

The Ostomy Support Newsletter Of Jacksonville, Amelia Island, Citrus County Support Group & Gainesville Ocala



The AD Mirror Systems platforms were designed to assist individuals with a variety of needs. There are no knobs, levers or fasteners to turn, so even individuals with limited dexterity can use the mirror system independently.

Some of the many uses include:

- Aiding individuals with an Ostomy or Colostomy in cleaning or changing their appliance.
- Aiding individuals with Diabetes or Amputees in inspecting and
- cleaning their skin or wounds.
- Aiding individuals with Spinal Cord Injuries or Disorders in performing personal care activities.
- Any activity that requires a third hand to make life a little easier to perform routine daily tasks.

AD Mirror Systems are the brainchild of the lead designer Ron Dolar. He is a medical needs patient himself and aspires to enhance the lives of those with health care needs that desire greater independence in their lives.

Greater Independence for a life lived with Fewer Limitations

#### AD Mirror Systems:

- Easy to both assemble and to disassemble.
- Adjust both the mirror height and viewing position to meet your needs.
- All of the sections slip together without tightening or loosening knobs, levers or fasteners.
- Systems can be used standing, seated or lying down.
- Features stainless steel construction that is durable & hygienic.
- Once the System is adjusted both hands are free to be used to perform the tasks required to maintain your independence.

#### Contact Us: ADproducts, LLC

PO Box 48122 Spokane, WA 99228-1122

Call Us: 1-888-959-6770 Email: admsinfo@adproducts.us Visit our website: www.admirrorsystems.com



#### AD MIRROR SYSTEMS By ADProducts, LLC

- HOME
- TROOPER
- FOOT INSPECTION

#### 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: Aug 20th

Gainesville Support Group Contact info: Brinda Watson (352) 373-1266

Brinda Watson (352) 373-1266 Jean Haskins (352) 495-2626 Meets the 1st Sunday of each month (except Holidays) at Hope Lodge2121 SW 16th St Gainesville, FL Next meeting: Sept 10th\* at 2pm \*Due to Labor Day

#### Ocala Support Contact info:

Lynn Parsons (352)245-3114 www.ostomvocala.com

Meets the 2nd Sunday of each month (except July & Aug) at 2 p.m. at the Sheriff's Station 3260 SE 80th Street between Ocala and Belleview. Next Meeting: **Sept 10th** 

#### **Citrus County Support Group**

Meets third Sunday of each month at 2:00 PM in the Seven Rivers Regional Medical Center, 6201 N. Suncoast Blvd., Crystal River, FL 34428, in the Community Room of the Medical Office Building Next Meeting: **Aug 20th** 

#### Amelia Island Area

Ostomy Support Group (904) 310-9054 Meets second Monday of each month at 6:30pm UF North Campus UF Health North 15255 Max Leggett ParkwayJacksonville, FL 32218 (Meeting Room 3-4) Free parking Next Meeting: Aug 14th

Medical Care Products, Inc. (904) 733-8500 (800) 741-0110

#### Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/?ref=aymt\_homepage\_panel





"Gutsy's FAB Gab-About: Stories of Ostomy 'Glories/Gories'!" "Speak Out and YOUR WORDS WILL Be Heard!"By Linda

## Amanda's story:

"Hi! My name is Amanda. I have been an ostomate since January, 23<sup>rd</sup>, 2017. I would like to tell you all my story. I am a 39-year-old mother of two boys, one is 13, and one is 11. My problems began a little over 13 years ago when I had my first son.

My pregnancy was absolutely a dream. I didn't even know I was pregnant half the time.

I felt wonderful, energetic, and generally great until the day that precious boy was born. He was a couple of weeks early but was still 8 pounds and 2 ounces.

I had a very long labor and as time progressed, my son's heart beat

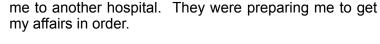
began to slow way down. He began to show signs of distress. He was too low in the birth canal at this point to have a C-section. The doctors needed to get him out of me quickly. It was so weird; I went from pushing and not having any problems to suddenly being told my baby's life was in danger. I remember them asking me if it was ok to use a vacuum to get him out. I was panicked. I didn't care what they did at that point provided they got him out as quickly as possible and that he was ok. I remember screaming, "Get him out of me!" So, they did. They attached a vacuum to his head and he was out in less than 10 seconds.

They placed him on my chest and the feeling I got was indescribable. I was so happy. I looked at my husband and he did not look happy at all. He looked terrified. I was so confused and kept asking him what was wrong. Everyone was scrambling around and I had no idea what in the world was happening. My husband kept asking me if I was ok. I was great! I didn't understand.

Later I found out I was bleeding profusely from my vaginal area. I had suffered a 4<sup>th</sup> degree tear. One that my OB doctor later told me was the worst she had ever seen. At the time, they told me they were going to sew me up and everything would be fine. They didn't tell me the whole story.

I laid there for 3 hours while they worked on me. I was not put to sleep.

Three weeks later I was readmitted to the hospital with what they thought was necrotizing fasciitis. That is a flesh-eating bacterium that is life threatening. They ended up transferring



I found out later that what was happening was not that serious. I had an infection, yes, but all they had to do was take apart the repair and redo everything. What a relief! When they did that, they found so many fistulas that had formed as I was healing that I needed three surgeries in a week to fix everything. I had another surgery 4 months later. I had several more in the years that followed. My relief was short-lived.

What happened was I had absolutely no sphincter muscles left. I was nearly completely incontinent. I

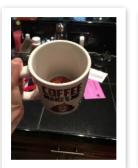
pooped myself regularly. I got to the point I was wearing diapers 24/7 and refused to leave my house unless absolutely I somehow held necessary. down a job during most of this time. I lived like this for 13 I had every surgery vears. imaginable to fix my problem. I did physical therapy for years. I tried everything. I eventually gave up about 3 years ago. Last year I decided to see another doctor. I would try to fix



this one more time. He ended up saving my life.

I had become suicidal. I had been on and off for years. Something about this time was worse. I did not want to live another day. This surgeon gave me the option of a permanent colostomy. I jumped at the chance. My surgery was completed in January.









The number of silly things I got as gifts leading up to the surgery was hilarious: And those are just a couple of the examples. I got shirts, earrings, slippers! If you can't have humor, you have nothing.

The day of surgery was one of the scariest days of my life. I cried from the time I got to the hospital to the time I fell asleep. This was something life altering. I also had my entire future riding on this. I was so happy to do it, but what if something didn't work out? What if the answer I had been searching for for years was not this? I couldn't take something else not working.





Before surgery (Somebody help me!)

After surgery (drugged)



First look at my stoma (not nearly as gross as I thought [very brave!]

Since then my life has been completely different. Have I had bad days? Absolutely, yes. Have I felt sorry for myself? Of course! But guess what? I can leave my house. I have a job. I am not scared to do things. I am not scared to get in my car. I can be a mother. Finally, I found my answer after years of searching.

There was a lot of mental damage done to myself throughout the thirteen years leading up to the surgery. My relationship with my son isn't the greatest. I haven't been there for him. Either of them. I haven't been a good wife. There are things that need repaired and I am getting there.

### AUGUST 2017



My body is whole, though. I'm finally whole.

Many people have intense anger when they get ostomies. Even though this is my answer to my problem, I still do sometimes. I mean, it is a weird thing to get used to. It took a bit, but now I am grateful almost all the time. I appreciate little things so much more than the average person. I have learned a great deal during this experience. I am a firm believer in "everything happens for a reason."

I have gone through many stages in the few short months I have had my ostomy. I love it though. I wish I would have done it sooner and I will never go back:

I want to help other mothers that have gone through what I went through. I want to be there to tell them it is ok when they are laying in a hospital bed with seemingly no future ahead of them. I think somehow I can accomplish this. Maybe that is my "reason."

My stoma is named "Rosie the Riveter." Not for political reasons. She does look like a rose; but mostly, it's is because together, "We *Can* Do It!"



! have a future now because of her!"



#### **10 Things I Wish I Could Tell Myself Before My Ostomy** By Amy Oestreicher, featured on ostomyconnection.com

When I first got my ostomy, I felt very alone. I felt selfconscious of the smell and sound, and sometimes I longed for my old body. When I couldn't take self-loathing anymore, I decided to make friends with it. I reached out. I inquired about support groups in my area and realized there are many people like me. I realized my ostomy is a beautiful thing and has enabled me to do all the things I've been able to accomplish over the years. It is my uniqueness.

These are 10 things I would have liked to tell myself when I first had an ostomy - 10 things I didn't know but eventually learned, which I am so grateful for today:

#### 1. What it was

I had no idea what an ostomy was before I had one. But I have a confession: I didn't realize exactly what it was until a year later! Coming out of multiple surgeries, I had so many bags and new anatomical surprises to think about that a little pink bulge on my belly seemed to be the least of my problems!

I've learned things in the past 10 years that have shocked, scared and relieved me, such as: you can't actually feel your stoma - no nerve endings! I've had three ostomies and four ileostomies over the years. I didn't realize how different they were. Once I learned about the differences and functions of each, I was better able to take care of them.

#### 2. What my limits were

When I saw that I'd have to live life with a bag stuck to my side, I assumed I'd be "fragile" for the rest of my life. But believe it or not, there are so many active ostomates out there! Swimming, karate, ballet, yoga - I've done everything I did before my ostomy and more.

#### 3. There are so many strong ostomates

I was privileged to be the Eastern regional recipient of the Great Comebacks<sup>®</sup> award and meet five other amazing ostomates doing incredible things. There is a huge, supportive ostomy community. Did you know Great Comebacks<sup>®</sup> was founded by former NFL linebacker Rolf Benirschke?

#### 4. Ostomates excel at innovation and inventiveness

It turned out I was able to do all those things I thought I couldn't - but that didn't mean it was easy. Some of the best things in life take work, and that makes you appreciate it even more. Let's just say that ostomy wraps, stoma guards and pouch covers have become good

friends of mine, all products that were created by ostomates.

I've also created a workshop for ostomy patients and healthcare professionals!

#### 5. How Amazing My Body Is

I have a new respect for my body and the way it can function now.

### 6. Judgment Hurts, But Fear Hurts More

Stay informed and know the facts. The more I actually understood how an ostomy worked, the more I realized how wonderful it was. After that, I took it as my responsibility to educate others. Instead of wondering if I was being "judged" by others, I took it as a privilege to inform them.

#### 7. Everything Is Connected

Take care of your full self: emotional, spiritual, mental and physical. If you're stressed, you might be bloated or feel pain or discomfort. Remember to take deep breaths in difficult times.

#### 8. The People Who Love You, Love You

If you're just getting comfortable with your ostomy, remember that your support system loves you for who you are. You are more than your ostomy. Reach out when you feel alone and never forget how loved you are.

#### 9. Eat Fresh

You are what you eat, so eat whole and nourishing foods. Your ostomy will thank you, and so will you!

#### 10. Life Can Go On

Throughout the years, I've been strong, determined and willing to do whatever it took to stay alive. I've dealt with tubes, bags, poles, you name it. And if this ostomy is all that I'm left with after everything, then I am truly grateful. More than that, I thank my ostomy for enabling me to live life to the fullest, to my fullest. I call it my Harry Potter thunderbolt scar: a symbol of strength, courage, individuality and life.

There are a few things I didn't know before my ostomy. But what I look forward to most is everything left to learn. Thank you, ostomy, for making the world a wide open door once again.

### **UOAA Discussion Board**

https://www.uoaa.org/forum/index.php



## What is a WOC (ET) Nurse?

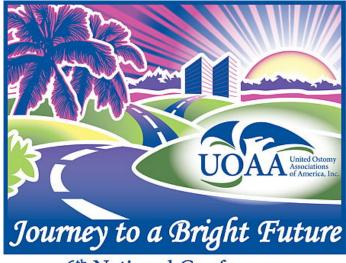
A "WOC" (Wound, Ostomy and Continence) nurse, referred to previously as an "ET" (Enterostomal Therapy) nurse, is often the best medical professional for dealing with problems involving ostomies.

A WOC Nurse is a graduate of an educational program accredited by the Wound, Ostomy and Continence Nurses Society (WOCN). WOC Nurses specialize in the care of patients with selected disorders of the gastrointestinal, genitourinary and integumentary systems. They provide stoma care which includes:

- pre- and post-operative education and counseling;
- stoma site selection;
- assistance with dietary, sexual, and lifestyle issues;
- post-discharge care and counseling.

In addition, WOC nurses manage draining wounds and fistulas; they treat pressure ulcers, vascular ulcers, and neuropathic ulcers; and they help manage incontinence.

To locate a WOC nurse in your area: Many of the individual Group pages linked to this site include listings of WOC nurses affiliated with the group. Also, the WOCN Website includes an online referral database that you can search with your web browser to locate a WOC nurse near you.



6<sup>th</sup> National Conference Tues.–Sat., Aug. 22–26, 2017, Hotel Irvine, Irvine, California



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