



The Austi-Mate Journal

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

www.austinostomy.org

NEW MEETING ADDRESS!

Assension Seton Northwest Hospital
11113 Research Blvd, Austin, Texas
Classroom A & B on the 3rd Floor

Upcoming 7-8 pm In-Person & Virtual Meetings:
August 7 - September 4 - October 2 - November 6 - December 4

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REGARDING THE NEW LOCATION

Seton Northwest is being renovated. As work goes on, the entrance will be through the Emergency Room rather than the original main entrance.

OAA Local Problem Solving

Text or call Karen Hollis, Retired RN, CWON
 512-785-7448

Please include your name, phone number, type of ostomy, and a brief description of the problem. Karen will contact you.

Contact Us

Email: info@austinostomy.org



Can't join us in person? See page 7 for instructions on logging in to our meetings via Zoom

This Quarterly newsletter is available online at:

www.austinostomy.org

Sad News for Our Group



Long time member of the Austin Ostomy Group, Dorothy Lillard De La Garza, passed away on June 1st of this year. It was a shock to us all given that just the previous week she participated in the Walk to End Bladder Cancer: May 17, 2025 here in Austin. From Dorothy: *"Your generosity to the Bladder Cancer Advocacy Network resulted in our ATX Bag Lady team being recognized as the top fundraiser, raising \$8,375. Thank you for caring. You also helped celebrate my eight cancer-clear years. Our Austin Walk's overall goal of \$20,000 was far exceeded with \$31,637.48 donated so far."*

Here are some excerpts from her obituary: Professionally, Dorothy was a Dallas Morning News reporter with White House credentials; public relations writer for Rice University; insightful Texas political party communicator; trusted senior

staff aide to U.S. Senator John Tower; personal assistant to Dallas Mayor Starke Taylor; speech writer at UT Southwestern Medical School in Dallas and news interpreter for the school's Nobel Prize laureate researchers; and finally, a beloved and respected middle school English teacher for 25 combined years at The Episcopal School of Dallas and St. Andrew's Episcopal School in Austin. Her students, and also her children and grandchildren, found that she would correct, rather directly, their spoken grammar mistakes. She always addressed her students as "Miss" and "Mr." followed by their last name. "Respect" was her mantra and Shakespeare her unique teaching tool. She enjoyed outdoor adventure travels and archaeological trips with her students.

While living in Dallas, she and John were active at Holy Trinity Catholic Church, where she was the first female lector and taught Sunday School. She fully supported John's journey to his 2000 ordination as a permanent deacon.

Dorothy played women's soccer with abandon on the Mudcats and Ruffians teams, earning two eyebrow cuts while contesting headers. She competed in women's softball and was a vicious Scrabble player, endearing the game to her grandchildren and students.

A survivor of bladder cancer in her 70s, she became active with the Bladder Cancer Advocacy Network, mentoring newly diagnosed patients across several states and organizing Austin's first Walk to Cure Bladder Cancer in 2023.

Dorothy leaves her husband, John; children Frances (Robin) Thompson of Austin, John III (Kathy) of Richardson, Susanna Brown (partner Bill Douglas) of Ann Arbor, and Katharine (fiancé Mark Chuberka) of Austin; grandchildren Davison Thompson of Nashville, Dorothy Thompson of Boston, Jamison and Parker Brown of Ann Arbor, and Gabriela and John Robert de la Garza of Richardson; and brothers George (Diane) Lillard of Burnet and Tom (Melanie) Lillard of Dallas.

For her complete obituary, go to <https://www.statesman.com/obituaries/paco1200591>

Difficulties You Might Experience After Hospital Discharge

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
7. 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.



The Phoenix magazine is the official publication of the United Ostomy Associations of America. The Phoenix magazine is published quarterly.

<https://phoenixuoaa.org/>

Toll-free 800-750-9311.

Peace of Mind in a Piece of Jewelry

By Ellyn Mantell with Jeanine Gleba UOAA Advocacy Manager

It's a fact; ostomies and continent diversions save lives. Most people are very private about having a fecal or urinary diversion and only share information with people to whom they are most close. Living with a diversion is often considered an "invisible disability". The concern is, what would happen with these individuals if they were in an accident, unconscious or unable to speak for themselves? They would be unable to notify an emergency responder of the unique needs of the diversion. For example, a Kock pouch is an internal pouch/reservoir that has a stoma that needs to be catheterized throughout the day to empty it. If an emergency responder were not aware of this need, it could result in over filling of the reservoir and damage to the reservoir.

There is a simple non-verbal way of communicating health issues and medical conditions in emergencies that deserves attention and should be considered. According to the Centers for Disease and Control Prevention (CDC), for personal health preparedness "help others help you" by wearing a medical alert ID bracelet or necklace engraved with important information for emergency responders and healthcare providers. By wearing a form of medical identification people living with an ostomy or continent diversion can effectively advocate for their health and safety protection when they are unable to speak up for themselves. It provides peace of mind should the worst- case scenario happen.

A real life example shared with UOAA may explain the efficacy of saving time in an emergency situation. An ileostomate was crossing the street and hit by a car. He was not terribly injured, but the force of hitting the ground caused his pouch to explode, causing the first responders to assume his abdomen had been perforated. They spent valuable time cutting clothing to find the cause of the seepage, an unnecessary waste of what could have been life-saving time. Had this gentleman been wearing a medical alert bracelet or dog tag necklace, he would have been assessed differently, and certainly more quickly.

Wearing a medical alert ID is far more effective than carrying a card in one's wallet or handbag, or counting on another person to provide imperative information. If there is an accident or incident, one may be thrown from a car, their wallet lost or removed, or one may be separated from a person who can advocate for us. Additionally, a family member or friend may also be incapacitated in some way, or in shock, unable to provide this lifesaving information.

It is suggested by paramedics that a medical alert bracelet be worn on the left wrist, since that is where they reach first for a pulse. A medical icon in red is an attention-grabber, but whatever form of ID you choose be sure it includes the [universal medical alert symbol](#). Include as much information as possible and be specific. If there are medical instructions, spell them out. A sample inscription might say: Continent Urostomy Catheterize every 4-6 hours with a 1 4Fr. Catheter.

If there are other medical conditions, state them for EMT's, as well. Include such life-threatening information as cardiac stents, aortic stenosis, diabetes, allergies etc. This is no time to be vague. Include a cell phone number of a family member if there is room, and DO NOT FORGET TO ADD YOUR NAME TO THE FIRST LINE!

The most notable and recognized medical alert IDs are from the companies [Medic Alert Foundation](#) and [American Medical ID](#). These companies can also keep on record more specific details of your medical history and current care with QR codes and ID cards in addition to the wearable ID. For those who simply don't like the look and style of the standard medical alert bracelet there are many more [fashionable forms](#) of ID. Other medical alert jewelry may be

found on websites such as [Lauren's Hope](#), and [Meridian Medical/Ostomy Supply Company](#) sells a specific bracelet for ostomies. Although first responders tend to look for medical alert bracelets, for those who don't want to wear jewelry, there are other types of IDs available including: Apple Watch slides, dog tags, and cell phone tags. Your ostomy nurse, primary care physician's office and most pharmacies can also provide guidance.

Some people may be uncomfortable wearing something that tells others they have an ostomy or continent diversion. Don't let stigma stop you from being emergency-prepared! Consider if you would wear medical alert identification if you had life-threatening allergies. When it comes to one's health, it should never be associated with shame.

Ostomies and medical alert IDs go hand in hand saving lives.

*Disclaimer: UOAA does not endorse particular products, manufacturers, or suppliers.



OAA Membership Application

Name _____

Ostomy Type _____ Surgery Date _____

Address _____

City _____ State _____ Zip _____ Phone _____

Year of Birth _____ Email _____

Spouse/Relative/Partner/Friend Name _____

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

Signature _____ Date _____

Annual dues: Checks payable to: Ostomy Association of Austin

\$25 Ostomate

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

\$25 Professional

Quarterly newsletters are located on our website: www.austinostomy.org

Prefer a paper copy be mailed, check here

Membership benefits include:

- Monthly support/informational meetings
- Social events
- The Austi-Mate Journal quarterly newsletter

Mail Application to:

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

Affiliated with....



EMOTIONAL SUPPORT:

A Crucial Component of Quality Care for Ostomy and Continent Diversion Patients

United Ostomy Associations of America, Inc. (UOAA) is committed to providing resources to those who are in need of emotional support as well as promoting recommended standards of care across the nation that is supportive of both the physical and emotional well-being of people living with an ostomy or continent diversion.



Important research findings¹ show evidence that a high percentage of patients **did not** receive these recommended standards of care as outlined within the Ostomy and Continent Diversion Patient Bill of Rights.²

When asked what patients struggled with most following discharge from their ostomy or continent diversion surgery, a survey of 412 respondents revealed "lack of emotional support/depression" to be in the **top 3** most commonly reported answers.

60%

Did not receive resources to organizations who support and advocate for patients living with an ostomy or continent diversion

68%

Did not receive information about support groups

70%

Were not provided the opportunity to talk with someone who has been through ostomy or continent diversion surgery

78%

Were not provided the opportunity to discuss the emotional impact of surgery

"It would have been great to speak to someone who had the surgery and was living with the ostomy."



"We had to search out an ostomy nurse, our hospital only had one at the time of surgery. They hold classes for knee replacements, diabetes, etc. but nothing for a urostomy."



"I'm still shocked at how we felt so alone and abandoned after we left the hospital."



"It really is crucial to join a support group and see a psychologist."

These quotes were taken directly from survey respondents.¹

DO YOU OR SOMEONE YOU KNOW NEED EMOTIONAL SUPPORT?

UOAA has 300 Affiliated Support Groups (some with visitor programs), a mental health provider finder, ostomy nurse finder, and an online discussion board.

FOR MORE INFORMATION PLEASE VISIT WWW.OSTOMY.ORG OR CALL 800-826-0826

412 respondents were surveyed in 2019 in a national survey performed by the United Ostomy Associations of America, Inc. for a research project under the auspice of the University of Oklahoma with research team members Leslie Raggio Miller, PhD, B. Mitchell Peck, PhD, Joanna Burgess-Stocks, BSN, RN, CWOCN, Jeanne Gleba, MEd
*To view all of the best in practice standards of care recommended in UOAA's Ostomy and Continent Diversion Patient Bill of Rights and the White Paper validating the standards of care, please visit <https://www.ostomy.org/bill-of-rights/>



ZOOM INSTRUCTIONS FOR ONLINE MEETINGS

Meeting ID: 886 3266 6521

Passcode: Welcome!

The Zoom web browser client should download automatically when you start or join your first Zoom meeting.

However, if that fails, or you want to download Zoom ahead of the meeting, you can do so manually.

Go to <https://zoom.us/download>

- Click "Download" under the "Zoom Workplace desktop app" heading.
- Once downloaded, click on "Open file" in the popup window in the upper right.
- You can then click on the open meeting link.

SenSura Mio

Find a better fit with SenSura® Mio!

"It just fits around the stoma. I don't have to worry that I'm going to have an accident. I can be free and just enjoy life."

Rachel®, SenSura® Mio Convex Flip user

Every body is different – so your pouching system should be, too! From flat, to convex, to the NEW convex flip – there are options to fit every body.

Find your fit today!

For free samples, call toll-free **1-855-430-9500** or visit www.sensuramio.us

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Hollister

people

program

products

services



Heinrich Köberle, Germany



Jonathan Mendez, USA

Mission

Through monthly meetings, newsletters and our website, the Ostomy Association of Austin provides non-medical pre/post-surgery management, support, guidance, education and advice for people with or expecting ostomy surgery. We provide access to WOC nurses, speakers, and the opportunity to learn from our fellow ostomates.

Vision

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.



We are a non-profit, tax-exempt 501(c)(3), health support 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.**

It's Summer, stay hydrated!