



AFFILIATED SUPPORT GROUP

Affiliate Group #004

Clearwater Ostomy Support Group

www.clearwaterostomy.org

clearwaterostomy@gmail.com

SUPPORT LINE 727-490-9931



January 2025

Next Meeting

Saturday, January 18, 2025

Support Meeting 10:30 am



The Masonic Lodge
1145 Highland Avenue
Largo, FL 33770

UPCOMING EVENTS

2024 MEETING SCHEDULE

Subject to changel

February 15, 2025

March 15, 2025

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

the President's Message

Hi Everyone,

Well, the holidays are gone, but a new year is upon us. The new year brings us hope for better health and greater prosperity. I send you wishes for both in this coming year.

Fortunately, our meetings will return to the Masonic Lodge as the hurricane repairs have been completed. However, we are still looking for a new home for our Ostomy Clinic and Angel Closet.

Blessings,

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

10 Expert Tips to Stop Stoma Pancaking (Even While Sleeping)

Stoma pancaking is an unpleasant surprise that ostomates frequently endure during their journey. And unfortunately, it has nothing to do with tasty pancakes in the morning.

A pancaking stoma, where output does not drop into the bag, is a common source for leakages and for sure for unpleasant and annoyed feelings.

If you are one of those ostomates who is tired of this, and instead want to enjoy a restful night and daytime, we got you! We have gathered these 10 tested tips to help you be aware and ready to recognize the reason behind your pancaking stoma. With those tricks, you will be able to solve the problem all by yourself. **So in short, this is how you can stop your stoma from pancaking right now:**

1. Try to put air in your bag
2. Cover the filter to avoid vacuuming
3. Use stoma bridges or add rolled toilet paper
4. Find the right appliance for you
5. Use a lubricant deodorant
6. Squeeze your bag
7. Increase fluid and fiber intake
8. Do not eat right before bed time
9. Measure your stoma frequently and cut the wafer to the right size
10. Avoid tight clothes

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.





Keep Calm: How to Manage Stress When Living with an Ostomy

Gemma Harris

Feeling anxious after stoma surgery or stressed about ostomy issues? Gemma Harris talks to experts, who reveal what you can do to relieve these worries.

Adjusting to life with a stoma after surgery can be an incredibly disorienting experience. Feelings of anxiety, panic, and even a sense of despair can take hold. Ostomate Becky Holmes understands this firsthand, recalling her own experience: 'I couldn't accept it, I couldn't touch it, I couldn't clean it or even change the bag. I suffered from panic attacks, severe anxiety, and felt like my life was over'. If these words resonate with you, know that you're not alone.

Having a stoma can be a big trauma not only for the body but for the mind. Over 20% of ostomates experience long-term significant psychological challenges, with stress being a common symptom. As this latest data is from a few years ago, these figures could now be higher.

While this doesn't sound great, there are things you can do to overcome these issues and live a full and active life. Becky is proof of this as she is now a registered counsellor who offers support to people who suffer from IBD or are living with a stoma. Becky's stoma doesn't stop her from doing anything; she runs ultramarathons and goes to the gym five to six days per week.

Take it one day at a time

When there has been a big life change, it can be easy to look far into the future and jump to conclusions. Rather than doing this, Becky says: 'Taking it one day at a time is best'.

'You could have a bad week or a bag that leaks on your stomach and causes a lot of pain. We have different days.' She remembers times she looked in the mirror and felt completely hopeless, and other times when she felt much stronger.

It is important to remember that things are temporary and that includes the difficult times.

Becky still plans in terms of events she's attending and emphasizes the importance of this to have things to look forward to, but she says staying in the moment can help to reduce uncomfortable mental emotions.

Be prepared

Becky says that initially, the most stressful thing about living with an ostomy was going out. 'I would have to try and plan ahead of time to locate the toilets. If I was going out for food, I would look at menus in advance to figure out what I was going to eat; I would try and stick to bland food to avoid potential leakages.'

Another thing Becky struggled with was stress causing her output to change and this caused further stress as a result. 'When I'm stressed the consistency is quite watery and that can burn my skin. For some, you might have to empty your bag more often when you're stressed and you might not be close to a toilet. If you then get a leak, it's stressful.' So how do we break this vicious cycle? Having supplies with you, such as food to thicken your stool or powders and creams to help with soreness, can help you to feel prepared and, therefore, more at ease.

Seek professional support

While having the support of friends and family is great, getting a suitable therapy can be beneficial.

Counselling can help you to come to terms with the change and rebuild your self-confidence. 'Family and friends haven't got the same listening skills as a counsellor,' Becky adds, 'we need someone professional, like a counsellor, who is not going to judge, will really listen to you and has empathy (for your situation).'

Meanwhile, forms of hypnotherapy have been proven to be effective at reducing stress and promoting relaxation. Certified hypnotherapist Lada Shustova-Carter, LSC Therapy, says:

Interestingly, many people with a stoma can actually be more, rather than less, receptive to relaxation. Physiologically, our energy is focused almost completely on coping with the alien changes in our body – and away from dealing with responsibilities, external events and long-term goals. This has the powerful effect of freeing the mind to live in the moment, to be more observant and more thoughtful.

Hypnotherapy can be a beneficial contributing factor in changing the thinking to a more positive, accepting and liberating state,' she continues. 'Just a few sessions with a professional hypnotherapist can give us the necessary mind shift and relief. This is because, in the state of hypnosis, we are able to access our subconscious mind which allows us to rewrite the unhelpful story we've been telling ourselves.'

Get to know your body

One thing Becky wishes she'd known when she first had stoma surgery is to 'listen to your body.'

'Don't jump into normal activities straight away. I wish I'd known that more,' she says.

If you're not up to vigorous exercise, simply going for a walk in nature can help. In fact, evidence shows exposure to nature can help to reduce stress. So, that's a double bonus. Walking therapy is another option that can aid your mental health.

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Keep talking

Whether it is with a professional or loved ones, Becky emphasizes the importance of having someone to talk to. It may be cliché but as the old adage goes: 'a problem shared is a problem halved.' Despite being a counsellor herself, Becky finds comfort in also speaking to a therapist.

She believes it's also important that loved ones actually get some support. 'My husband has been my rock,' she says, 'but, (in the early days), no one ever really asked him how he was.'

'There are also lots of support groups on social media,' Becky adds. 'Remember not to be ashamed and to be proud.'

While she still might have occasional issues with her stoma, her fears and trauma are in the past. Now Becky reflects proudly on what she has achieved, from running 26.2 miles in under five hours to overcoming her mental hurdles, and you can too. Her final takeaway: 'you might feel alone, but remember you are not.'

Mindful activities you can try

Meditate: similar to hypnotherapy, meditation helps you to focus inwards and reach a state of calm. Becky is a big advocate for meditation and does it daily. 'If I'm stressed during the day, I'll do a quick three- or five-minute meditation,' she says. 'I also meditate three times a week for 30 minutes.' There are various meditation apps available such as Headspace and Calm which offer some free meditations and others at a cost.

Breathwork: Pause for a few minutes and try a breath technique whenever you feel stressed. Box breathing is a great exercise for calming the body and mind. Here's how to master box breathing:

- Hold for four seconds
- Breathe out for four seconds
- Hold for four seconds
- Repeat this cycle four to six times.

Use calming scents: surrounding yourself with certain smells can be powerful when it comes to stress reduction. It's well known that lavender in particular is effective at reducing anxiety. You could try using a lavender-scented pillow spray when you go to bed or putting a few drops of essential oil in a diffuser and letting it spread around the room

Read: Perhaps snuggling up with a good book is more your thing. According to a study, conducted by Mindlab International at the University of Sussex, reading for just six minutes can reduce stress levels by as much as 68%, even more than listening to music or going for a walk.



- Breathe in for four seconds



What do the classes cover?

How to live an active life with an ostomy. What to expect for the first three months. How to secure ongoing supplies, bathe, swim, dress, exercise, travel, return to work or school, and connect with resources. These vendor-neutral classes will also help familiarize you with basic ostomy supplies, pouching systems, and accessories. Live class lasts approximately 90 minutes.

Who leads the classes?

Patient Classes are co-led by a real person living with an ostomy and a volunteer ostomy nurse (WOCN) from a University Medical Center. Class leaders are volunteers and not affiliated with any vendor.

Cost and registration?

Ostomy 101 Patient Classes are free, vendor-neutral, and hosted by volunteers. No registration is required. No participant data is collected or shared.

Is this class recorded?

No. This is a live class where participants have the opportunity to ask ostomy lifestyle questions. This class is never recorded.

How do I join a class?

Ostomy 101 Patient Classes are live and held monthly via Zoom. Simply click the link on the [Ostomy101.com](https://www.Ostomy101.com) webpage at 9:30 am (pacific time) on any of the dates listed.

2025 Class Dates: Jan. 11, Feb. 8, Mar. 8, Apr. 12, May 3, June 7, July 12, Aug. 9, Sept. 13, Oct. 11, Nov. 8, Dec. 13

10 Ostomy Tips for Managing Your Ostomy—A Beginner's Guide

As an ostomate, managing your ostomy can be a challenging but ultimately rewarding experience. Whether you are a beginner or have been living with an ostomy for a while, there are always ways to improve your daily routine and make life with an ostomy more manageable. Here are ten tips to help you get started:

1. **Learn as much as you can about your ostomy.**

The more you understand about your specific type of ostomy (colostomy, ileostomy, etc.), the better equipped you will be to manage it. Research online, talk to your healthcare team, and consider joining a support group to get the information you need.

2. **Choose the right ostomy supplies.** There are many different types of ostomy bags, wafers, and other supplies available, and it's important to find the ones that work best for you. Experiment with different brands and products to find what fits your needs and lifestyle.

3. **Practice good hygiene.** Proper hygiene is key to preventing skin irritation and other problems with your ostomy. Keep the area clean and dry, and consider using a protective barrier cream to prevent irritation.

4. **Embrace a healthy lifestyle.** Eating a balanced diet, getting enough exercise, and managing stress can all help you feel your best and maintain your overall health.

5. **Know your limits.** It's important to listen to your body and pay attention to how your ostomy is functioning. If you are feeling overwhelmed or experiencing problems with your ostomy, it may be time to take a break and rest.

6. **Find the right support.** Living with an ostomy can be challenging at times, and it's important to have a support

system in place to help you through the ups and downs. Consider joining a support group, connecting with other ostomates online, or seeking out a therapist or counselor who can provide additional support.

7. **Plan ahead.** Whether you are traveling or just going about your daily routine, it's important to plan ahead and be prepared for any eventuality. Keep extra supplies on hand, and think about how you will manage your ostomy in different situations.

8. **Wear ostomy clothing** that fits well and is comfortable. Ostomy clothing, such as ostomy wraps and ostomy belts, can help keep your ostomy bag secure and in place, and can also provide an extra layer of protection against leaks. Choose clothing that fits well and is comfortable to wear, and be sure to follow the manufacturer's instructions for care and maintenance.

9. **Stay active.** Just because you have an ostomy doesn't mean you have to give up your favorite activities. With a little extra planning, you can continue to exercise, participate in sports, and enjoy other forms of physical activity.

10. **Find your own way.** Every ostomate is different, and what works for one person may not work for another. Experiment and find what works best for you, and don't be afraid to try new things.

By following these tips, you can learn to manage your ostomy effectively and live a full, active, and fulfilling life. Remember, you are not alone, and there is always help and support available if you need it.

UOAA Virtual Ostomy Clinic

Whether it's a colostomy, ileostomy or urostomy, a new ostomate learning to care for their stoma or an existing ostomate grappling with new complications, the journey can be overwhelming. UOAA's Virtual Ostomy Clinic provided by The Wound Company offers support through telehealth visits and ongoing touchpoints via texting and emailing to make sure ostomates have the right supplies for their unique situation and thoroughly understand how to care for their ostomy.

- * Assess a person's ostomy in one comprehensive telehealth assessment by Zoom in the beginning of the 30-day period
- * Assist ostomates and their caregivers in choosing supplies and recommend pouching options that fit the person's lifestyle and health goals
- * Help ostomates and their caregivers prevent and manage skin irritation, rashes, and other complications around the ostomate's stoma.
- * Answer ostomy questions from ostomates over email or SMS for the 30-day program.

- * Provide personalized education, care, and support throughout the program, including tips on diet, nutrition, hydration and intimacy.
- * Follow up with one additional comprehensive telehealth assessment during the program when necessary.
Provide a summary of the assessment and recommendations for ongoing care after each telehealth assessment.

Ostomies change bodies and lives. People living with an ostomy need personalized suggestions and ongoing support from medical experts who really understand ostomies. In the healthcare system today, too many ostomates do not have the regular access to a certified ostomy nurse they need for a successful health journey. This is why UOAA has partnered with The Wound Company – to bring certified ostomy nurses to ostomates and their caregivers across the United States virtually. For a one-time direct payment of \$125, The Wound Company's certified ostomy nurses provide people with personalized support via Zoom, text SMS and email for 30 days – in the privacy of their own home.



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



UOAA's Main Website -
www.ostomy.org

UOAA Discussion Board -
www.uoaa.org/forum

Facebook: [Facebook.com/UOAA](https://www.facebook.com/UOAA)

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humor.



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Need Emergency Ostomy Help?

Our Ostomy Clinic and Angel Closet are temporarily closed.

We are searching for a new home for the clinic/closet. If you have any ideas on where we might be able to house them, please contact Marilyn at 727-366-0807 or Lila Watkins at 727-744-2660. We would like to have this resolved as soon as possible!

There are no bad ideas! Thanks for your help!



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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.

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