



Research Survey

Attention individuals with all types of ostomies, I want to hear from you! My name is Teresa K. Novy, I am a practicing certified Wound and Ostomy Nurse in Central Illinois. I have noted barriers to patients' ostomy education. I currently work in a hospital setting and I have received feedback from patients who wished they had learned more about their ostomy care before, during, and after their ostomy surgery. They report really lacking that basic information that we know they deserve and need to be successful. I want to look at improving this, so I am initiating a survey of ostomates all over the U.S. to get their perceptive.

I am seeking to learn more about the education you received prior to and following your ostomy procedure and what you think is important for individuals who undergo the procedure in the future. If you want to participate in this research study which includes the following anonymous survey, hover over the QR code or click the link to answer the questions. This survey will take between 10 and 15 minutes to complete.

Survey Link: <https://bit.ly/3SqUubl>

If you have any questions, you can email me at: tknovy@ilstu.edu
Respectfully, Dr. Teresa K. Novy DNP, GERO-BC, CNEcl, CWON



**ILLINOIS STATE
UNIVERSITY**

Mennonite College of Nursing



Jacksonville Contact Information:

Patti Langenbach
(800) 741-0110
(904) 733-8500

patti@ostomymcp.com

Support group meets the 3rd Sunday
of each month 3 p.m.

4836 Victor Street

Next Meeting: **December 17th**

Also join us by Zoom

<https://us06web.zoom.us/j/94640600811>

Meeting ID: 946 4060 0811
or call +1 301 715 8592 US

The Villages Ostomy Support

We meet on the 2nd Tuesday evening
of each month at 6:00 PM at (except
July & August

Linda Manson

tvostomy@gmail.com
865-335-6330

Next meeting **Dec. 12th @ 6 pm**
Saddlebrook Rec Center (near Polo Field)
Masks Required

Contact Linda tvostomy@gmail.com

Medical Care Products, Inc.

(904) 733-8500
(800) 741-0110

Ostomy Discounts offers ostomy
supplies at great prices to uninsured
or underinsured ostomates:

<https://ostomydiscounts.com/>

Visit the Peristomal Skin Assessment
Guide for Consumers

[http://psag-consumer.wocn.org/
#home](http://psag-consumer.wocn.org/#home)

Lee-Ann Watanabe Living with an Ostomy



My ulcerative colitis, IBD and ileostomy journeys have been a long road for sure! I spent most of my 30s trying every single pill, steroid, infusion, shot, diet, and remedy you could possibly fathom, all without relief. When the Mayo Clinic in Rochester, MN suggested that I undergo ileostomy surgery, I knew I was ready. After a decade of suffering, I was reborn on December 7th, 2015, following a permanent and total proctocolectomy with ileostomy.

My advice for others diagnosed with IBD and/or contemplating ostomy surgery, would be for them to ask ALL the questions; especially of your medical team. I was young and naive when first diagnosed with ulcerative colitis. Upon initial diagnosis, I didn't think it was that serious. I didn't believe I was sick, and all I wanted to do was get well and get back to racing triathlon. I took any and every medication doctors gave me, and I never questioned any of it. I never asked for a different way. I never thought that 10 years later, all the medications would stop working or not work at all. If I could do it over, I would find a doctor who was highly experienced with IBD patients.

If I could let people know something about IBD, it would be that I am a living, breathing example of invisible illness. I never looked sick. Even when sick, I continued my competitive triathlon racing. Don't judge a book by its cover. My sport was my outlet; something I could control while my body continually failed me. Everything happens in your mind. With a positive

outlook and a great attitude, everything is possible!

For many years, sick was my new normal. I was not living life; I was just surviving life with UC. Now, as an ostomate, I can say with 100% certainty that I am free. When I made the decision to have surgery, I decided I would advocate to show the world what people living with an ostomy can do. And you know what? There isn't anything someone living with an ostomy CAN'T do!

Read more: <https://meplus.convatec.com/articles/meet-lee-ann-watanabe/>

Editor's note: This blog is from one of our digital sponsors, Convatec. Sponsor support along with donations from readers like you help to maintain our website and the free trusted resources of UOAA, a 501(c)(3) nonprofit organization.

Infections with a Urostomy

NKUDIC – National Kidney and Urologic Diseases Information Clearinghouse

Bacteria often enter urostomies and continent urinary diversions and begin growing in number. At times, bacterial overgrowth causes a symptomatic urinary tract infection. Symptoms of infection may include:

- fever
- milky urine or urine containing extra mucus
- strong smelling urine
- back pain
- poor appetite
- nausea
- vomiting

Patients with symptoms of infection should call their healthcare providers at once. Drinking eight full glasses of water every day can help prevent infection by flushing out bacteria and keeping bacterial counts low. Patients should talk with their healthcare providers about appropriate times to have their urine tested and when to have treatment with antibiotics. Urine testing and infection treatment play a critical role in successful long-term care with minimal complications.

Guide to Healthy Skin

Maintaining healthy skin is more than simply checking if you are applying and removing your ostomy pouching system correctly and with the right frequency. The length of time between changes will vary for each individual. Using the following 'Apply Remove Check' process described here will help ensure you are in the right routine.

Apply

- Make sure the skin is clean and dry before applying.
- The barrier should fit snugly around your ostomy.
- Accessories, such as rings or a paste, can help you achieve a good seal around the stoma.
- Ensure that the barrier has made full contact with the skin by applying gentle pressure to the barrier during application – begin in the area closest to the stoma, and then move outwards towards the edges.

Remove

- Protect the skin around your stoma by gently removing the ostomy barrier
- Pull down on the removal tab to loosen the barrier from the skin
- Gently push down on the skin as you pull down on the barrier going side to side to gently release the adhesive from the skin
- This is called the push-pull technique

Observe or Check

- Observe the skin underneath the barrier
- If necessary, use a mirror to check your skin
- Check the back of the barrier
- If you see one or more of the following signs, it may be because you need to change your barrier more often:
 - Erosion of the barrier
 - Leakage on the barrier or your skin
 - Irritated, broken or red skin

Experiencing skin irritation?

If you see any changes in the appearance or color of the skin around your stoma (compared to the skin on the rest of your stomach), consider comparing photos or notes from your pouch changes.

Information from Coloplast Care is for educational purposes only. It is not intended to substitute for professional medical advice and should not be interpreted to contain treatment recommendations.

You should rely on the healthcare professional who knows your individual history for personal medical advice and diagnosis.

Article from digital sponsor Coloplast. Sponsor support along with donations from readers like you help to maintain our website and the free trusted resources of UOAA, a 501(c)(3) nonprofit organization.

Falling into Step – Post Surgery Experience

By Carrie Flaherty – WOCN Corner, OstoGem Newsletter, Boise, Idaho

After surgery there can be many adjustments that need to be made. Getting back to life can feel like an uphill battle. There can be both physical and emotional changes. These can both be challenging and at times feel like a never-ending pit. Do not disappear! Getting back into the step of things will fall into place before you know it. Here are a few tips and activities that can help you fall back into the swing of things.

Experience is unique to each person. Try not to compare your recovery to anyone else's.

Your own progress can be hard to see when recovering. Try to be patient and do not expect too much too soon. A daily diary can help you see your progression. Keep in mind that it will likely take months for your body to fully recover from surgery and the illness that led to the surgery. For many people it is important to connect to others that have a similar experience. Support groups can be a wonderful way to connect to others.

Posture after abdominal surgery can be a problem as it is common to slump or stoop. This can cause lower back pain. Try to remember to stand tall. This helps support your back and core.

Simple breathing techniques and meditation can be very helpful in relaxation, improving healing, and reducing anxiety. Deep breathing also encourages you to use your lungs after surgery. There is an online resource called Mind Space that has some helpful breathing activities as well as some guided meditation. It can be accessed at www.mindspaceapp.com.

Walking can be a wonderful way to build confidence and promote recovery. This is an activity that can be done with friends and partners. Walking encourages you to get out of the house and fall back into the community. Take it at your own pace and increase your steps as you feel your body is ready.

Pelvic floor muscles are very important. Participating in pelvic floor strengthening can help with recovery for both temporary and permanent ostomies. There is a wonderful online resource that has been put together by Convatec. They have many tips and tricks as well as online material that can be printed to assist with getting you back into the swing of things. This information can be found at <https://meplus.convatec.com/articles/about-meplus-recovery-series/>

Naming Our Stomas

by Ellyn Mantell, morethanmyostomy.com

When I was in high school, a close uncle had a double amputation of his legs. He suffered from a rare situation that caused him to have the “arteries of a 90-year-old man” despite the fact he was only in his 30s. His two young daughters were terrified of his new anatomy, as well as all of the changes in their lives that were necessary. The social worker from his rehabilitation center suggested having the girls name his stumps, giving them the ability to feel closer to their dad, hoping to ameliorate their fear. I do not remember both names, just Shapey, and remember wondering what was in Laurie's and Shari's minds as they chose that name. In fact, that time in my life was so impactful that I chose my first career, speech therapy, because of the time I spent visiting my uncle in rehab. I was incredibly impressed with the work I saw being done in physical, occupational and speech therapy, and knew that was my future.

All of these years later, I am in the position of recommending naming our stomas in order to become more comfortable with, and able to, embrace our new anatomy. In reality, according to the Food and Drug Administration, an ostomy is considered an amputation. That is because our stoma actually replaces the function of an organ that no longer functions, such as the colon or bladder. (Continued on page 5.)

As many of you know, I call my stoma Lily, since my mother was Lillian, and she gave me my first life. Lily has given me my second life, and my gratitude is enormous. Each time I meet a new ostomate, I am very aware that they may have a while, perhaps a long while, to go before they feel gratitude. But eventually, I believe they will be grateful. Our stomas save our lives!

The first phone call or visit I have with new ostomates allows me to listen to what has brought them to this new anatomy. All of us have the same thing in common...we are survivors, having been through so much. Whether it is an intestinal blockage, cancer of the colon or bladder, an accident, a perforation, a disease process such as Ulcerative Colitis or Crohn's Disease, or pathological dysmotility, the outcome is pretty much the same. There must be an adjustment period, and I try my best to support them in that process. The key, I believe, is to point out how strong and determined they are to have survived, and they will use that determination to find their best lives in the future.

I also recommend joining an ostomy support group, since there are so many questions they will have, and to make the United Ostomy Associations of America website part of their recovery. I am always amazed at the amount of information available for the patient and their caregiver.

Lastly, I want to remind all who are adjusting to a new situation to have grace with themselves. We are much stronger than we ever thought possible, but even the mightiest of warriors needs to take time to assess their goals and the path to achieve them. And that may include reaching out to another. Please let me know if you need my support, from one thriver to another!



Medical Care Products
Now Carrying
Ostomy Pouch Covers
TOLL FREE 800-741-0110

UOAA Discussion Board
<https://www.uoaa.org/forum/index.php>

Get Ostomy Answers!

The *Phoenix* magazine provides answers to the many challenges of living with an ostomy. From skin care to nutrition to intimacy, in-depth articles are written by medical professionals, ostomy experts and experienced ostomates. Subscriptions directly fund the services of the United Ostomy Associations of America.


Now \$19.95




☐ One-year subscription \$19.95 ☐ Two-years: \$29.95
☐ Send **FREE** product samples, special offers and information.**

Payable to: The Phoenix, P.O. Box 15755, North Hollywood, CA 91615

Name _____
 Email _____
 Address _____ Apt/Suite _____
 City _____ State _____ Zip _____

*Based on cover price of \$9.95. \$29.95 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 your subscription.



www.phoenixuoaa.org
 or call 800-750-9311

Check Out The MailBag Now On FaceBook
https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel
 Find all the past issues of the MailBag at <http://ostomymcp.com/id6.html>

Medical Care Products, Inc
PO Box 10239
Jacksonville, FL 32247-0239

To: