

The Austi-Mate Journal

Ostomy Association of Austin Monthly Publication P. O. Box 143383 Austin, Texas 78714

www.austinostomy.org

Gethsemane Lutheran Church 200 West Anderson Lane, Austin, Texas 78752

Upcoming In-Person & Virtual Meetings ~ 7- 8:00 pm

Thursday, February 1, 2024 March, March 7, 2024

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This Bi-monthly newsletter is available online at <u>www.austinostomy.org</u>

Have you paid your dues?

The Ostomy Association of Austin is a volunteer based Non-Profit Health Support group dedicated to providing mutual aid and education, information and advocacy for persons and their families who have had or will have ostomy surgery. It is our vision to educate, empower and inspire through information and mutual support in all phases of life.



New Year Resolutions of an Ostomate

I resolve to...

- ✓ keep myself neat and presentable at all times.
- ✓ not begrudge the time necessary for my personal care.
- ✓ keep my bathroom sharable.
- ✓ value the cooperation of my family.
- ✓ appreciate the fact that I am one of the lucky ones.
- \checkmark try to do the things I want to do but think I can't.
- ✓ be patient.
- ✓ LIVE all day, every day.
- ✓ help others whenever I can.
- ✓ go places and do things.
- ✓ give credit to modern medicine.
- ✓ urge my fellow ostomates to see people.
- ✓ be grateful for my present good health.
- ✓ be of good cheer. renew my pledge the first of every month!

February Mtg: Emily Brooke, Licensed Clinical Social Worker at the

Digestive Health | UT Health Austin, Ascension Seton Department of Health Social Work | Dell Medical School, The University of Texas at Austin; Assistant Professor of Practice | Steve Hicks School of Social Work, The University of Texas at Austin. JOIN US!

What Can I Do with a Urostomy? What Can't I Do?! By Annemarie Finn

Y

When I received my <u>bladder cancer diagnosis</u> and the treatment plan, a radical cystectomy with an ileal conduit, I was devastated. Like so many, I went through many stages: Denial, Anger, Bargaining, Sadness and Depression, and finally, Acceptance. It felt like a

double whammy. It seemed like the "cure" was worse than the disease. I would be forever changed. It was hard to wrap my brain around. It is one of the reasons I decided to write about my experience. I had no idea what to expect and did not know where to turn. I saw some videos of survivors with <u>ileal</u> <u>conduits</u> but, I did not relate with the speakers. They were 20-30 years older than I was. I really did not want to envision a life as an elderly person before it was time.

I can use a public restroom without having to sit on the gross toilet!

What would my quality of life be? I was terrified that life, as I knew it was over. Would I be able to work? What activities would I be able to do? What would I never do again? I had so many questions and fears.

So, what can I do now that I have a urostomy?

Honestly, I can do everything I could do before. When you first get out of surgery, you are hardly able to walk around your room. When you go home, the end of the driveway is a monumental trek. By persevering and trying to walk more every day, I was able to go from measuring distance in feet to measuring in miles. Today, I try to walk 5-10 miles a day! I have hiked intermediate trails in the hills of Eastern Massachusetts. I have discovered miles of trails in my hometown that I didn't even know existed. I am probably healthier than I was before I got sick.

Can you take a bath?

People often ask if you are able to bathe with a bag. It is very nerve wracking initially to expose your stoma. They are fairly active. I call my stoma, Squirt, when he (yes, it's a he) acts up. He does spray urine. Picture a male toddler squirting. That's what it's like. We have no control over it. That's why we wear a pouch. As you can see, a urostomy after a radical cystectomy is a life changer, but in a good way. You can wear your urostomy bag in the shower. You do not need to cover it or keep it dry. It is a good idea to dry the skin around it with a hair dryer on low when you are done. You can even take your bag off and shower without it. I am over two years out from my surgery and that is how I prefer to do things on my change day. I change my bag every 3 days. I prepare all of my materials (bag, ring, barrier, paper towels, remover spray) then remove my bag. I then take a shower. I wash the skin around the stoma with just water or soap for sensitive skin. Just make sure you do not leave behind any lotion or any residue that would affect the barrier sticking to your skin. I keep paper towels ready to catch any drips when I am done and dry the skin with a hair dryer on the cool setting. I then just put on my prepared bag. I have some skin issues and find this helps with the itching and discomfort. It feels so good not to have the bag on for a while.

What about swimming?

I am a water rat. I can be in the water for hours, literally hours. It doesn't matter if it is in the ocean, a lake, or a pool. I have done them all. Personally, it has not affected the amount of time I am able to wear a pouch. I am still able to go 3 days. I am able to swim, kayak, and paddleboard with my urostomy. I even just float. It has not interfered with my love of water at all. Even better, I can wear a regular bathing suit. I have worn tankinis for years, and not because of my urostomy. I no longer have a toned teenage body. I don't even have a toned 30 something body. I like 2-piece tankinis as they hide a multitude of sins. After I got my urostomy, I decided to buy regular 2-piece bathing suits. Ironically, I am much more comfortable with my new imperfect body than I ever was before. My family laughs at me because, where I was self-conscious before, I now show off my body. Maybe it was having so many strangers looking at my most intimate body parts in the hospital or maybe I am proud of my battle scars. You cannot see my bag with my bathing suit on. It's honestly no big deal.

There are so many other things I have been able to do since my urostomy. I ride my bike. I participated virtually in the Norton Cancer Institute Bike to Beat Cancer, a 35-mile bike ride. I did it in steps but I gave myself a pass since it was only months after my surgery. I garden, do yard work, spread mulch, work, travel, you name it. As you can see, it has not limited me in any way. Because of my urostomy and

thanks to my night bag, I can sleep through the night without having to get up to use the bathroom. That means I can drink up until I go to bed! I can sit through long car rides and movies with said night bag. I can use a public restroom without having to sit on the gross toilet! I can write my name in the snow!!! That is not conjecture, I actually did it. My sex life is good. I am planning a European vacation. Both of those will be the topics of future blogs.

What about what I can't do?

The list of what I can do is long. What about what I can't do. I can't pee like I used to. I am careful about lifting. I had a hysterectomy with my radical cystectomy so no more children for me. Since I was in my late 50s when I had my surgery, it's not really an issue but, I am trying to be honest here. That is something to consider if you are younger. Definitely talk to your doctor if you want children. I can't play the piano, but I couldn't before. That's about it.

As you can see, a urostomy after a radical cystectomy is a life changer, but in a good way. You can still do what you did before and even try new things. Even better, it is a life saver. Go out and live your best life. That's what I am doing!



Top 8 Signs Your Peristomal Skin Is Irritated or Damaged

UOAA online information

After your ostomy surgery, your healthcare team likely taught you how to care for your peristomal skin and what it should look like when it is healthy. Ideally, it should be intact without irritation, rash, or redness. The skin around your stoma should look just like the skin on the other side of your abdomen, or anywhere else on your body, free of redness, irritation, or damage. Healthy skin should be the rule, not the exception.

However, if your peristomal skin is irritated or damaged, there may be some signs of a peristomal skin complication (PSC), such as:

- 1. Discomfort, itching, soreness, or even pain around the stoma
- 2. Recurrent leakage under your pouching system or skin barrier
- 3. Excessive bleeding of your stoma it's normal for your stoma to slightly bleed after you wash it, but the bleeding should resolve quickly
- 4. A bulge in the skin around your stoma
- 5. Skin color changes from normal pink or red to pale, bluish purple, or black
- 6. A rash around the stoma that is red, or red with bumps this may be due to a skin infection or sensitivity, or even leakage
- Wart-like, pimple-like or blister-like bumps under the skin barrier this type of irritation can happen any time, even if you've used the same product months or years
- 8. Any type of wound or scratch on the peristomal skin

Peristomal Skin Complications – Potential Causes and What to Do

Irritated and damaged peristomal skin can occur for a variety of reasons. It can be caused by anything from a poor-fitting pouching system, to frequent skin barrier changes, to an allergic reaction to anything that contacts the skin, such as soaps or products used to prepare the peristomal skin. Some studies report up to 75 percent of people with an ostomy experience a PSC.* Although it is a common issue, it should not be ignored. If you experience any signs of a PSC, contact your stoma care nurse. You should work with your healthcare team to determine the exact cause and the appropriate solution.

* Rapp CG, L Richbourg, JM Thorne. Difficulties Experienced by the Ostomate After Hospital Discharge. JWOCN. 2007;34(1):70-79.





Sex and Stomas: Myths & Truths

UOAA online information (edited)



Yes, people with ostomies do find intimacy and have active sexual lives after recovering from surgery. Surgery type and emotional confidence factor in sexual health.

Sexual problems may emerge after surgery beyond any physical challenges. Emotional issues may include embracing your new body image. Having confidence in a pouching system fit can also be critical. Tips and adjustments can help put your mind at ease.

MYTH: ...AND THEY LIVED HAPPILY EVER AFTER.

TRUTH: This is a fairy tale. Relationships are like tides; sometimes they're up and sometimes they're down. Adjustments can be made to keep the joy of sex alive, but sex alone doesn't make a relationship secure.

MYTH: INTERCOURSE IS THE ONLY WAY TO BE INTIMATE WITH A PERSON.

TRUTH: Regardless of your sexual orientation or gender identity, giving and receiving pleasure can be expressed in many ways-hugging, kissing, cuddling, holding hands, masturbation, oral sex, stimulation with the hands, and even sleeping in the same bed.

MYTH: MY PARTNER SHOULD KNOW WHAT PLEASES ME. I SHOULDN'T HAVE TO EXPLAIN IT.

TRUTH: Unless your partner has extrasensory perception (ESP), they can't read your mind. Tell your partner what you like, what you don't like.

MYTH: YOU CAN'T GET PREGNANT WITH A STOMA.

TRUTH: People with stomas can and do get pregnant and have healthy babies. It is important, however, to be followed by healthcare professionals throughout the pregnancy.

MYTH: NO ONE WILL EVER LOVE ME BECAUSE I HAVE A STOMA.

TRUTH: It's reasonable to feel this way. People who've lost a breast to cancer or lost a limb feel this way too. Your attitude and how you treat yourself sets the tone on how others treat you. If you feel comfortable and accepting of your new body, your partner is likely to do the same.

MYTH: I'LL NEVER HAVE AN ERECTION AGAIN.

TRUTH: If there's no erection the first time you try after surgery, don't convince yourself this is the way it's going to be. Rest. Relax. Regain your strength and try again. If the problem persists, talk to your doctor.

MYTH: YOU MUST EJACULATE TO HAVE AN ORGASM.

TRUTH: It is possible to have an orgasm without ejaculating (a dry orgasm).

MYTH: HAVING SEX WILL SPREAD MY CANCER TO MY PARTNER.

TRUTH: Cancer isn't spread through sexual contact. However, 'safe sex' should be used to prevent sexually transmitted infections.

MYTH: THE ODOR FROM MY STOMA WILL BE A TURN-OFF FOR MY PARTNER.

TRUTH: Deodorizers especially designed for use with an ostomy are available to help reduce odors from stool and urine. Some are used in the pouch and some are taken by mouth. Modern pouches are made of odor free materials. To remain fresh, keep your body and pouching system clean.

MYTH: BODY MOVEMENTS AND PRESSURE OF OUR BODIES DURING SEX WILL HURT MY STOMA.

TRUTH: Close body contact and movement during sex won't hurt your stoma. However, nothing (fingers, objects) should be put into the stoma. A stoma is not a sexual organ.

MYTH: OLDER PEOPLE DON'T HAVE SEX.

TRUTH: Ha! Many seniors, including ones with an ostomy, are sexually active.

Is Cracking Your Knuckles Bad for You?

Cleveland Clinic Health Essentials January 6, 2023



The sound of knuckles cracking signals relief for some and sends others running for the hills. Whether you're a habitual knuckle cracker or cringe at the thought, you've probably heard that cracking your knuckles enlarges them or causes arthritis in your fingers. But is that really true?

Nope! Conventional wisdom is wrong when it comes to knuckle cracking. As long as you're cracking them correctly, you're not damaging your joints. We talked to orthopedic surgeon <u>Kim L. Stearns, MD</u>, to find out what's actually happening when you crack your knuckles, and whether that momentary satisfaction comes with long-term consequences.

What happens when you crack your knuckles?

According to Dr. Stearns, cracking your knuckles releases gas — in the form of nitrogen bubbles — from the space around your joints. The sound is triggered as the bubbles are compressed.

"Researchers aren't sure if the sound emitted from cracking your knuckles is that of gas bubbles being formed or released," Dr. Stearns notes. "But either way, it's just gas."

Risks and long-term side effects of knuckle cracking

We've established that cracking your knuckles correctly won't enlarge them or cause you to develop arthritis. But that doesn't mean there aren't *any* risks associated with the practice.

As is so often the case, technique matters. Don't pull or press with too much force, and be mindful of direction. You'll know quickly if you've made a mistake because it'll hurt, and cracking your knuckles isn't supposed to hurt. If you happen to notice swelling (or if your fingers appear crooked), Dr. Stearns advises that you go to the doctor. You may have injured a ligament or even dislocated your finger.

While a 1999 study found weaker hand grips and more hand swelling among knuckle-crackers, those findings haven't held up particularly well over the decades. And a <u>2017 study</u> found exactly the opposite: There was no difference in grip strength between knuckle crackers and non-knuckle crackers. That same study *did* find a difference in metacarpal head cartilage thickness — which can indicate osteoarthritis — but did not go so far as to suggest knuckle cracking *caused* it.

While the existing research on knuckle cracking is thin, the available evidence tells us that there are few if any long-term side effects to be concerned about.

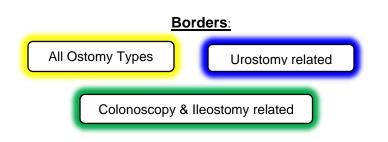
How much is too much?

A 2011 study looked at what they called "crack years," to see if the amount of knuckle cracking one does over time might impact their risk for osteoarthritis. The news was good: It appears that the amount and duration of knuckle cracking do nothing to increase (or decrease) your risk of joint swelling or osteoarthritis.

Is it good or bad for you?

Knuckle cracking isn't good for you *or* bad for you. It's just a thing people do. For some, it feels like the only way to alleviate stiffness. For others, it's just a habit. Some people do it for the noise or because it's fun to send non-knuckle crackers running out of the room. Whatever your reason, rest assured: Cracking your knuckles actually *is* all it's cracked up to be.

As long as it's done correctly, knuckle cracking is safe!





January & February 2024 Yearly Anniversaries

Sammie Buchanan, John Duncanson, Lou O'Hanlon, Vernon Emken



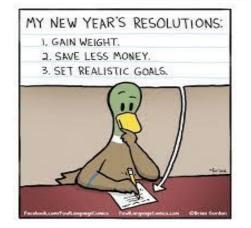
Meetings: 7- 8 pm First Thursday of the month Meetings are combined in Person & Virtual

> March 7 April 4 May 2 June 6 No July meeting

Join Zoom Meeting (click on live link) Meeting ID: 886 3266 6521 Passcode: Welcome!

*Must download the <u>Zoom App</u> prior to joining the link







Are you in need of donated supplies?

Please contact Carol Laubach, (512-339-6388) and indicate what type of ostomy you have, brand preference, size, and whether it's a one or two piece. This will help to get you the best fitting supplies possible.

We are a health support group, a non-profit, tax-exempt 501(c)(3), organization of volunteers whose purpose is to provide mutual aid and education to persons who have ostomies and their families. Membership fees and donations are tax deductible.

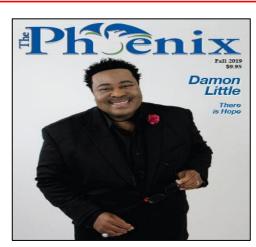
The information contained within our newsletters is for informational purposes only and may not be applicable to everyone. Please do not follow any medical advice in our Newsletter without first checking with your physician or Wound Ostomy Continence Nurse.

Name Ostomy Type			
Address			
City	State	Zip	Phone
Year of Birth	Email		
Spouse/Relative/Partner/Frier	nd Name		
Annual Dues: 625 Ostomate			
	/Dartnor/Erion	d/Other	
\$15 Spouse/Relative			
\$15 Spouse/Relative \$25 Professional			Membership benefits include:
· •			 Membership benefits include: Monthly support & informational meetings Social events The Austi-Mate Bi-Monthly Newsletters

Problem-Solving Clinic is Open

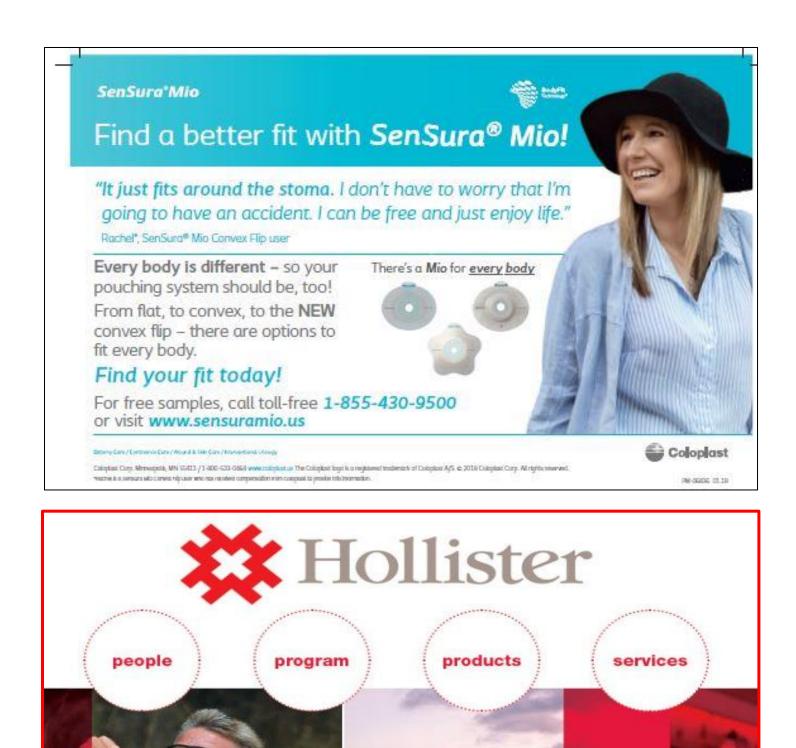
The Ostomy Problem Solving Clinic is open on the first Thursday of the month at the Gethsemane Lutheran Church from 1-4 pm

- Text or call Karen Hollis, RN, CWON, at 512-785-7448
- Text/leave your name, number, type of ostomy and problem.
- Karen will contact you



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Toll-free 800-750-9311.



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