very large percentage of ostomates. Hernias cause bulges under the skin that can change the size or appearance of your stoma. Many hernias in ostomy patients are repaired surgically or supported using specialized **hernia belts**. Unfortunately, recurrence of hernias is quite high following surgical repair (2) and every new surgery puts a patient at risk of developing one (since the integrity of the abdominal wall is compromised with surgery). It's best to consult with a stoma nurse if you have a parastomal hernia because it's important to manage it in some way to prevent it from worsening.

Pregnancy

As one observant reader mentioned, pregnancy can have an effect on the size, shape, and location of a stoma! (*Thanks, Laura!*) These changes are normal and are more common in the second and third trimester. Regardless, the rapid changes to your body can cause difficulties in managing your appliance.

If you do become pregnant and have an ostomy, I would suggest working with both a stoma nurse and an obstetrician so that both your baby and stoma are being looked after :) My good friend Stephanie Hughes from the Stolen Colon has detailed some of the other changes she's experienced during pregnancy with an ostomy on one of many articles.

Tips to Manage a Changing Stoma

Here are a few general guidelines for dealing with a stoma that's not staying a consistent size or shape.

- **Measure your stoma**. The reason why I like cut-to-fit appliances is that it doesn't matter what size or shape your stoma is because you'll be creating the hole yourself. But in order to get the best fit, you should be **measuring your stoma** before each appliance change (or whatever frequency makes sense to you). If you're using pre-cut products, I would suggest measuring before placing any new orders, just in case the size is different from what you've used previously.
- **Try moldable products**. If cut-to-fit and pre-cut appliances aren't working out for you, consider using a moldable appliance. These allow you to fit the wafer around your stoma and then shape it without needing to measure or cut anything.
- **Expect change.** No stoma will be exactly the same size and shape for a person's entire life. Knowing that your stoma will change can help you to plan things out and make it less likely to be a surprise when it happens.
- **Manage your parastomal hernia.** A parastomal hernia can change the landscape of a person's abdomen, and one that isn't properly supported or corrected can make ostomy life very inconsistent. Speak with your nurse if you're having difficulties.
- **Learn to "read" your stoma.** Our stomas can often give us clues as to what's going on inside. If you know that your stoma prolapses when exercising or retracts when you have an obstruction, you have an opportunity to prevent these things from happening. You may still need to consult a nurse or surgeon for help, but learning how to "read" your stoma is a great way of providing information that can help them to come up with a plan.
- **Don't take it personally.** You may be experiencing a lot of anger or frustration over your shape-shifting stoma. Know that it's not your fault, but it is something you can learn to manage and work around. The more experience we have with taking care of our stoma, the better we get at anticipating and solving these challenges.

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To: