



The Austi-Mate Journal

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

www.austinstomy.org

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**We are cancelling monthly meetings until further notice.
Stay safe, stay healthy, and stay home!!**

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This Bi-monthly newsletter is
available online at

www.austinstomy.org

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.



Our Non-profit participated in Austin's "We Live Here ~ We Give Here" during the month of March. We collected a total of \$1600 from donors like you. We thank you!

Here are a few inspirational thoughts as we experience a new "normal" to stay safe and healthy.

"What lies behind us and what lies ahead of us are tiny matters compared to what lies within us." Ralph Waldo Emerson

"These difficult times are giving us the opportunity to look inward, reflect on what truly matters, and connect with ourselves and our loved ones on a deeper level." Sun Tsu



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Have you paid your dues?

The Ins & Outs of Continent Diversions for the Bladder: What You need to Know

By UOAA Advocacy Committee Members: Joanna Burgess-Stocks BSN, RN, CWOCN, Anita Prinz RN, MSN, CWOCN

Why does one have their bladder removed?

The most common reason for removal of the bladder (radical cystectomy) is due to bladder cancer. Less common reasons are due to gynecological cancers of the vagina and uterus and rectal cancers. These cancers may invade the bladder. Indications for bladder removal not related to cancer include bladder dysfunction due to a neurological impairment, radiation cystitis, interstitial cystitis or some kind of trauma that has occurred. Whatever the reason for bladder removal, it takes consultation with a surgeon to determine the most effective bladder diversion and one that will result in the best quality of life. This article focuses on continent urinary diversion types.

To pouch or not to pouch?

Patients facing radical cystectomy may be presented with several surgical options; urostomy (ileal conduit), a continent pouch, or orthotopic neobladder. Many candidates naturally want an option that does not require wearing an ostomy pouch. However, continent diversion surgery needs to be thoughtfully and seriously considered as these surgeries are extensive and have possible complications including incontinence.



Continent Urinary Diversion Types:

With a continent urinary diversion one has **control** over when the bladder is emptied versus a urostomy (ileal conduit) where one does not have control and urine output must be contained in a pouching system. Individuals with continent diversions will either catheterize a continent pouch several times a day or they will learn to urinate through the urethra. These surgeries are typically done at large teaching hospitals which for many, may be located quite a distance from where they live. This should be considered, as regular post-operative visits are necessary.

The continent pouch is a surgical procedure in which a “reservoir” is created by opening up loops of bowel (small or large intestines) and sewing them back together to create an internal pouch or pseudo-bladder. This is now where urine is stored in the body. The urine is drained on a regular basis through a stoma (intestinal channel) located on the abdomen and connected to the reservoir. The stoma is continent (does not leak urine) because it is created with a valve already located in the body (the ileocecal valve) or a valve is created surgically. The valve is placed between the internal reservoir and the stoma. The valve stops urine from exiting the body until a catheter is inserted. These diversions do not require the use of an ostomy pouch but are managed with a stoma cover (foam dressing) or a piece of gauze for protection. Emptying the bladder is done by inserting a catheter into the stoma. Manual dexterity is a must for learning this technique. Catheters, water-soluble lubricant, and stoma covers will be your needed supplies. Catheters can be cleaned and reused. Over the first year of surgery the capacity of the continent pouch will increase from 300 to 500 mls. Thus, the time between each catheterization will increase until a frequency of every 4-6 hours is achieved.

The Indiana, Modified Kock Pouch, Mitranoff, Miami and Mainz are types of surgical procedures to create a continent pouch. The choice of which one to use is based on the surgeon’s assessment of which one will be most appropriate for the individual. Want to know what it’s like having an Indiana Pouch? Watch this YouTube [video](#).

Specific Considerations in choosing a continent pouch:

- Frequent self-catheterization
- Occasional irrigation to cleanse the pouch of mucous
- Sufficient manual dexterity
- Acceptance of the appearance of a stoma
- Evaluation and preoperative stoma site marking by a WOC nurse is important in preparing for this surgery.

The orthotopic neobladder, a bladder substitute, is created from the small intestines much like the continent pouch. With this technique, a reservoir or pouch is created to hold urine which is then connected to the urethra to allow urination in the usual manner. The individual will sit to urinate and must learn to relax the urethral sphincter and bear down and/or press on their belly to empty all the urine. It is recommended that neobladder candidates should have their pelvic floor muscles' (PFM) strength, tone, and endurance evaluated prior to surgery. Learning how to do pelvic muscle exercises before surgery is helpful and will need to be continued after the catheter has been removed following surgery. Achieving continence will take consistent daily practice with timed toileting and strengthening the pelvic floor muscles. People who undergo surgery for a neobladder must be aware of the potential for both daytime and nighttime incontinence and urinary retention. However, this will improve but it may take up to one year. Current studies show vast ranges in complete continence after one year from 22-63%¹. Patients need to be educated regarding regular toileting and use of continence aids to manage this potential problem. Another consideration is that individuals will need to learn self-catheterization as periodic irrigation with a catheter will be required to remove mucous that can build up in the bladder and may be needed to help with urinary retention. When considering surgery for a neobladder, one must be open and honest with both self and the surgeon concerning your feelings of caring for a neobladder and the potential problems of incontinence and urinary retention. Additional neobladder facts are [here](#).

Specific Considerations when choosing a neobladder:

- Must be able to adjust to scheduled voiding every 2-3 hours
- Must be able to perform self-catheterization as needed to drain urine or mucous.

Special Considerations with Continent Diversions

A continent diversion does not have muscles to expand or contract like a natural bladder, nor does it have nerve endings to alert you when it is full. These changes require the individual bear down and press on their belly to aid in emptying it and/or insert a catheter into the stoma or the urethra. Individuals must become very in-tune with their bodies as to when it is time to empty. In the beginning, most individuals must rely on alarms to remind them to empty their new bladder. After a period of time, many state that they get a "sense" that they need to empty. Individuals with continent urinary diversions have an increased risk for many complications, the most common being urinary tract infections. Metabolic problems can also occur as the "new" bladder absorbs urine byproducts such as ammonium, hydrogen and chloride. Other complications include pouchitis (inflammation of the pouch), pouch rupture, kidney infections, stomal stenosis (when the diameter of the stoma at the skin level narrows or constricts), urethral strictures, bladder stones, and B12 deficiency. The prostate is most always removed in radical cystectomy procedures making sexual performance a concern in men. Women may also experience painful intercourse. One of the most difficult and emotionally challenging complications of these surgeries is the development of incontinence (urine leakage; the inability to control urine). This can happen either from the stoma or urethra. Those with continent pouch diversions can wear an ostomy pouch to contain the leakage. Those with neobladders may need to catheterize themselves on a regular basis or wear incontinence garments. Treatments vary and surgical interventions may be necessary.

Why would continent urinary diversion surgery not be considered?

Continent diversion surgery requires a patient to have a healthy bowel. They are also surgically challenging to create making it a lengthy OR procedure. The following are reasons why a surgeon may not consider continent diversion surgery:

- The intestine is diseased (i.e., inflammatory bowel disease)
- Past history of multiple bowel surgeries
- Overall general poor health
- Treatment with pelvic radiation therapy
- There is disease of the bladder neck and/or urethra (in cases of cancer for neobladder)
- Poor working urinary sphincter (for neobladder)
- Liver dysfunction
- Kidney disease
- Poor manual dexterity
- Poor motivation to care for self

In Conclusion

Those who choose continent diversion surgery can lead a happy and successful life without the need of wearing a pouching system. However, one must be counseled prior to surgery of the work that goes along with daily life in managing the diversion and the possible complications that may result. Individuals should wear a Medic Alert bracelet at all times in the event of an emergency to alert caregivers. Support is imperative to adapt to a new body, and new life, physically and emotionally. UOAA is here for you. Check out our helpful continent urostomy [guide](#).

I Just Need a Moment ~ Taking a Break from The Expectations of Ostomy Life

By Tricia Hottenstein

The problem with being strong is that people expect you to always be strong. When your body has been put through so much, people expect it to willingly fight through anything. After life hands you a few too many lemons, you're expected to just make an extra-large lemonade. The problem is, sometimes I can't be strong. Sometimes I just don't want to be.

When I get a new diagnosis or the old one flares up, I don't always react with immediate strength. When I wake up to a leak or suffer through an obstruction, I don't always react with immediate strength. When I need to call off work or cancel with friends and feel like I'm letting people down, I don't always react with immediate strength. And sometimes, my lack of strength is why I need to cancel. Because it is damn exhausting sometimes. Dealing with life, dealing with an ostomy. Dealing with doctors and tests and medicine. With random pain or nausea. With what seems like a constant cycle of bad news after the last bad news. Dealing with an independent and stubborn 5-year-old when I'm not at my best. It's exhausting.

And I just don't want to be strong. I want to slump down in my seat and sob. I want to be needy, and helped. Most of the time, I feel like the benefit to this life is that it made me a better person, a better friend. I can support someone through their hard moments because I've been through enough of my own. I may not be the most compassionate person in the world, but I will be there. For even an acquaintance. I will help anyone I can, however, I can. But the downfall is that sometimes I want to be the person on the other end. I give my strength to so many other people, yet for the most part, I feel I rely mostly on my own. And most of the time, I am strong enough for that to be possible.

Although I always think I've had this strength, having an ostomy made it necessary to rely on myself. By the time I had the surgery, I learned what I could and couldn't eat. I had to self-navigate my triggers and try to make sense out of them. Oftentimes, I needed to coordinate doctors with specialists and be competent enough to fill in the blanks of my medical history. Mainly, I just had to deal. With the embarrassment, the unpredictability, and the often crippling pain. And then I had surgery, and had to be strong all over again. I had to relearn what I could and couldn't eat and figure out all the tricks for keeping my ostomy happy. The learning curve was a tough one. Sure, there are [support groups](#). But this is also an individual journey and I needed to be self-sufficient and strong.

But mid-meltdown? I am not. I want to be weak. I need to take a moment to feel sorry for myself. I do not want to hear about how I can beat anything because my body has already tackled everything else. I need to cry and process all the thoughts swirling in my head. I need to feel frustrated at the nonstop barrage of crap being thrown at me. I need to let my shoulders fall and my eyes sink. I need someone to be there for me the way I hope I would be there for them. I just need a moment. Because honestly, I AM strong. And I am damn proud of it. I try to be positive and handle things with composure and as much grace as my body (and personality) can put forth. And once I stop feeling sorry for myself, I will stand up and shake off and go forward and tackle everything on my plate with a vengeance. I just need a moment...

Borders:

All Ostomy types

Colostomy-related

Ileostomy-related

Urostomy related

CORONAVIRUS EFFECTS ON THE OSTOMY COMMUNITY

UOAA ARTICLE, MARCH 2020



The ostomy community is understandably very concerned about how the COVID-19 outbreak is affecting their daily lives, health, support networks, and access to ostomy supplies. In this time of great uncertainty, UOAA recommends all individuals consult with their own primary care physicians with questions concerning their risk factor or if they exhibit any symptoms. Please follow the [Center for Disease Control](#) (CDC) website for actual up to date information.

We recognize that many people living with an ostomy or continent diversion are older people and those with chronic disease and are therefore at higher risk of developing serious illness. Please also see [CDC guidelines for people at risk](#).

UOAA is also hearing from many [Affiliated Support Groups](#) who have prudently decided to cancel their upcoming meetings. Members should expect that their meetings will be canceled for the foreseeable future. Affiliated Support Groups are each independently run and members should [contact their local leaders](#) if they have any questions about their meetings. [Community guidelines](#) are also available from the CDC to assist leaders in deciding steps they should take to address public health concerns.

UOAA reached out to the major ostomy manufacturers to see if the outbreak is currently impacting their production or supply chain. As of March 4, 2020 none of the manufacturers reported any issues in their operations as a result of the COVID-19 outbreak. Read our previous [blog post](#) for statements from individual manufacturers on this topic. Check with your distributor to see if there are any shipping delays due to increased demand of all goods at this time.

If you develop a fever, cough and have difficulty breathing always contact your healthcare provider. They will determine if you are a candidate for a COVID-19 test. Medicare and private insurance should [cover a test to see if you have coronavirus](#) if requested from a physician. Additionally, Medicare is offering [telemedicine options](#) so people can stay home as much as possible during this crisis. Contact your private insurer to discover any additional benefits they may be offering at this time. For [frequently asked questions](#) and facts about this virus follow updates from the [CDC](#) on the latest COVID-19 guidelines.



CORONAVIRUS

WHAT YOU NEED TO KNOW

A large family of viruses that cause not only the common cold but also cause a more serious and fatal respiratory illnesses.

Coronaviruses are a large family of viruses found in both animals and humans. Some infect people and are known to cause illness ranging from the common cold to more severe diseases. Corona virus (2019-nCoV) was identified in December 2019 to cause pneumonia in a cluster of people in Wuhan China. The infection has subsequently spread to other countries in the world.

HOW DOES IT SPREAD

Coronavirus spread the same way other cold-causing viruses do:

- + through contaminated people coughing and sneezing
- + by touching an infected person's hands or face
- + by touching things such as door handles that infected people have touched
- + saliva droplets getting into eyes

WHAT ARE THE SYMPTOMS

Symptoms may include:

- + History of fever
- + Coughing
- + Difficulty breathing
- + A general feeling of being unwell

+ Human coronaviruses can sometimes cause lower-respiratory tract illnesses, such as pneumonia or bronchitis

+ This is more common in people with cardiopulmonary disease, people with weakened immune systems, infants, and older adults

PREVENTION

- + Wash your hands frequently
- + Practice respiratory hygiene
- + Maintain social distancing
- + Avoid touching eyes, nose and mouth
- + If you have fever, cough and difficulty breathing, seek medical care early

TREATMENT

- + Can be fatal in severe cases
- + No vaccines or antiviral drugs
- + Symptoms, maybe treated like the common cold
- + Drink plenty of fluids
- + If you are concerned about your symptoms, you should see your healthcare provider



Yearly Anniversaries: May & June 2020

Sadie Faught, 31 and Linda Schmeltekopf, 60

Problem-Solving Clinic **CLOSED**

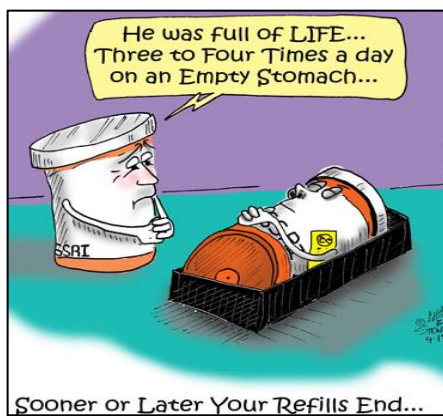
The Ostomy Problem Solving Clinic is closed for face to face meetings until further notice.

In the meantime, if you have questions:

- Text Karen Hollis, RN, CWON, at **512-785-7448**
- Text your name, number, type of ostomy and problem.
- Karen will call you back as soon as possible.

Thursday Meetings

May 7
June 4
No July Mtg
August 6
September 3
October 1
November 5
December 3



Are you in need of donated supplies? We have **plenty** available!

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.**

OAA Membership Application

Name _____
Ostomy Type _____ Surgery Date _____
Address _____
City _____ State _____ Zip _____ Phone _____
Year of Birth _____ Email _____
Spouse/Relative/Partner/Friend Name _____

I do ____ I do not ____ give permission for my name to be included in our newsletter or membership directory.

Signature

Date

Annual Dues:

\$25 _____ Ostomate

\$15 _____ Spouse/Relative/Partner/Friend/Other

\$25 _____ Professional

Mail Application to:

Ostomy Association of Austin
P.O. Box 143383
Austin, TX 78714

Newsletter Preference: Check one

_____ Printed version via US mail

_____ Email notification/download to your computer via website www.austinstomy.org

Membership benefits include:

- Monthly support & informational meetings
- Social events
- The Austi-Mate Bi-Monthly Newsletters



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1-800-866-3002

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