



LETTER FROM THE EDITOR

If errors are noted in your name or address, please bring these to my attention. If you know of someone to add or delete from our mailing list, please notify me. I can be reached at work, 325-670-4302, or by e-mail, callen@hendrickhealth.org. We are now sending our newsletter electronically to those who request it be sent that way. **Please send me your e-mail address if you would like a link to the newsletter.**

If you know of someone who would be a good speaker at one of our meetings, please contact us.

– Charlotte Allen, MSN, RN-BC, CWOCN



LAST MEETING

We did not meet in July.

NEXT MEETING

Our next support group meeting is August 13. We will have our traditional ice cream social and have a social activity like a game of Jeopardy or Stoma Bingo. Vanilla ice cream will be provided. If you would like another flavor, feel free to bring one. Also, please bring your favorite ice cream topping, cookies or brownies to go with the ice cream.

Everyone is welcome. Bring your spouse or a friend or come alone.

Mark your calendars: We will NOT meet October 8.

We meet in the Diabetes Center at 1742 Hickory St. (corner of Hickory St. and N. 18th St.) at 6:30 p.m. Hope to see you there!

CONTACT US

For more information, please contact us at 670-4302.

Newsletter Editor & Professional Advisor:

Charlotte Allen, RN, CWOCN
670-4302
email: callen@hendrickhealth.org

Ten (New) Commandments for Ostomates

Via: Vancouver Ostomy Highlife & Regina Ostomy News

1. Thou shalt allow thyself to be sad, or angry or depressed on occasion. Who said you always have to have a good attitude.
2. Thou shalt not let the above emotions become a way of life.
3. Thou shalt seek help, education and support if thine unhappy emotions overcome thee.
4. Thou shalt learn to care for thy ostomy. Letting others do it for you if you are physically able is a cop-out.
5. Thou shalt seek out thy ET nurse if thou art notified with thine products.
6. Thou shalt not hide thyself away. Get out and do the things you used to do. You can.
7. Thou shalt not be ashamed.
8. Thou shalt cultivate a sense of humor about thine ostomy. There are worse things. Far worse.
9. Thou shalt set an example to the non-ostomy world. An example of triumph over adversity, courage over pity and pride over embarrassment.
10. Thou shalt help other ostomates. Join your local UOA chapter, donate money and volunteer your time.

New from The Phoenix: Ask Nurse Brown, CWOCN

Showering With an Ostomy

Dear Nurse Brown,
I really enjoy a long, hot shower. The problem is my pouch gets wet and then takes too long to dry. Is there a way to keep my pouch dry in the shower? W.R.

Dear W.R.,
There are many products on the market to cover your pouch, but with a long, hot shower, even the steam will dampen the pouch. Have you tried drying your pouch and wafer using a hair dryer on a cool setting? You can also fold your empty pouch up during the shower and secure it with a clip or large bobby pin. This can limit the amount of the pouch that gets wet and then towel dry or use the hair dryer. Some ostomates that use a two-piece system keep a "shower pouch" that they only use during showers, replacing it with the pouch they were going to wear, and allowing the wet pouch to dry until the next shower. Get more Ostomy Answers in the 88-page Summer issue of The Phoenix, the official publication of UOAA.

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 12-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:

- 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 still try completing my routine left-handed once a week –just in case. Things were going great until the strong antibiotics kicked in and then came diarrhea – an ostomate knows about that clean up!

If You Could Do It Before an Ostomy, You Can Do It After

by Joel Jacobson; via Halifax (NS) Ostomy Gazette

Colleen Burton, an ostomy resource nurse at the QEII, held more than 40 members of the Halifax chapter enthralled with her presentation on the Psychological Aspects of Having an Ostomy.

With a PowerPoint presentation, Colleen described, from soup to nuts, how people deal with ostomy surgery, what one goes through when faced with ostomy surgery, and how they react afterwards. Drawing from her more than 20 years of experience, she spoke of how people deal with the five steps in the grieving process – denial, anger, bargaining, depression and acceptance. She stressed that not all people grieve, that many are so happy to be free of the pain and discomfort of Crohn's or ulcerative colitis, that they are happy to move ahead with their lives. They come to terms immediately, knowing there will be challenges, but ready to face them.

She said many people hear so much during the postoperative period in hospital that they forget half of what they hear. Yet, at home, they become comfortable very quickly and begin to feel good about themselves. "It's so important for people to communicate with those at home," she said. "You, and everyone around you has to be comfortable with your ostomy."

Communication with co-workers is also important so you don't feel embarrassed about anything to do with the ostomy. If your stoma "burps", so be it. You know the pouch can't be seen. Why worry someone will see it? You know there is no odor. Why worry someone might smell something?

"What helps after surgery?" Colleen asked, rhetorically.

"Family or friend support is key. Being treated as 'normal' is vital. And learning self-care (changing the appliance) sooner

Get Ostomy Answers!

Save 38%*

The Leading Source for Information, Education and Inspiration!

Each *Phoenix Ostomy Magazine* answers the many questions about returning to a full and active life after surgery. Topics include diet, exercise, intimacy, skin care, odor control, new products and so much more. Medical doctors and nurses offer concrete advice and solutions while personal stories show that almost anything is possible with an ostomy. - **Subscribe Today!**

Privacy Guarantee: The Phoenix is mailed with discretion. Your contact information will never be given, rented or sold to a third party.

FREE New Patient Guide!

Get real-world answers to common questions after ostomy surgery. Yours free with a subscription.



New Patient Guides are made possible by the UOAA. www.ostomy.org



Choose Your FREE New Patient Guide: Colostomy Ileostomy Urostomy

Please send me FREE ostomy product samples, special offers and product information**

One-year \$29.95 (Save 25%*) Two-years \$49.95 (Save 38%*)



Send Magazine To:

Name _____ Email (opt.) _____
 Address _____ Apt./Suite _____ Phone (opt.) _____
 City _____ State _____ Zip Code _____

Send Payment to: The Phoenix magazine, P.O. Box 3605, Mission Viejo, CA 92690



*Based on cover price of \$9.95. \$39.95 for Canadian one-year subscription. U.S. funds only. **Your contact information will be disclosed to third party companies to fulfill the request. Published March, June, September and December. If you are not satisfied for any reason, we will gladly refund the unused portion of your subscription. ASC0516

Plan Ahead for An Unexpected Change in Your Ostomy Routine

by Janet McNiven, Editor of *The Ostomist*, Seattle WA; via Metro Maryland Ostomy Association

Recently I had an accident that put my right hand out of commission for 12 days. While sitting in the emergency room, I thought not about my injury, but how am I going to change my ostomy wafer and bag left-handed? My right hand was not only unable to be used, but unable to get wet. The way it was bandaged and with a splint, all sorts of images flashed through my brain.

It was very interesting and difficult when I started my new left-handed routine for my colostomy. I wish that I had pre-cut a box of wafers (I cut them myself since my stoma is oval). Wow, would that have helped! My husband said he would help me, and he cut the wafer but I could not even mark it with my right hand, and anyway, I just "cut the wafer" by doing it for over 13 years.

Struggling and frustrated I did manage to cut the wafer with the last three digits of my right hand...not the best; but it was functional.

Taking the wafer off with one hand and not pulling the skin was a challenge, but finally I just dripped the remover on the edge of the wafer and worked the wafer off. Carefully, I placed the new wafer on. I started celebrating – oops, too soon.

I use a two-piece system and trying to attach the bag to the wafer was interesting. I must have checked all around the seal numerous times and usually found an area that had not been attached properly.

Finally on, and my change complete, I was thrilled to get that over with. I now keep my wafers cut in advance and still try completing my routine left-handed once a week – just in case. Things were going great until the strong antibiotics kicked in and then came diarrhea – an ostomate knows about that clean up!