



AFFILIATED SUPPORT GROUP

Affiliate Group #004

Clearwater Ostomy Support Group

www.clearwaterostomysupportgroup.org

clearwaterostomy@gmail.com

SUPPORT LINE 727-490-9931



Feb 2023

Next Meeting

Sat, March 18, 2023

Support Meeting 10:30 am

The Masonic Lodge

1145 Highland Ave NE

Largo, FL 33770

UPCOMING EVENTS

2023 MEETING SCHEDULE

Subject to changel

April 15th

May 20th

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

the President's Message

Hi Everyone,

This month we will be having our Roundtable. Be sure to bring all of your issues and questions regarding your ostomy. The Roundtable is extremely helpful as the information comes from those that have likely lived through the same issue and have now discovered the answers you may need.

Looking forward to seeing you there!

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

5 Ostomy Skin Care Tips

Good skin care habits and routines will help you avoid peristomal skin complications. Below are some practical tips to help you maintain healthy skin while saving time too.

Keep it simple. Less is better when caring for the skin around your ostomy. For most people, water is sufficient for cleaning the skin. If soap is needed, use a mild soap without lotions or creams that may leave a residue or film on your skin. This can interfere with the skin barrier adhesive.

Use an ostomy skin barrier with ceramide. Just like a brick wall needs mortar to keep it strong and firm, the skin needs ceramide to bond the cells of its outer layer.

Be proactive about preventing peristomal skin complications – don't accept them as normal. Many people living with a stoma who have a peristomal skin complications do not seek help or guidance, believing it is normal. It is not. Quick identification and treatment are important.

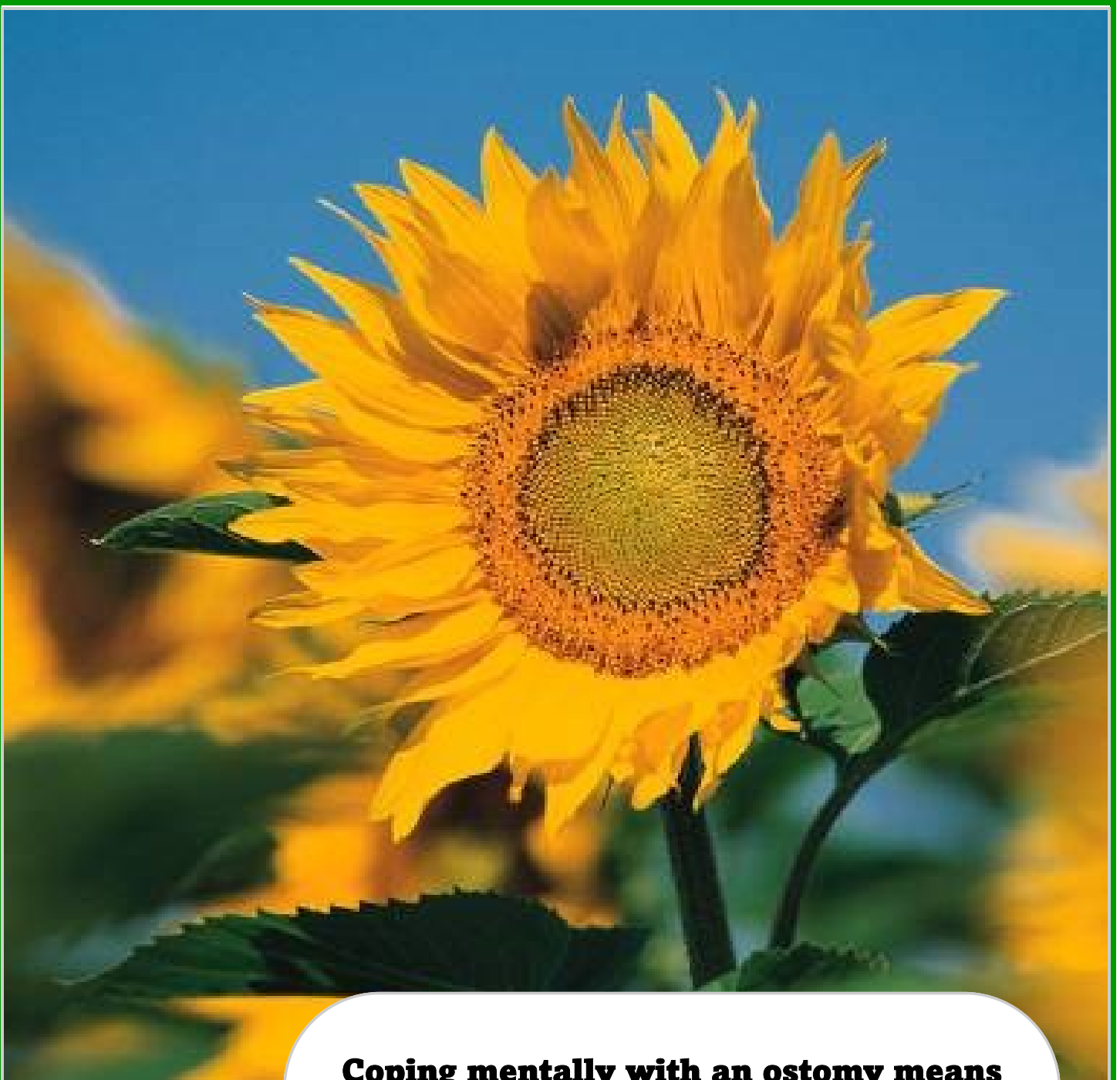
Remove and replace your ostomy pouch if you experience itching. Peristomal itching can be a problem, even if you don't see any visible skin damage. If you start to itch, your best bet is to remove and replace your pouch. If itching persists, however, contact your stoma care nurse.

Use stoma powder to absorb moisture from broken skin. Stoma powder (not talcum powder) absorbs moisture and to help protect peristomal skin to facilitate healing. When using stoma powder, make sure to brush off the excess before applying your pouching system. Too much powder can interfere with your pouch seal.

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.





**Coping mentally with an ostomy means
different things to different people**

By Amy Robson

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For me, mental health with a stoma is being psychologically and emotionally “well enough” to cope with day to day life, and not letting its ill effects turn into a downward spiral. My view of physical health is being free from illness or injury, which many have benefited from since getting ostomy surgery. Looking after your physical health can lead to good mental health and vice versa. But what do you do when physical health issues are beyond your control? Being diagnosed with Crohn’s disease at 7-years-old, it’s always been a struggle looking after my physical health, which in turn has impacted my mental health.

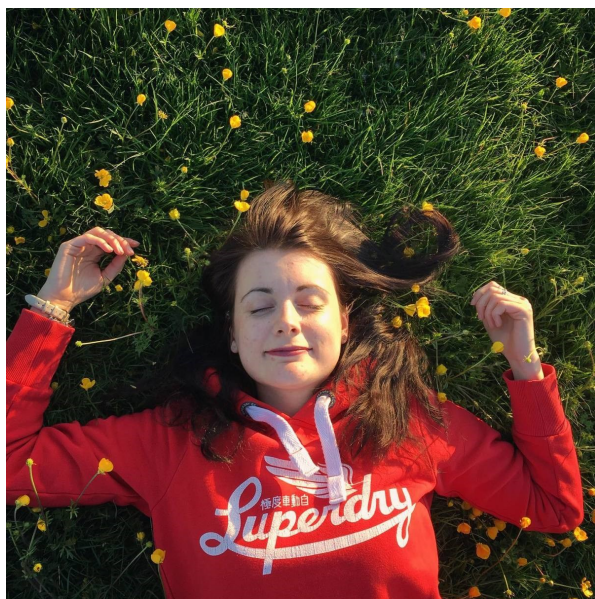
I don’t remember a whole lot when I was first diagnosed, apart from my doctors giving the pain a name. In that way, it gave my parents comfort knowing what was causing me to be so ill, and comfort there would be some

way to help me get better. For nearly 10 years, I was treated with quite a few different medications and endured many horrible procedures. I couldn’t attend school regularly and was often too sick to play with friends. Eating food was never enjoyable. Some of those unpleasant experiences are embedded in my mind and always will be. I feel like I missed out on so much and know that I’ll never get my childhood back.

Finding out that I needed a permanent ileostomy didn’t come as a surprise to me. My doctors were reluctant to rush into surgery because they were worried it would be too much mentally to cope with at age 19. But I was ready for it. The prospect of living in constant pain even one more day pushed me forward. I made up my mind to have the operation as soon as possible with the hope of getting my life back. After the surgery in 2011, my mental health has

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been on an up and down roller coaster ride. Being a young woman surrounded by so many social and self-image pressures is hard enough, but I feel even more overwhelmed having physical complications from illness and an ostomy bag. Because I struggle mentally with “Stacey Stoma” I decided to see a counselor who has helped me (immensely) with anxiety and dealing with triggers like being around hospitals. I struggle with fear of abandonment from having spent A LOT of time alone in the hospital as a child. Sometimes I get flashbacks of seeing myself in pain, rocking back and forth to stop losing control of my bowels. I get depressed thinking about how my family couldn’t be around more to support me (through no fault of their own). Counseling helped me learn coping strategies to move beyond the struggles and dark thoughts.



I find it so infuriating when I hear people say that if you “stay positive” about a rubbish situation then it will hurt less. I agree to some extent that if you’re positive then things may have less power over you, but what is actually wrong with feeling negative once in a while? I am human and I have emotions. I will feel how I want to feel without any guilt that I’m doing something wrong when I don’t see the bright side. Sometimes, I just can’t see the bright side, even if it’s right in front of me. Sometimes, I just want to be mad at the world and take a day off where I can sulk and hide. And that’s perfectly okay. On those days, even though it’s super tough to do, I try to practice self-care and rest. Personally, I find that being *positive* but *realistic* helps me remember that tough times don’t last and things will get better.

Article by Amy Robson. Article dated August 26, 2019. Retrieved from OostomyConnection.com. <https://ostomyconnection.com/opinion/coping-mentally-with-an-ostomy>.

IMPORTANT NOTICE: *Articles and information printed in this newsletter are not necessarily endorsed by the Clearwater Ostomy Support Group and may not be applicable to everyone. Please consult your doctor or Nurse for the medical advice that is best for you*

7 Myths About Ostomies Debunked!!!

MYTH: An ostomy is a death sentence.

This couldn't be farther from the truth. For many facing ostomy surgery, they are extremely ill, and the alternative to having surgery is facing fatal complications. Many patients will say that getting an ostomy gave them their life back.

MYTH: Only cancer patients have ostomies.

Most people hear about patients with cancer having ostomies. However, patients with common diseases, like [Crohn's disease](#), [ulcerative colitis](#), diverticulitis, familial polyposis, neurogenic bladder disease, and birth defects, may require ostomy surgery at some point in their life.

MYTH: Ostomies are permanent for everyone.

For some patients, an ostomy is permanent. However, for many, an ostomy is performed to [allow part of the intestines to heal](#) from scarring, inflammation, infection, abscesses, and fistulas before the procedure is reversed to create an internal pouch.

MYTH: People with ostomies stink.

Most ostomy products are built with air filters in them that use charcoal, which neutralizes potential odors. Unless the individual has an ostomy leak, you won't be able to smell anything.

Take Aria — diagnosed with ulcerative colitis when she was in kindergarten, Aria was seven years old when she had a [proctocolectomy](#) (removal of her colon and rectum). Following the surgery, she

lived with an ileostomy for two months while her j-pouch healed. She is just one example of the many young people who live with ostomies.

MYTH: Everyone can see if you have an ostomy.

Not if you don't want them to. Ostomies are designed to be hidden easily under most clothing. The person with the ostomy may be concerned about the visibility of their ostomy, but to the average person, it is typically unnoticeable.

MYTH: You can't dress regularly if you have an ostomy.

If you have an ostomy, you can wear the same clothing you wore before your surgery with very few exceptions. To provide peace of mind and additional support, some ostomates may wear special accessories to help keep the ostomy in place and prevent it from showing.

[According to the United Ostomy Associations of America](#), "many pouching systems are made today that are unnoticeable even when wearing the most stylish, form fitting clothing for men and women."

MYTH: You can't be physically active if you have an ostomy.

This is also wrong. Many people with ostomies are physically active and participate in sports of all types. Rolf Benirschke played as a placekicker for the San Diego Chargers while living with an ostomy.

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Lots 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)

Twitter: [Twitter.com/UOAA](https://twitter.com/UOAA)

Phoenix Ostomy Magazine:
<https://phoenixuoaa.org/my-account/>

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Follow us on Facebook and Twitter for lots of great information and some humor.



<https://www.facebook.com/clearwaterostomysupoSrtgroup/>



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Need Emergency Ostomy Help?



Lila Watkins at Bay Breeze RX has graciously set up a beautiful private room where she can see people and help them with problems they may be having with their ostomy.

Bay Breeze RX is located at 3350 East Bay Drive. Largo, FL 33771
P: 727-614-9933 | www.baybreezerx.com

We'd love to see you at the next meeting!! Everyone is welcome!!

COSG #004
12931 88th Ave. North
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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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