



AFFILIATED SUPPORT GROUP

Affiliate Group #004

Clearwater Ostomy Support Group

www.clearwaterostomy.org
clearwaterostomy@gmail.com
SUPPORT LINE 727-490-9931



MAY 2024

Next Meeting

Saturday, May 18, 2024

Support Meeting 10:30 am

The Masonic Lodge
1145 Highland Ave NE
Largo, FL 33770

UPCOMING EVENTS

2024 MEETING SCHEDULE

Subject to changel

June 15

July 20

Future dates and locations are still to be determined and confirmed.

the President's Message

Hi Everyone,

I want to thank you all for being at our last meeting and hope to see even more at our May meeting.

Our May meeting will be a Roundtable where you can ask any questions or to discuss areas where you need help. Please bring all of your questions and let the support group help you out.

Don't forget our new website is live at ClearwaterOstomy.org. You will find lots of helpful information there too!

Looking forward to
seeing you there!

Marilyn



Our meetings are open to new ostomates, the experienced ostomates, the caregivers, the families, the healthcare workers, the support persons, the nursing students, the social workers and anyone who has a connection with ostomies and would like to join us. We welcome you all!

TIPS & TRICKS

Ostomy Tips

- ♦ **Change your ostomy pouch on a routine basis**, before it leaks. You will get more comfortable with this after you learn what works best for you.
- ♦ **Twice a week changes are considered usual.** Seven days is generally recommended as the maximum length of time you should wear a single skin barrier.
- ♦ **If your wear time becomes erratic or unpredictable, consult your ostomy nurse.**
- ♦ **Pouch wear time may decrease during warmer seasons** when you are perspiring more or during times of increased activity. This is normal, so anticipate and plan appropriately.
- ♦ **When traveling, plan ahead.** Some suggestions include: take extra ostomy supplies, pack your ostomy products in your carry-on bag when flying, pre-cut your cut-to-fit skin barriers so you don't need to carry a scissors on the plane and obtain a travel ID which explains your need for specific medical supplies when traveling.
- ♦ **You can shower or bathe with your pouch on.** If you use a two-piece pouching system keep your pouch on during the shower.
- ♦ **When emptying your pouch** it is not necessary to rinse it out. A lubricating pouch deodorant may make emptying easier.

WHEN TO CALL A DOCTOR OR WOC NURSE

1. If cramps last more than two or three hours.
2. If you get a deep cut in your stoma or bleeding at the juncture of the skin and stoma.
3. If you have excessive bleeding from the stoma opening or a moderate amount in the pouch after several times emptying.
4. If you have a strong odor lasting more than a week.
5. If you have severe skin irritation or deep ulcers.
6. If you have severe watery discharge lasting more than five or six hours.
7. If you have an unusual change in the size or appearance of your stoma.





SEVEN STEPS TO IMPROVE YOUR MEMORY

If we can preserve and maintain some kinds of memory as we age, can we do even better? Can we hope to improve? The answer from the experts is a heartening “Yes!” “Everyone can improve memory,” says Danielle Lapp, a memory-training specialist at Stanford University, and author of *Nearly Total Recall*. In her training program at

Stanford, Lapp has helped thousands of people to sharpen their storage and retrieval skills. Here are some memory strengthening tips from Lapp’s book, and from Thomas Crook’s “How to Remember Names”:

Set Priorities: “Don’t expect to be able to juggle six things at once,” says Lapp. Get mentally organized; distinguish between what’s important to remember and what isn’t.

Sharpen the Focus: Crook suggests paying special attention to landmarks when you’re doing your routine driving. “This will help you develop a more active sense of awareness,” he says.

Pause and Ponder: You can improve the amount of written material you can recall by as much as 300% if you simply stop to think about what you’ve read.

Make Associations: Find key words, pictures, or letter combinations to help you remember. This is known as mnemonic memory. If you meet a woman named Rose, for example, remember her name

by picturing the flower.

Use Your Senses: “When you order dishes at a restaurant,” Crook writes, “note the texture, the subtle flavorings, the temperature, and the colors.” In general, use as many of your senses as you can to aid in remembering.

Do Your Exercises: Memorize numbers that may be important to you, such as your driver’s license and Social Security numbers. When you’re at a party, make it a point to remember the names of at least four of the new people you meet. When you write your shopping list, try to remember all the items without looking at your list when you get to the market.

Be Kind to Yourself: Losing the car keys or forgetting the name of your bridge partner for a moment is not a sign of mental disintegration.



ESTABLISHING YOUR OSTOMY ROUTINE

The early days following your ostomy surgery can be challenging. There are many new things to learn and adjust to, including how to properly care for your ostomy. What's one way to help make caring for your ostomy a little easier? Create a daily routine! Having a system that works for you will help you with adjusting to your ostomy and minimizing your chances of uncomfortable bloopers. Below are some of our tips and tricks for caring for your ostomy.

Emptying your ostomy pouch

It will be helpful if you can establish a routine for emptying your ostomy pouch - try to keep it as simple as possible. You should empty your pouch when it is 1/3 to 1/2 full to help reduce your risk of leakage and other accidents. While emptying or changing your pouch, it is also a good time to make sure that your barrier is still well adhered and has not started to peel.

Routine pouching system change

Keep a log of how long your pouching system lasts and build into your weekly routine. Remember, you will need to allocate more time on appliance change days, so make sure to plan accordingly. You may find that changing your pouching system first thing in the morning before you've had anything to eat or drink is a good time for you, however, you will need to determine what schedule works best for you.

You should make it a habit to examine the area around your ostomy and make a note of any changes you notice. Whenever you empty or change your ostomy pouch is a good time to inspect your skin to catch and manage any irritation. Start by

comparing the skin around your ostomy to the skin on the other side of your abdomen to see if it looks similar (using a mirror may help you with this). Being aware of even the smallest changes to the area around your stoma and adjusting your products to those changes may help you reduce the risk of leakage and skin irritation.

Log your meals and pouch change times. In the beginning of your ostomy journey, you may find it helpful to keep a journal of what you eat, mealtimes, and what time you empty or change your pouch, so you can better anticipate when you will need to make a trip to the bathroom. Keeping a consistent meal schedule will also help your digestive system be more consistent. What you eat can also contribute to how quickly food moves through your system and out your stoma, which is why keeping track of what you eat can be helpful when identifying which foods agree with your body.

Avoid foods and beverages that don't agree with your stoma

As you get used to your ostomy, you'll start to recognize patterns with certain foods and how they affect your digestive system. You'll likely be able to identify which foods move quickly or slowly through your system, which cause excessive gas, and which create more output than what was consumed. Keep this in mind if you decide to indulge in a food or beverage that's not in your regular diet.

Learn your stoma's night time habits

Sticking to a consistent dinnertime and knowing how the contents of your meal affect your stoma will also help you determine your night time routine.

In the beginning, you may find it helpful to set alarms periodically throughout the night to check the quantity of output in your bag. Empty or change as necessary and keep a log so you can tweak your alarm schedule accordingly.

It's all about you

At the end of the day, it all comes down to

what works best for you. Every person's experience is unique, and how you care for your ostomy will likely be unique to you as well. Over time, you will find your own routine that works best for you and your lifestyle, so try to remember to be patient and open to finding new resources.

A MINI GUIDE TO USING BARRIER RINGS

What Are Barrier Rings?

Barrier rings, which are sometimes called Eakin rings (although Eakin is just one brand of many), are often used when an ostomate experiences leaks. Barrier rings work by swelling up around the stoma when it comes into contact with liquid or ostomy output, providing effective protection for any skin that's exposed.



How Are Barrier Rings sold?

Barrier Rings are boxed in quantities of 10 - 20 individually wrapped packages. Some brands offer two thicknesses. These rings are usually not cheap if you're paying for supplies.

How to Use Barrier Rings

These rings can either be placed around the stoma before applying the wafer, or to the wafer directly (after you remove the release liner on the wafer).

They tend to be quite sticky, and should be applied to dry, unbroken skin for best results.

Because these rings are pliable (like Play-doh), they can be molded around your stoma for the perfect fit. Barrier rings can also be applied to a wafer.

It's best to use gentle pressure over your appliance after fitting it on top of the barrier ring, for a few minutes. This will help the ring stick to your skin better, and will allow the wafer to stick better to the ring!

Tips When Using Barrier Rings:

Just because you get a ring, doesn't mean you have to use a ring! You can easily tear these rings in half and use whatever you need.

These rings do tend to break down and often "melt" when they are worn for prolonged periods of time, or if you sweat a lot. Some brands break down sooner than others, so it's best to sample a few, since these tend to be expensive. Barrier rings can also help to fill in gaps near your stoma.

TO BE or NOT TO BE ... OPEN ABOUT YOUR OSTOMY ... THAT IS THE QUESTION.

Every person with an ostomy has their own unique story and journey. Some-one may have been suffering from Inflammatory Bowel Disease for many years before finally agreeing to surgery and an ostomy. Someone else may have been blindsided with a new rectal cancer diagnosis and find themselves with an ostomy just a few short weeks later. Others may have lived their entire lives with an ostomy due to trauma or congenital anomaly, and therefore, know no other way of life.

No matter the reason for the needing it, every person has a different path to acceptance of their ostomy. Some are immediately open about their ostomy and are happy to discuss their new situation with friends, family or even new acquaintances. Others remain incredibly private and choose only to reveal knowledge of their ostomy to a minimal few. And I think the majority of ostomates fall somewhere on the spectrum between these two extremes. A person's place on this spectrum can also change over time (in both directions), depending on both positive and negative experiences someone might have. The important thing to remember is that as an ostomate - it's YOUR CHOICE. There is no right or wrong way to live with an ostomy. It can also be comforting to know if a patient is facing an upcoming ostomy surgery or as a new ostomate that there are many



things one can do to conceal and hide their ostomy should they to do so.

Here is a list of tips:

- * High waisted clothing - Luckily high waisted pants, shorts and swimsuits are currently in fashion, making it easy to find articles of clothing to conceal your ostomy without having to purchase specific items made for ostomates.
- * Clothing that is patterned or loose fitting will help to make a full ostomy bag less noticeable until you are able to empty it. Also, keeping with you a light jacket, sweater or scarf that can be worn or placed around your waist can be useful.
- * Control top underwear or belly band. You don't want anything that is extremely tight that will occlude stoma output but a snug fit will help to conceal any bulges as the bag may fill up.
- * Empty your pouch often. If you empty often output will not accumulate in bag and will be less noticeable.
- * Use an ostomy appliance with a filter. A filter will help to prevent gas build up in the bag even when you have no output. Because the filter uses carbon, gas is able to be released without odor.

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- * Avoiding foods with increased gas production can help to prevent the ballooning that can happen as well. Over-the-counter anti-gas medication can also help to prevent/treat increased gas. However, please discuss with your medical provider before trying this.
- * Remember - you are likely more self-conscious of your ostomy than any

one else around you. Even if you may think it is very noticeable, chances are it is not!

No matter how open you choose to be about your ostomy, remember that it is your choice. But also remember all that you have been through with the journey that led you to your ostomy. Your stoma is like a scar or wound, proof of a hard battle you have fought and won.

Self Advocate! Being Your Own Health Care Advocate

- ◆ While you are in the hospital... Bring a paper and pen to write down your questions for your caregivers (doctors, nurses, etc.) as you think of them and ask for answers to those concerns.
- ◆ Consider keeping a journal if your health care experience is extensive, involving many health care professionals over a prolonged period of time.
- ◆ Ask caregivers for their names and titles, and write them down.
- ◆ Ask what tests and procedures are being done and why.
- ◆ Find out when your doctor's rounds will be done and have a family member or friend there to listen to the information, to ask questions, and to talk with after the team leaves.
- ◆ Before you sign any consent forms, make sure you read and understand for what you are giving consent.
- ◆ Ask questions such as, "what is the nature of the procedure"? And "who will be performing it"? Bring a list of all medications you have been taking at home.
- ◆ When it is time to go home ask about and understand the normal or abnormal side effects of your procedure. (For example, how much pain should be expected?)
- ◆ Ask for educational material on your condition, procedures and treatments.
- ◆ Ask how much you should do when you get home and what you will need help with.
- ◆ Ensure that you, your family and your caregivers make arrangements for help.
- ◆ Ask about your home care options. Find out exactly what home care arrangements have been made and ask for the contact name and phone number. If something is not covered

make sure you plan for the help you need.

- ♦ Ask about your expected recovery time. Find out when you can return to work.

- ♦ Ask if you should have a follow-up visit scheduled with your physician.
- ♦ If you need help resolving your concerns or want to give feedback to the hospital, ask to speak with the hospital's patient representative.

Coping With Ostomy Surgery Anxiety—5 Tips for Caregivers

By Kerri Consigli

Everyone copes differently, but what matters most is that self-care becomes a priority and that you accept that it's not being selfish. It's survival. My husband Adam and I met on Match.com, and on our first date he discovered that I was an ostomy nurse and I discovered that he had an ileostomy. We hit it off immediately. Then, six months into our relationship, Adam had a routine visit with the physician who performed his ostomy surgery. He learned that he was going to need another abdominal surgery involving relocation of his stoma.

After a successful operation, he recovered better than I ever thought he would. But, let me tell you that before, during, and after his surgery I was a mess! I guess you could call it "surgery anxiety". I had finally found the love of my life, and now all the "what-ifs" were running through my mind, and it ultimately left me anxious, depressed, and scared.

Sound familiar? That's the tip of the iceberg of emotions that we, as caregivers, often feel when a loved one needs surgery. My experience left me asking an important question: What about support for the caregivers? I'm an ostomy nurse, so the ostomy itself wasn't a source of stress for me. However, I recognize that this can certainly come as a challenge for many family caregivers.

My experience has taught me that part of my assessment as an ostomy nurse is to check in with who I liked to call the "loved one's other half" or the caregiver. You are what makes your other half whole.

Bottom line: You matter too! You, as a caregiver, are as much part of the process as the person being cared for. You aren't the one being operated on, but you are certainly going through that surgery anxiety. And, trust me, that doesn't stop even after the surgery is over.

Looking back on my experience with my husband's ileostomy, it shed some light on why I wasn't coping well with his surgery. Self-care didn't exist for me. I was so focused on making sure that he was okay that I forgot about caring for myself. As a result, I admittedly became a weepy, irritable, anxious monster. My physical and emotional defenses were down, and it was affecting my day-to-day life.

Everyone copes differently, but what matters most is that self-care becomes a priority and that you accept that it's not being selfish. It's survival. You must make sure that you maintain your health and well-being, in order to be available for your loved one.

I came up with 5 tips, while seemingly basic, that are vital to your survival in the

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process from pre-op to post-op ostomy surgery and beyond:

#1 - Sleep: Get your 8 hours. I know that when I am sleep-deprived, I am useless. Take a nap if you want and don't feel the least bit guilty. During the post-op period, go home and sleep at night. The nurses and doctors will take good care of your "special patient". Rest is important. You need to be bright-eyed and clear-headed the next day so you can start the recovery process alongside the person with an ostomy.

#2 - Eat: Avoid a typical "stressed-out" diet of comfort foods, sweets, and junk food. Maintain a well balanced diet of fruits and veggies, complex carbs, and lean protein. Drink plenty of water. It's okay to leave your loved-one's bedside to grab a bite to eat. Head to the cafeteria, bring food in, or go home and make yourself a healthy meal. Eating and hydrating properly will fuel your brain and body so you can be physically and mentally available for your loved one.

#3 - Exercise: Keep up with your regular exercise routine. This is the time to release those endorphins. A brisk walk around the hospital will get your muscles moving and your blood flowing. Any type of physical activity will help keep you alert and less stressed.

#4 - Educate Yourself: During the pre-op phase, prepare yourself for an educational session with an ostomy nurse. Visit reputable websites for information. United Ostomy Associations of America (www.ostomy.org) is very helpful. You can even search for a local UOAA support group by visiting www.ostomy.org/support-group-finder/. * Avoid online negativity and misinformation. During post-op, be there

with your loved one to receive valuable information and instructions from the ostomy nurse. Take notes and ask questions about the stoma, ileostomy bag, or anything that comes to mind. Remember, no question is ever too frivolous to ask. Knowledge is power.

#5 - Talk or Laugh it Out: Express your feeling with your loved one. Have a good cry if that's what you need. Call that person in your life who can make you laugh. Watch a funny movie or TV show. A few good belly laughs always feel amazing! Family caregivers can become overwhelmed. Talk it out with other family members or a close friend. Do not worry or suffer in silence. Look for a shoulder to lean on.

Yes, surgery is stressful both for the patient and the caregiver. And having an ostomy creates a major life change for both people in a relationship. You need to just keep in mind that you are the most important person for your loved one, and because you are so important, you must remember not to lose yourself in the whole process. Simply put, take good care of you.

Kerri Consigli is a certified Wound, Ostomy and Continence Nurse Specialist (CWCN) at Midford (MA) Regional Medical Center. Ostomies are a constant in her life, as husband Adam has an ileostomy. She balances her time being a wife and mother with making a difference for ostomy patients in her community. Financial Disclosure: Kerri Consigli received compensation from Hollister Incorporated for her contribution to the eNewsletter. Source: Greater Cincinnati Ostomy Association Phoenix Risings - November 2021

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*Loads of information can be found
at the United Ostomy Association
of America website.*



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www.ostomy.org

UOAA Discussion Board -
www.uoaa.org/forum

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ASG052016