



The Roadrunner



Newsletter of the
Ostomy Association of Albuquerque, NM

Next Meeting

Sunday, August 5, 2018

1 PM

Executive Board Meeting, Aspen Room (Open to All)

2 PM

Support Group Meeting, Aspen Room

Support Group Updates and Events

Recap of last quarter: In May, nurse Barbara gave an in-depth lecture on the anatomy and physiology of the Small Intestine and how it is affected by nutritional shortfalls, overgrowth of bad bacteria, food allergies and diseases such as celiac disease.

In June, we had a very informative presentation and Q & A session with TSA officers who are in the frontline every day to keep us safe in airline travel. We all agreed it was very worthwhile.

In July, nurse Sue presented updated ostomy information from the Wound, Ostomy, and Continence Nurse (WOCN) conference. She focused on legislative advocacy efforts to provide best products for ostomy clients. She showed some of the new and interesting ostomy products.

***Please mark your calendar.**

August 5, Normal Support Group Meeting

September 2, Normal Support Group Meeting

October 7, New Coloplast Representative for our area, Shannon Pierce, will show new products and answer questions.

As always, be alert to emails, calls, or announcements at meetings concerning changes or upcoming guest speakers.

Volume 52 Issue 3

August 2018

Upcoming Meetings:

- August 5, 2018 (quarterly)
- September 2, 2018
- October 7, 2018
- November 4, 2018 (quarterly)

Meetings are at 2 PM

in Aspen room

at Kaseman Hospital unless otherwise stated.

Inside this issue:

"Dementia Stoma Care" 2

"cont. from page 1" 3

"Fashionable Living" 4

"Ostomy Reversals" 5

"5 Foods to Eat If" 6

Resources 7

Membership Forms 8

All About OAA 9

Contact Us 10

Dementia Stoma Care by R.S. Elvey; via UOAA Articles to Share, June 2018 and UOAA Blog Post

Caring for an ostomy can often be a frustrating and challenging experience at any age. But combine advanced age and dementia and it becomes even more of a challenge for caregivers and loved ones. According to the Population Reference Bureau, the number of Americans 65 and older will gradually increase from 15% of our population to 24% by 2050. With this growth has come a rise in existing and new ostomies combined with Alzheimer's or other dementias. The Alzheimer's Association of America (www.alz.org) reports in their 2017 Alzheimer's Disease Facts and Figures report, "Of the estimated 5.5 million Americans with Alzheimer's dementia in 2017, 5.3 million are age 65 and older." The association predicts a half a million new cases of Alzheimer's dementia will develop annually.

This explosive growth in new cases of dementia is putting an enormous strain on family caregivers. The Family Caregiver Alliance (www.caregiver.org) estimates, "44 million Americans age 18 and older provide unpaid assistance and support to older people and adults with disabilities who live in the community." These caregivers often have little or no preparation or support in providing care for people with disabilities such as stoma care. They become frustrated and worn out. In an online forum, an anonymous writer expressed her frustration about caring for her mother's stoma as follows, "I am TIRED of it. I need someone to take over dealing with an ostomy and ordering the correct supplies for her, etc... And I am just going to make whatever decisions seem right regarding her bladder care, as I find out more info. I really wanted to yell at her tonight and that makes me feel like a terrible, awful person. I didn't, but I did get a little firm."

Studies have shown that family caregivers who provide care to family members with chronic and disabling conditions are also putting themselves at risk of developing emotional and physical health problems. When seeking stoma care information, caregivers often participate in online chat rooms and forums for anecdotal advice. Additionally, visiting nurses with wound and ostomy training often make home visits and teach ostomy care. But when they leave the caregiver is often faced with ever-changing challenges as their loved one's dementia worsens. Most often they face the challenge of not knowing when a pouch needs to be emptied, appliances being ripped off by their loved one or attempts to empty and change the appliance that miss the mark and require massive cleanups.

Realizing the complexity of stoma care and dementia and the pressure it causes to caregivers, the Colostomy Association of the United Kingdom and the Dementia Association of the United Kingdom combined to issue a twelve-page downloadable leaflet at www.dementiauk.org entitled, "Caring for a person with a stoma and dementia." They readily recognize that not all persons with dementia will profit from learning to care for their stoma. But where it is possible a person should be encouraged to participate in their own stoma maintenance.

The leaflet's content is based on input from health professionals who care for ostomates with dementia and a stoma. A few of the hints and tips included in the publication are:

(Continued on page 3)



Continued from page 1

(Continued from page 2)

- “People with dementia who are actively involved in changing their bags should be encouraged to wear gloves. This reduces the risk of infection, feces under the nails and fecal spreading.”
- “Some people with dementia who require their bag to be changed for them might resist. In these cases distraction could help. For instance, encouraging the person to clean their teeth or brush their hair during the process might be helpful. Standing the person in front of a mirror so they can focus on the task they are performing and not the bag change can help.”
- “Bag choice is important. One-piece bags with pre-cut aperture have the advantage of being uncomplicated for both person and caregiver. Two-piece bags, where the flange can remain in situ for up to three days, helps protect the skin where frequent changes are necessary.”

Individual and professional caregivers also provide additional advice based on their experiences. Many staff who work in nursing homes put a plastic bag over the pouch so that in case of any leakage, there won't be a much larger incident. Many persons with Alzheimer's or other dementias either pick or rip off their pouches. To prevent this from happening, many caregivers dress their loved ones in special clothing that has no openings in the front but still gives the appearance of normal clothing. One source for this type of clothing is Buck and Buck. Their online catalogue features adaptive clothing by gender and condition. Lastly, in this Smartphone age there is even an app that might help. 11 Health has created the Alfred Alert

Sensor. The sensor is applied to the pouch at a point where it should be emptied. When that point is reached it connects by Bluetooth wireless technology to the Alfred Alert app on your Smartphone to tell you it is time to empty. The app can also capture patient output volume over a period of time. The data is stored in a HIPAA compliant cloud server where it can be shared by medical professionals and family members.

In the final analysis, caring for a loved one with dementia is a joint effort between the person with dementia, their loved ones, their medical consultants and other professional caregivers.

* * * * *

OAA Roadrunner Newsletter

Membership is \$20.00 a year and includes the Roadrunner newsletter and monthly informative meetings. This money is used for promotional purposes and expenses of the OAA. Although chapter membership is encouraged, anyone with financial hardship, should see the Treasurer or President for help in this matter. No one is denied based on ability to pay.



Fashionable Living With an Ostomy by Ellyn Mantell, Summit NJ Ostomy Support Group; via UOAA Newsletter, April 2018 and UOAA blog post

Our Ostomy Gives Us Power! (Ostomy Visitor talks clothing and embracing life)

As president of our Ostomy Support Group in Summit, New Jersey, I have met many future ostomates over the years since I have had mine, and we have met in various places, depending upon their health, etc. The one that stands out in my mind is a meeting at a shopping mall a few weeks prior to her ostomy, with Carol, a woman who wanted not only to see the stoma for herself but to understand how it would fit into her life. She loves clothes, as do I, and was frightened she would need not only to purchase a new wardrobe but to change her style of dress. The best way to show my stoma to her was to go into a fitting room in a store. We brought in some clothes that were of interest to her, and I proceeded to try them on, demonstrating how my stoma (Lily, as I have named her) would fit neatly and snugly under the clothing. I was reminded that as soon as I had my ostomy four years ago, I gave away all of my belts and fitted pants. I was certain I would never wear them again, despite being told that wasn't true. To the contrary, I saw pictures of great looking women with ostomies online in tight jeans with belted waists. It was just too hard to imagine myself wearing belts and jeans with a pouch, and since these women were not in front of me, I couldn't ask them "how do they manipulate their appliance to be comfortable and secure?" Knowing it would have been invaluable to me to actually see an abdomen in clothing, I wanted Carol to have the proper introduction to dealing with her wardrobe. We laughed as I told her of my quest to replace my jeans and belts over the years – since I have learned I can wear almost anything! In truth, my "go-to" outfit is most

frequently leggings and tunics, dresses and full-legged pants with a tank, covered by cropped tops. I am what is known as "funky and fashion-forward dressing," as I learned when I was the fashion trainer for Macy's years ago, and happily, my style hasn't had to change due to Lily, who requires a high-output pouch that is so long, and I am so short, that it rests on my thigh! Wide-eyed, but a little more able to envision her own "Lily," Carol and I left and grabbed some tea at the nearest Starbucks. We sat and talked about the changes she anticipated and feared, and then she asked me what I really, very truthfully, feel about being an ostomate? Without missing a beat, I very simply said POWERFUL! I told her that as I look around at the many people shopping, I know I have a secret, and that secret is that I am strong, a survivor, and I can help others. Knowing that gives me the most positive feeling, and I am grateful, and want to share it! I have checked on and even visited Carol as she recovered from her surgeries – since there were a few. Sadly, there is no straight line for any of us, and depending upon the reason for the ostomy, recovery can have many twists and turns. My own led me to need to spend weeks in the hospital and then a rehab facility. But she is improving daily and gaining back her strength and determination. I know she will join our support group or another closer to her home. I also know that before too long, she, too, will be accomplishing her goal of like me, being trained to become an Ostomy Visitor...to meet with and help others learn how to cope with their ostomy, and how POWERFUL they truly are, as well!

Ostomy Reversals

by Joanna Burgess-Stocks, BSN, RN, CWOCN; via UOAA Articles to Share, June 2017

- Not everyone who has an ostomy as a result of colorectal cancer and other diseases will have the option of having their ostomy reversed. Some people will need to keep their ostomy for life.

- Your surgeon will determine when an ostomy will be reversed. There are many factors that determine a reversal such as the extent of the disease, a patient's overall health and treatment process (radiation and chemotherapy). Most patients with temporary ostomies will have the ostomy for about 3-6 months.

- Surgery for reversal of an ostomy is usually much less involved than the surgery that you had to create the ostomy. So, if you are feeling nervous, keep that in mind. A typical hospital course is 3-4 days on average.

- For some patients, interrupting bowel function with a temporary ileostomy increases the chances that you will experience alterations in bowel function after reversal of your stoma. These symptoms can include rectal urgency, frequency, fragmentation of stool and incontinence. It is important that you notify your surgeon as soon as possible with these symptoms. Treatment includes behavioral strategies based on the symptoms and includes dietary modifications, incontinence products, skin care (use of barrier creams such as zinc oxide) and medications such as loperamide. More involved but helpful recommendations are pelvic muscle retraining (PMR) to regain sphincter strength and biofeedback. This therapy is done by a highly trained physical therapist.

- If the temporary ostomy is due to cancer some physical therapists recommend PMR prior to surgery or radiation to assess muscles and teach strategies for

ongoing muscle strengthening that can be carried over after surgery. This helps to address any coordination or existing weakness prior to radiation due to chemo or post-operative recovery. If PMR is recommended after surgery, it is best to wait at least 6 weeks and with the surgeon's approval.



5 Foods to Eat If You Have Diarrhea or Chronically Loose Stool via Vancouver (BC) Ostomy HighLife .

- Bananas. Bananas are a great food to eat when you have diarrhea. Bananas are easy to digest, and they are high in potassium which is lost through diarrhea. Bananas are soothing, filling and readily available.

- Rice. Eat plain rice during bouts of diarrhea. Rice is easy on the digestive system. It is also low in fiber and helps slow down the gastrointestinal tract, which is beneficial for cases of diarrhea.

- Applesauce. Incorporate applesauce into your diet when you are suffering with diarrhea. Applesauce contains pectin, a water-soluble fiber, which is known to help reduce diarrhea. Applesauce is also very nutritious, containing an appropriate balance of vitamins and sugar.

- Boiled Eggs. The body loses energy during diarrhea. Eggs provide protein which energizes the body and gives it strength. Avoid fatigue by eating well-cooked eggs during periods of diarrhea.

- Pretzels. Eat salted pretzels while dealing with diarrhea. This will help your body retain water and keep you from becoming dehydrated from your diarrhea. The salted pretzels will also help soothe and settle your stomach.



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Finally an explanation of “Third Party Payer”

A man suffered a heart attack while shopping in a store. The store manager called 911 when he saw him collapse to the floor. The paramedics rushed the man to the nearest hospital where he had emergency open heart bypass surgery. He awakened from the surgery to find himself in the care of nuns at the Catholic Hospital. A nun was seated next to his bed holding a clipboard loaded with several forms, and a pen. She asked him how he was going to pay for his treatment. “Do you have health insurance?” she asked. He replied in a weak raspy voice, “No health insurance.” The nun asked, “Do you have money in the bank?” He replied, “No money in the bank.” “Do you have a relative who could help you with the payments?” asked the irritated nun. He said, “I only have a spinster sister, and she is a nun.” The nun became agitated and announced, “Nuns are not spinsters! Nuns are married to God.” The patient replied, “Perfect. Send the bill to my brother-in-law.”



Medical and Support Group Resources

New Mexico Ostomy Support Groups:

Albuquerque: Ostomy Association of Albuquerque meets monthly in Albuquerque, NM. For current info call voicemail: (505) 830-2135

Email: oa.albuquerque@gmail.com

Albuquerque: VA Ostomy Support Group for military veterans. Meets at the VA Hospital, Albuquerque, NM. For current info call ostomy nurse at VA Medical Hospital voicemail: (505) 265-1711, Ext. 5171

Las Cruces: Ostomy Support Group of Southern NM. Meets in Las Cruces, NM. For current info call ostomy nurse at Memorial Medical Center voicemail: (575) 640-5242 or (575) 521-5038

Other Hospital Contacts in Albuquerque, NM

(not having a support group):

Lovelace Medical Center Ostomy Nurses:

(505) 727-8250

Presbyterian Main Hospital Ostomy Nurses:

(505) 841-1251

Presbyterian Outpatient Wound Care Clinic:

(505) 823-8870

University Medical Center Hospital Ostomy Nurses:

(505) 272 9098



Manufacturer Resources

Coloplast Ostomy Supply Manufacturer:

Local Representative: Shannon Pierce

Phone: 1 (806) 676-4666 Email: usspie@coloplast.com

Coloplast Care Program

1-(877) 858-2656

ConvaTec Ostomy Supply Manufacturer:

Local Representative: Jon Egan

Phone: 970-373-7452 Email: jon.egan@convatec.com

CYMED Ostomy Supply Manufacturer: (Microskin products) Local Representative: none
www.cymedostomy.com 1 (800) 582 0707

For samples: samples@cymedostomy.com

EDGE PARK Medical Supplies:

www.edgepark.com 1-888-394- 5375

Hollister Ostomy Supply Manufacturer:

Local Representative: Position Currently Vacant

Email, will add when new representative is named.

1 (***) ***_****

Cust. Svc: Richard Wysocki 1 (888) 808 7456

Marlen Ostomy Supply Manufacturer: www.marlenmfg.com

1 (216) 292 7060

Nu-Hope Ostomy Supply Manufacturer:

1 (800) 899 5017 www.nu-hope.com

Stomacur Ostomy Supply Manufacturer: www.forlife.info

TORBOT Ostomy Supply Manufacturer: 1 (800) 545 4254
www.torbot.com

Join Our Albuquerque Ostomy Support Group

OSTOMY ASSOCIATION OF ALBUQUERQUE MEMBER APPLICATION

The Ostomy Association of Albuquerque (OAA) is a member of the national American Ostomy Association. This allows us to have access to all the latest ostomy information available for our use. The OAA annual membership fee is \$20.00 and can be paid by check or cash. If being paid by check, make the check payable to Ostomy Assn. Of Albuquerque. Your payment can be mailed to OAA, PO Box 35598, Albuquerque, NM 87176-35598 or at any monthly meeting. If you are financially unable to pay this fee, please call 505-275-2470 and leave a message with your name and telephone number and someone will contact you. Please complete the form below as best as you can and all information will be used for our records and be kept confidential.

NAME: _____ DATE OF BIRTH: _____

STREET ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

E-MAIL: _____ PHONE NUMBER: _____

OCCUPATION (If retired, enter former occupation): _____

HOBBIES: _____

CHECK ALL THAT APPLY:

Colostomy Ileostomy Urinary Diversion Continent Ileostomy Continent Urostomy Pull-Through
 Parent with Child Procedure Spouse/Family Member Physician Nurse Other _____

Year of Surgery: _____ Reason for Surgery: Crohn's Ulcerative Colitis Cancer Birth Defects

I have enclosed an additional \$ _____ as a donation to support the ongoing work of the OAA

**Join United
Ostomy
Association
of America**

**Save the Date
The next UOAA
National Conference
will be held
August 6-10 2019
Philadelphia, PA**



UOAA's Mission

UOAA is an association of affiliated, non-profit, support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.

- It is dedicated to the provision of information, advocacy and service to, and for, its affiliated support groups, their members and the intestinal/urinary diversion community at large.
- It is organized to grow and develop while remaining independent and financially viable.

Membership in UOAA is open to any non-profit ostomy support group that meets UOAA's affiliation requirements. UOAA has an IRS Group 501(c)(3) charity status that its affiliated support groups can use.

1-800-826-0826

Website: www.ostomy.org

Get Ostomy Answers!

The Phoenix is the leading national magazine for ostomates, their families and caregivers. Subscriptions directly fund the nonprofit United Ostomy Assoc. of America – the only national organization providing vital information, resources, support and advocacy for ostomates.

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Officers and Chairpersons of OAA Chapter

President: Brian Leen

505-856-0203

Vice President: Ben Palmer

505-828-0936

Treasurer: Barbara Regan

703-261-3920

Secretary: Mark Walker

505-242-2173

Voicemail and Visitation Coordinator:

Brian Leen, 505-856-0203

Telephone Reminder:

Gerry Copeland: 505-856-6045

Ostomy Supply Closet:

(donations & supplies)

Eunice Hoeft

Call ahead; 505-889-9705

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About Us

Ostomy Association of Albuquerque (OAA) is organized to support people with ostomies and their caregivers in the New Mexico region. OAA publishes *The Roadrunner* newsletter quarterly to inform and update its members.

Membership is \$20.00 a year and includes the Roadrunner newsletter and monthly informative meetings. This money is used for promotional purposes and expenses of the OAA. Although chapter membership is encouraged, anyone with financial hardship, should see the Treasurer or President for help in this matter. No one is denied based on ability to pay.

Meetings are monthly at 2:00 PM in the Aspen Conference Room at Presbyterian Kaseman Hospital. Meetings are usually held on the first Sunday of every month. Since there are occasional changes due to holidays, please

refer to *The Roadrunner* for information or call the association's voicemail.

Executive Board Meetings are held at 1 PM prior to the Quarterly meetings (Feb, May, Aug, and Nov.) in the Aspen Room. Everyone is welcome to attend and participate.

Directions: Address: Kaseman Hospital, 8300 Constitution Pl., NE; Albuquerque, NM. Kaseman Hospital is one block North of I-40 and Wyoming Blvd. Then it is about one block West of Wyoming on Constitution. Drive to West end of parking lot and enter the Emergency Room entrance. Take an immediate left, go through double doors and find Aspen room on the right side.

Affiliation: Ostomy Association of Albuquerque (OAA) functions as a chapter affiliate of the national organization supporting people with

ostomies-- the United Ostomy Association of America (UOAA).

The UOAA holds biennial national conferences. They publish the wonderfully informative *Phoenix* magazine four times a year. There is a subscription cost for this publication. They have a great website with all kinds of information available for free. Much of it is available in any language on earth!

Contact Information:

United Ostomy Association of America
P.O. Box 525

Kennebunk, ME 04043-0525

1-800-826-0826

Web: www.ostomy.org

Find them on Facebook and Twitter.

Postmaster: Contains Dated Material.
Please do not delay.

P.O. Box 35598
Albuquerque, NM 87176

Ostomy Association of Albuquerque



Helping each other to live well and do the things we love!

How to Keep in Touch with Us

Contact us: For info please call voicemail 505-830-2135 or Email us at oa.albuquerque@gmail.com

Unsubscribe or Change to Mailing Address or Email: For any of these changes, please notify the sender by return Email. If your change concerns mailed copies, please call person in charge of mailing or send back cover page with your address and changes requested to return address. Thank You.

Supplies: If you have new and unused supplies you no longer need, please bring them to a support group meeting to be given to those who need them.

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