HENDRICK OSTOMY SUPPORT GROUP



LETTER FROM THE EDITOR

IIf 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

During the April meeting, Mike Horton from the Hendrick Sleep Disorders Center discussed what is involved in a sleep study and who should have one. It was most interesting.

NEXT MEETING

We will conduct visitor training for the May 8 and June 12 meetings. This program trains ostomates on how to visit patients with new ostomies. Mark your calendars now to attend. The WOC nurses need volunteers to be encouragers to new ostomates! Even if you do not want to be a visitor, you will learn some valuable information at this training. We will serve Subway sandwiches during these two meetings, so please RSVP to Charlotte at 670-4302 or Vina at 670-4312. The meal will be ready at 6 p.m., so come early!

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

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

CONTACT US

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

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Stomal Stenosis

By Joel Craeter, RN, CWOCN , Via Rose City Ostomy News, Tyler, Texas

There are multiple complications which may occur with stomas. Stomal stenosis is one that rarely happens and will need lifelong attention, but usually becomes little more than a nuisance when properly treated. Stomal stenosis is a narrowing of the opening of the stoma. This can happen where the bowel is brought through the muscle or at the skin level. Most often this happens at the skin level and can be a result from a mucocutaneous separation. To explain, when stoma is created, the bowel is sutured to the skin. Most often this suture line heals without complications. Occasionally, this does not heal and becomes separated. This leaves open areas which begin to heal from scarring. When this scarring begins to reduce the opening of the stoma, we have a stomal stenosis.

Another cause of stomal stenosis is peri-stomal skin complications. Sometimes, especially with an ileostomy, the peri-stomal skin becomes very irritated from the caustic stool leaking on the skin. If not treated, this can cause scarring of the skin and narrowing of the stoma. Additional causes may be from poorly fitting appliances, swelling, tumors, radiation, disease or other causes.

Often stomal stenosis causes thin or "ribbon" like stools. When gas is passed, the sound is very high pitched or even like a squeal. Specific symptoms for urostomates may be projectile urinary stream and/or pain. Some may determine stenosis by visually noting a decrease in size of the stoma.

In rare cases, surgical revision is needed to treat stomal stenosis. Usually the stenosis is treated with dilation, if needed at all. Dilators are available in many increasingly larger sizes. When used properly and over a period of time, they will slowly increase the size of the stoma. Most often, the smallest gloved finger is inserted into the stoma and allowed to stay in this position for 10-15 seconds without twisting. The finger is withdrawn, turned 90 degrees and inserted again. This continues until the stoma is of appropriate size.

If you have stomal stenosis your physician or ET (WOC) nurse most probably has been the one who told you about it. Follow their advice on the care and treatment. If you believe you have stomal stenosis, contact your physician or ET (WOC) nurse for necessary care. Do not attempt to dilate your stoma without proper instructions. When in doubt, contact an expert. Stomal stenosis does not happen often and usually requires minimal specialized care but must be properly treated to avoid complications.

What to Do When You Feel Overwhelmed with Ostomy Life

By Stephanie Hogan, OCSW, ostomyconnection.com

The experience of managing a new stoma or dealing with ongoing skin problems can be a lot to handle. Add in the demands of normal everyday life—it can feel completely overwhelming. Whatever the reason you're feeling frazzled, there are ways to help prepare yourself to handle whatever may come your way. Here are eight tactics that can help you deal with ostomy overwhelm:

1. *Know how long things take.* I'm notorious for assuming tasks take much less time. For instance, I'll block out 15 minutes and then discover it actually takes 30 minutes! I've learned this simple rule: whatever time you think a task will take, double it. That way when your appliance change doesn't go smoothly, you'll feel less stress because you know you have extra time to apply it properly.

2. Simplify your life. Is your life too complicated? "Take a good look at everything you do and ask yourself if there is a better, easier way to do it or maybe not do it at all. If you don't get through your to-do list, it's okay. Figure out your priorities, like having a system in place for organizing and ordering ostomy supplies. Check if your supplier has automated reordering. There is also a handy ostomy tracker app available for smartphones that alerts you when supplies are low or when to get a new prescription.

3. Get into daily habits. Getting the most important things done in an orderly fashion is taking care of you, first and foremost. For instance, the first thing I do each morning is hydrate. Then I'll change my appliance prior to eating breakfast. Next, I might take vitamin supplements if I'm not eating properly. Then I prep for that day's events by packing healthy snacks and my water bottle. These daily tasks allow me to feel prepared for the day. And if you're not a morning person, pack things the night before.

4. Allow for Murphy's Law. No week is complete without something going wrong, so plan for it. Take for instance that terrifying feeling of your wafer peeling off your skin while you're at work, or a very inconvenient leak at the movie theater. Allow time in your week for preparing an emergency ostomy kit and extra clothes, and always carry it with you.

You'll be better off knowing these things are readily available, just in case you need them.

5. Lean on others for support. Don't underestimate the power of peer support. When you ask for help in a considerate way (and understand they may need to turn you down), there's no need to feel guilty about leaning on others. It can be something as simple as coming over to watch a movie when you're not feeling well or asking for a ride to a doctor's appointment.

6. Be kind to yourself. If you're having ongoing ostomyrelated issues, this kind of overwhelm can lead to feelings of inadequacy and failure. This is not the time to beat yourself up. It's extra important to pay attention to your mental radio and turn down the volume on your inner critic station. Practice self-compassion, and remember all the things you've been through. Talk to yourself as if you were talking to a loved one or best friend.

7. Dump it all on paper. When you're fed up with your ostomy, sometimes taking time to write down your frustrations can help. At Oak Park Behavioral Medicine, we give our patients journals to help with this. One of my favorite assignments is having ostomates write a letter to their stoma with all their truest emotions.

8. Connect with others who have been there. There are many ostomates who have gone before you, and many who have yet to receive an ostomy. We can all learn from each other, so it doesn't hurt to reach out to a UOAA support group or discussion board. Sometimes, this kind of understanding can really help when you're feeling overwhelmed with ostomy life. If you want a pen friend, Girls with Guts has a Pen Pal Program where you can request another ostomate to send snail mail back and forth.

The Rules: Just pick ONE (maybe two) of these tips and do them. I don't want you to get overwhelmed by trying them all.

Stephanie had ileostomy surgery in 2009 due to Crohn's Disease. She is a licensed clinical social worker who specializes in health psychology and chronic illness at Oak Park Behavioral Medicine in Illinois.

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As a new ostomate, I attended my local ostomy support group and shortly afterward started receiving newsletters and other information. I got a flyer on an upcoming Appliance Fair. I assumed it had to do with refrigerators, stoves and dishwashers. I live in an apartment and those items are included in the rent, so I thought an Appliance Fair was of no use to me. Thinking it was odd that an ostomy group would send a flyer for that, I glanced at the flyer again, and then realized I had misunderstood and the Appliance Fair was for people to learn about various ostomy products. When I went to the fair, I shared my story with WOCN Pat Keegan. She put her arm around me and said, "Oh, honey you really are a rookie, aren't you?" Debbie Hull, of Minnesota, was a typical healthy 20-year-old when she suddenly became ill with Crohn's Disease in December 1977. In 1984, she had ileostomy surgery and has been well ever since. Debbie says, "All the bad memories have faded, I can do anything I want: travel, work, exercise, eat what I want—life is good. I am grateful there was a solution for my situation."

Pancaking

Via Hartford (CT) Ostomy Update

Pancaking occurs when stool does not fall into the bottom of the pouch and instead collects around the top near the stoma. This can build up to the point where it gets under the flange or bulges under your clothing. Pancaking affects almost all colostomates at some time or other (and some ileostomates).

The most common cause of pancaking is stool that is too dense or sticky to slide cleanly down the inside of the pouch. Clothing that is too restrictive across the top of the appliance can also cause pancaking. In some cases, it's believed that if the pouch has no air in it, this causes a vacuum which prevents the stool from going to the bottom. Whatever the cause, it's really annoying.

How can you prevent pancaking? The first and easiest solution is to lubricate the inside of the pouch near the top.

Apply some lubricating deodorant—any of the brands made by the manufacturers will do—to the inside top of the pouch and smear it around. If you don't have any ostomy lubricant, baby oil or olive oil will do, or non-stick cooking spray, though these don't have any deodorant qualities. Whatever you use, don't get lubricant on the flange or the stoma itself. None of these products will hurt the stoma, but oil around the base of the stoma will most likely decrease wear time. Another trick is to put scrunched up tissue inside the bag. This will help eliminate the vacuum effect and hold the sides apart so things don't get stuck so easily.

Consider changing your diet to include more roughage or old standbys like prune juice. Drink more water! If the problem is really persistent, you might consider a bulk-forming type of laxative—ask your pharmacist to recommend a mild form of this laxative. (Check with your doctor or WOCN before trying this). Last—are you getting enough exercise? Lack of movement can contribute to, well, lack of "movement." Get off that couch and get some exercise! Conversely, have some applesauce at breakfast. It's an old standby.

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April 16-22 is WOC Nurse Week

What in the World is a CWOCN?

July 08 UOAA UPDATE

CWOCN is an abbreviation for Certified Wound-Ostomy Continence Nurse. Formerly known to all or most ostomates as an E.T. nurse or more formally correct as an Enterostomal Therapy Nurse. That area of nursing has greatly expanded.

A CWOCN is a registered nurse (RN) who has received extensive training in managing conditions related to complicated wounds, ostomies or problems related to fecal and urinary incontinence. Some RNs choose to become specialists in only one of these areas. A CWOCN has at least a bachelor's degree in nursing. In addition, the CWOCN has received extensive training in anatomy and physiology; wound, ostomy and continence management; patient teaching; prevention of complications; appliance fitting and refitting; and evaluation and consultation. The CWOCN must pass a rigorous certifying examination for each area of speciality, and become certified by the national organization. The CWOCN must also attend relevant continuing education sessions each year and be recertified every five years.

The WOC nurses at Hendrick are Charlotte Allen and Vina Gilbert.