August 2022



"We help ourselves by helping others to help themselves."

# Ostomy Association of the Houston Area

We are a volunteer-based organization dedicated to providing education, information, support and advocacy for people who have had or will have intestinal or urinary diversions. P.O. Box 25164 Houston, TX 77265-5164 www.ostomyhouston.org

## My Life With An Ostomy—Josh

Interview with Josh Nelson, Courtesy of UOAA ostomy.org, July 2022

Are you a new ostomate? Or a soon-to-be ostomate? No matter how far you are in your ostomy journey, adapting to your new situation is an inevitable part of the process. Talking to others who have already been in your shoes can help you in adjusting to this time of your life. That's why we asked Josh Nelson, the first activeduty U.S. Airforce Pilot living with an ileostomy, to share his story and his experience with his ostomy journey to give insights on how getting an ostomy can be just the beginning of an exciting new chapter.

### **Before surgery**

#### What was your life like before your ostomy surgery?

I was diagnosed with ulcerative colitis in November of 2017. Throughout the next year after my diagnosis, I tried maximum medical therapies starting with oral medications, then biologics, and then transitioned to combination therapies with biologics. Unfortunately, my body just did not respond to the medications, and the disease just took over my life. If you want to talk about quality of life with ulcerative colitis before I had the surgery – I didn't have one. I was 145lbs. I was having 18 to 20 bowel movements a day. I wouldn't leave my house. I knew where every bathroom, rest stop, and gas station were from my house to where I work. Any time I did leave the house, the only thing on my mind was, "Where's the bathroom?" in case I had that sudden urgency to go. My wife and daughters left me alone. They wouldn't even ask if I would go with them anywhere because

### **Patient Visiting and Support Services**

#### Doctors and WOC Nurses, please note:

Upon request from a doctor, nurse, or social worker, a specially trained visitor will be asked to contact an ostomy patient by phone or visit them in person before and/or after surgery. The visitor will be matched as nearly as possible according to sex, age, and type of ostomy. The visitor does not give medical advice, and there is no charge for this service. Please contact our Visitation Coordinator, Marian Newman at 713-392-5768, or newmarian@gmail.com.

they just knew I did not want to go anywhere. I had no quality of life. I was a prisoner in my own home, and that's no way to live your life.



How did you feel when you learned you would be having ostomy surgery? What questions of fears did you have?

I made the decision to have an ostomy surgery in November of 2018, and I had about three days' notice before the surgery was going to take place. The staff at the University of Minnesota Medical Center, where I was inpatient for 30 days prior to surgery, did a great job of introducing what life with a stoma will be like. My questions were, "What is a stoma?" "What are the appliances that I'm going to have?" "How do I care for this thing, and how do I recover?" and "How do I slowly adapt to having an ileostomy and then getting my life back?" The WOC nurses were great, because they would just simply start to explain, "Oh, here's what a wafer or barrier looks like," "Here's what a pouch looks like," "Here's what some of the accessories are." They also explained,

(continued on page 3)

We are a health support group, a non-profit, tax-exempt, organization of volunteers whose purpose is to provide mutual aid and education to persons who have ostomies and to their families. We are a Texas non-profit corporation. Membership fees and donations are tax deductible.

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News from the OAHA Board

The Ostomy Association of the Houston Area hosted its biennial Ostomy Visitor Training Workshop virtually on Saturday, July 23, 2022. With our very talented Allison Rosen facilitating the Zoom meeting the 24 attendees were treated to not only educational but also interesting presentations from Marian Newman (Basic Visiting Policies and Procedures), Cindy Barefield BSN, RN-BC, CWOCN (Ostomy 101 Anatomy and Physiology), Joan Burnham MSN, RN, ONN-CG, OCN, MED SURG-BC (Psychological and Social Issues) and Lorette Bauarschi and Kathleen Duplessis (Visiting Skills). We managed to stay on schedule with plenty of time at the end of the workshop for Q & A's. I have already received positive feedback from attendees and on behalf of the OAHA I would like to thank all of our presenters and attendees who gave up their Saturday morning in order to give back to the greater ostomy community. This group of certified visitors are now ready to support new ostomates and those considering this life saving surgery. Thank you all

As always, please feel free to attend any or all of the group meetings. Everyone is welcome—ostomates, family, friends and medical professionals.

The OAHA Board

### **Northwest Group News**

In July, there were about 6 people on the Zoom call. We discussed group needs and future topics. We also welcomed two new ostomates to the group. In August we will have a short presentation on nutritional needs and tips by Lisa Kelly, CWON, for Mölnlycke. Our next meeting will be August 17 at 7 pm. You can find the link in your email letter.

#### Billy Locke 337-515-6354

### **Baytown Group News**

No update this month, but there will be a meeting on Monday, August 15.

### Cindy Barefield, BSN, RN-BC, CWOCN

 $281\text{-}428\text{-}3033, \\ \underline{\textbf{cbarefield@houstonmethodist.org}}$ 

We encourage you to bring your spouse or significant other and members of your immediate family to our meetings.

### **Central Group News**

The Central Group did not hold a support meeting in July because of the July 23rd Ostomy Visitor Training Workshop. We had 24 attendees, we enjoyed fun and informative presentations, and it was wonderful to see everyone. Please see the News from the OAHA Board for details.

We will resume our 3rd Monday of the month, in-person support meetings on August 15th and hope to see you there!! We want to hear from you and learn about the type of presentations that would be helpful in the future months and we are always there to support you and our ostomy community—all are welcome!

Kathleen Duplessis, President, OAHA, Kathleen.duplessis@outlook.com or 713-299-3180

### Sugar Land Group News

### Meeting Summary

Joan started the meeting and introduced new Nurse Navigator, Jennifer Cerda, who will be taking over the GI oncology Navigation care.

Amanda (Mandie) Wasik with Convatec presented the various products that are available through the website OstomySecrets<sup>TM</sup>.

Products include intimate apparel form both men and women, swimwear, and other accessories such as adhesive remover, barrier, Eakin rings, and Stomahesive<sup>TM</sup> products.

### **Open Forum**

Our discussion covered multiple topics. We reviewed crusting, with Joan giving a demonstration. The topic of showering with a stoma brought out the creative side of the attendees. Multiple attendees shared their special secret on how to shower with a stoma including using Glad Press and Seal to cover the bag and prevent it from getting wet, to how to dry your bag after a shower. Daniela provided a reminder to use the filter cover before getting the bag wet. We also talked about stool solidifiers for ileostomies or diarrhea, and diet issues on fiber, and dairy products.

Our next meeting will be on Thursday, August 18, 2022 at 6:00 p.m., virtually, our topic will be from Joan on Social Media and Ostomies.

Joan Burnham, MSN, RN, OCN, MEDSURG-BC

Oncology Nurse Navigator 281-274-0188 jmburnham@houstonmethodist.org

### HOPE—TCH Woodlands, Pediatric Group News

Due to Summer schedules of many of the teen members, the group will reconvene for virtual meetings in September. In the meantime, the group members will continue to reach out to new ostomy patients on an individual basis and will be available to support those needing additional supplies or troubleshooting.

MaryAnne Lewis, maryannelewis@hotmail.com or 281-948-1490

## My Life With An Ostomy—Josh

(continued from page 1)

whether it's ileostomy, colostomy, or urostomy, people do go on to live fully functional lives.

I definitely had some goals, but I had no fears when it came to having the surgery. I mean, okay, fine – I had maybe a couple fears of having surgery, but the stoma itself I was not afraid of. The reason for that is because I was kind of at my lowest of lows, and I thought to myself, "How could this be any worse than what I'm dealing with right now?" I remember my surgeon and the medical staff told me that once the surgery was done, I would no longer have the pain, and each day moving forward I could start to focus on getting my life back.

# What advice do you have for people who are considering ostomy surgery?

My advice to anybody who is considering having the surgery is to keep an open mind. It will take some work. You will need to adapt to what you have. That means taking care of yourself physically, mentally, and emotionally because it is a step-by-step process. It is a big transition, but I've done everything I could to make sure my quality of life has improved. I do not regret my decision one bit. I have my life back and that's what I think is most important.

### **Coming home**

### What was your experience like right after your ostomy surgery?

I had about five days in the hospital after surgery, and during that time I was focused on recovery, protecting my abdomen, and getting my strength back. The nurses did a great job of explaining step by step what it takes to change out the pouch and care for my stoma. Before I left the hospital, I needed to make sure that my pain was under control, starting to move around, and understood how to change my appliance by myself.

### What were your goals after your surgery?

I focused on transitioning to home life again, figuring out how to slowly heal my body, and how to start eating foods again.

My goals were:

- 1. Getting healthy food into my body so that my body can recover.
- 2. Finding out what schedule I should be on for changing out my appliance.
- 3. Observing my stoma area regularly to keep my skin healthy, prevent skin breakdown, and make sure that my stoma was healing properly.

# What would you tell someone else returning home from their surgery?

- Don't be afraid of touching the stoma because your stoma doesn't have any nerve endings you can feel.
- It's extremely important to have a solid understanding of how to change your pouch and ask for products before you leave the hospital.
- Your WOC nurse will probably explain that what works best for you in the hospital may change after you go home and are healing up. Initially, it might be multiple times a week that you're changing your whole appliance out because your abdominal area might've been swollen from the surgery, and as it starts to reside some of those wafers might fit differently.
- Everybody's different. Everybody responds to products differently. Those first couple of weeks to a month is just trial and error to find out which products work best for you. After you figure out your change routine, your quality of life can start to improve. You no longer need to worry about having multiple leaks or having multiple issues with your appliance, and you can start to focus on making other goals for your life with an ostomy.
- Just take it day by day. Don't think of the end state right away because it's going to take time to get there. Create small goals on a day-to-day basis and then think long term and how to get there. It's definitely a marathon; it is not a sprint. You're going to learn something new every single day until you get comfortable living your life and understanding how to handle your ostomy.

### Managing life with an ostomy

### How has your life changed now that you have an ostomy?

I've had my ileostomy for over three years, and I can honestly say I haven't looked back or had any regrets whatsoever to surgically remove my colon. I try to tell people my worst day as an ileostomate far exceeds my best day ever living under the umbrella of Inflammatory Bowel Disease. I am no longer bound by any type of medication. I have no special diet, nor do I have any restrictions, and my quality of life is through the roof. I could not be happier, and I do not regret the decision one bit whatsoever. But how did I get there?

First off, I accepted the fact early on that I was going to have an ileostomy for the rest of my life because it was a decision I made for a better quality of life. After accepting it, I could focus on moving forward versus dwelling on the "how's" and "why's" with ulcerative colitis.

Secondly, after trying multiple different products, I came across a Coloplast product that worked really well for me. Once I found the product that worked well for me, that gave me the confidence *(continued on page 4)* 

## My Life With An Ostomy—Josh

### (continued from page 3)

to continue moving forward with my life and not have to worry about having leakage or skin issues. I have a couple routines, I'll change my pouch no more than twice a week, but no less than once a week. I observe how the wear and tear of my wafer and appliance is working.

On top of that, I wanted to do everything that I could to make sure that I am living the best life that I can. I made some personal decisions, such as eating better and taking care of myself. I exercise quite a bit, and I try to eat fairly well. I try to focus on eating healthy foods so I can get the nutrition that my body needs.

# What are some other tips you want to share about managing life with an ostomy?

It's important to understand that this affects everybody differently, and it's up to you to determine what works best for you to adapt, overcome, and live your life with any type of ostomy. I reached out to local support groups, and I think that's extremely beneficial because you get connected with like-minded individuals. No matter whether they have a colostomy, ileostomy or urostomy, you can touch base with them and share your fears and concerns. A lot of these people have lived decades with their ostomy, and they're proof to you that you probably can too. Finding that help and resource is extremely beneficial in helping you understand how to navigate life now that you have an ostomy and what's out there for you.

I hope this helped you to understand what it was like to be diagnosed with the disease, have a permanent ileostomy, and how I live my life moving forward. Thank you! -Josh

\*Josh has received compensation from Coloplast to provide this information. Each person's situation is unique, so your experience may not be the same. Talk to your healthcare professional about which product might be right for you.

## So You're Getting an Ostomy

By Robin Glover, Courtesy of UOAA ostomy.org, June 2022

Oh no! An ostomy! You're going to be pooping or peeing into a bag attached to your stomach?? Your life is over, right? No more dating. No one will ever like you. Children will run from you! It's so gross!

Don't worry. We've all been there. As great as they can turn out to be, the idea of getting an <u>ostomy</u> is never really welcomed news. Add on to that, you're probably very sick and haven't eaten well in weeks and you're tired and worried and feel alone. You know nothing about ostomies and are wondering what life will be like with one.

### Will having an ostomy bag eventually become second nature and you won't even really think or worry about it? Yes.

First of all, life is going to be great! You'll feel better. You'll eat better. You won't be bleeding out of unspeakable places and constantly panic-stricken about finding the nearest bathroom. Your life will become more consistent and routine and you'll end up being happy you had a lifesaving, life-improving surgery.

It's possible that you don't believe that right now, though. And while it does turn out to be a good thing for most, there is an adjustment period and a lot of unknowns and <u>myths</u>. For instance, how do I change my ostomy bag? Will I stink? What if I have an accident in public? Can I ever play sports again? Or exercise? Or go swimming?

In short- is it easy? No. Will it be fine? Yes, yes and yes. But for a little expanded information and peace of mind, we can go into a little more detail.

### How Do I Change My Ostomy Bag?

You gently peel it off, wipe things off a bit, and put another one on. It really does become as simple as that. But, at first, you'll

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## **Donating Ostomy Supplies?**

Here are a few options if you would like to donate ostomy supplies. These non-profit organizations are all volunteer run.

**Medical Bridges:** they collect medical supplies locally. On their website, click the Get Involved link and then the donate supplies link. It provides you with various options. <u>https://www.medicalbridges.org/</u>

**Friends of Ostomates USA:** provides ostomy supplies and educational resources at no cost to ostomates in need around the world. Their warehouse is located in Louisville, KY. A fun fact: Our very own Cindy Barefield, BSN, RN-BC, CWOCN is President of Friends of Ostomates! Please go to their website for details: <u>https://www.fowuso.org/</u>

**Kindred Box:** is dedicated to improving the lives of people with ostomies and they distribute donated ostomy supplies to support the care of uninsured and underinsured ostomates in America struggling with financial hardship. Go to <u>https://www.kindredbox.org/</u> and find out what ostomy products they can accept and to learn about their Postage Program which helps with your shipping expenses. The Kindred Box is located in McKinney, Texas.

More options can be found on the UOAA's website: https://www.ostomy.org/donate-ostomy-supplies/

## So You're Getting an Ostomy

### (continued from page 4)

hopefully have a specialized ostomy nurse that will teach you how to do it. After your surgery, you likely won't have to change it yourself the first several times. But, you should practice doing it and will be better off if you make the effort to know how before you leave the hospital. It also helps to know what the <u>standards of</u> <u>care</u> should be for ostomy patients and speak out before you are discharged and sent on your way.

If you did not have access to a certified ostomy nurse in your hospital be sure to seek one out. You can also <u>find a Wound, Ostomy</u> <u>and Continence (WOC) Nurse or an Ostomy Management Specialist (OMS)</u> through product manufacturers and telehealth services.

### Will My Ostomy Bag Leak?

At first, Yes. It likely will. You might even get really frustrated in the beginning because you can't seem to put it on as well as the nurse in the hospital. Even if you put it on "perfectly" and follow all the steps your ostomy pouch can still leak. You'll get the hang of it, though. Every ostomy and everybody is different. You'll learn what supplies you need, where to get them, and how to use them to make sure the fit is just right.

While you might be hesitant to leave the house for a while, you'll soon feel totally confident going anywhere you want, any time you want. And better yet? You won't be constantly worried about being near a bathroom! There's always the <u>risk of a leak</u>, though. But it won't be a big deal. You'll be able to detect it quickly and take care of it.

### Will I Smell?

No. If the appliance is attached correctly, you should never stink. No one will be able to smell you. You can be as close as you want to other people. You can go out and be in a crowded bar and nobody will know you have an ostomy bag. There are also plenty of clothing and garment options to fit well with your pouch and conceal it from anyone ever knowing – if that's how you choose to approach it.

If you do ever smell, that means you need to check your pouch for any leaks or openings allowing odor to escape. And if you happen to be in public, you can carry tape or any of a variety of things to sneak off into the bathroom and do a quick fix. Will it be uncomfortable or scary the first time it happens? Yes. Will having an ostomy bag eventually become second nature and you won't even really think or worry about it? Yes.

(Quick note: The answer to a lot of questions about having an ostomy is that "you'll figure it out" or "you'll become comfortable" because everything will be new when you first have an ostomy bag. There's no step-by-step guide. There will be frustrations. Maybe some tears. It's an adjustment. Nobody just has ostomy surgery, learns to put on a pouch, and then goes about their business. You will have issues. You may have some stained clothes and probably need to change your bedsheets one or two times. But, you will figure it out.)

### Can I Do Whatever I Want?

Generally speaking, yes. Of course, this depends on every unique situation, and only you and your doctor can accurately answer this question. But, in general, you'll be able to do whatever you want.



Simply having an ostomy won't restrict you from doing anything. You might even be able to do a whole lot more than you could before.

You'll be able to go <u>swimming</u>, play rugby, do mixed martial arts, teach yoga, <u>travel</u> the world, go on dates, and do anything you were physically capable of before having surgery. All without worrying about being in constant pain or eating the wrong thing or needing to run to the bathroom every five minutes. However, make sure to wait 6-8 weeks or until your doctor approves you for any strenuous physical activity before winning the local 5k again. (Perhaps you'll even want to take part in UOAA's own <u>Ostomy 5k</u>.)

### Getting An Ostomy Is Totally Worth It

All the details about how to change your ostomy pouch where to get supplies, and when you can go back to doing the things you love will get worked out. But the important thing to remember is that having ostomy surgery is going to be totally worth it. Even if your head is spinning now about what life will be like, it will calm down.

And also remember that you're not alone. One of the best ways to prepare is to call or visit an <u>ostomy support and information group</u> before you have surgery. Many others have been through the same process and are more than eager to offer a listening ear and emotional support. UOAA also offers a <u>new ostomy patient guide</u> and has tons of online resources to get you started on the right path.

You'll get the hang of everything, then look back and be so grateful that you are a warrior. Countless other ostomates will tell you the same thing. That is, when they're not busy living an incredible life they wouldn't have otherwise.

### You got this!

Robin Glover is a writer based in the Houston area. He has a permanent ostomy after being diagnosed with Crohn's Disease in 2017.

#### Ostomy Association of the Houston Area

### **Central Group**

Date:	Monday, August 15, 2022
Time:	7:00 p.m.
Place:	In-Person Meeting: Tracy Gee Community Center,
	3599 Westcenter Drive, Houston, Texas 77042
Program:	Roundtable
Contact:	Denise Parsons 713-824-8841 rockynme2@gmail.com

### **Baytown Group**

Date:	Monday, August 15, 2022
Time:	6:00 p.m.
Place:	In-Person Meeting
	Community Resource Credit Union (CRCU)
	Community room. Avoid the front of the hospital
	(Garth entrance). The CRCU Meeting Room is
	located just inside the door of Plaza 2 on the back side
	of Houston Methodist Baytown Hospital. Park behind
	the hospital (exit off of Baker Rd.) (Contact group
	leader for more information.)
Program:	TBD
Contact:	Cindy Barefield, CWOCN, 281-428-3033

### **Northwest Group**

Date:	Wednesday, August 17, 2022
Time:	7:00 p.m.
Place:	Virtual Meeting (Information is provided in the email
	of your August OAHA Newsletter.)
Program:	Nutritional Needs and Tips, presented by Lisa Kelly,
	CWON, for Mölnlycke
Contact:	Billy Locke 337-515-6354

### **Sugar Land Group**

Date:	Thursday, August 18, 2022		
Time:	6:00 p.m.		
Place:	Virtual Webex Meeting (Information is provided in		
	the email of your August OAHA Newsletter.)		
Program:	Social Media and Ostomies		
Contact:	Joan Burnham, MSN, RN, OCN,		
	RN-BC, Oncology Nurse Navigator at 281-274-0188		
	or jmburnham@houstonmethodist.org		

### Woodlands Pediatric Group

Date:	Meetings will resume in September.	
Time:	Sundays at 2:00 p.m.	
Contact:	MaryAnne Lewis, <u>maryannelewis@hotmail.com</u> or 281-948-1490	

### J-Pouch

For J Pouch questions, attend any of our group meetings, or call or text Ron Meisinger at 281-491-8220

### **Opportunities and Announcements**

### **Use Those Shopping Cards**

Kroger (LB326) and Randalls (3698) return a percentage of your purchases to the Ostomy Association on a quarterly basis. For information about shopping cards, please visit the website: http://www.ostomyhouston.org/

#### **Anniversary Gift**

As you celebrate the anniversary of your ostomy surgery each year, consider making a monetary gift to the Ostomy Association. Checks should be made payable to the **Ostomy Association** *of the Houston Area* and sent to the Treasurer at the address shown below.

### AmazonSmile

On your first visit to AmazonSmile (smile.amazon.com), you are prompted to select a charitable organization from the list of organizations. You can change your selection at any time. To change your charitable organization: Sign in to smile.amazon.com on your desktop or mobile phone browser. From your desktop, go to Your Account from the navigation at the top of any page, and then select the option to Change your Charity. Or, from your mobile browser, select Change your Charity from the options at the bottom of the page. Select Ostomy Association of the Houston Area as your charity.

#### Memorial Fund

Donations can be made to our Memorial Fund to memorialize or honor individuals. Checks should be made payable to the **Ostomy Association of the Houston Area** and sent to the address below. When sending a donation, be sure to include the name of the person being honored so that acknowledgement can be sent.

### Moving? Changing Your Email Address?

Please make sure we have your current contact information so we can reach you by email, U.S. mail, or phone. Send updates to Lorette Bauarschi at <u>lorette@bauarschilaw.com</u>.

### For Anniversary Gifts, Memorial Donations, Mailing Changes, or Sponsorships, please send all correspondence to:

Ostomy Association of the Houston Area Attn: Mike McGinity, Treasurer P. O. Box 25164 Houston, TX 77265-5164

(When sending a donation, please include the name of the person being honored so that appropriate acknowledgement can be sent.)



The United Ostomy Associations of America (UOAA) can be contacted at: www.ostomy.org or 800-826-0826



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qualified practitioner. Always check with your doctor if you have any questions or concerns about your condition.

Membership Application				
Membership in the Ostomy Association of the Houston Area rec directed with payment as shown. Dues of <b>\$25.00 per year</b> ar <b>Ostomy Association of the</b> <b>P. O. Box 25164, Houston</b>	re payable to: e Houston Area, Attention: Treasurer	the following form and mail as Date:		
Name:	Phone:			
Street Address:				
City: State: ZIP:	E-mail: ( <b>required</b> )			
Surgery Date: Birth Date:	Sex: □ Male □ Female	□ Other		
Reason for surgery □ Crohn's □ Ulcerative Colitis □ Cance	r □Birth Defects □Other			
In additional to English, I also speak the following language(s). Foreign language spoken:				
Procedure or Relationship:				
To help us complete our records, please answer the following.         □       Colostomy       □       Continent Ileostomy         □       Ileostomy       □       Continent Urostomy         □       Urinary Diversion       □       Pull-Through         □       Other:       □       J-Pouch	□ Parent of Child with procedure	Membership benefits include: Monthly Support/Information Meetings, Social Events, Monthly Newsletter		
□ I would like to attend meetings with the ( <i>please circle o</i>	one):			
Central Group Baytown Group Northwest G	roup Sugar Land Group Wo	odlands Pediatric Group		
□ I would like to become a member but cannot pay dues	at this time. (This will be kept confident	ial.)		
I learned about the Ostomy Association from □ WOC Nurse □ Physician □ Newsletter □ Surgica	l Shop □ Website □ Other:			
I am interested in volunteering. $\Box$ Yes $\Box$ No				
I have enclosed an additional \$ as a donation to	support the association's mission of he	lping ostomates.		



# CeraPlus<sup>®</sup> Soft Convex Ostomy Products — Protection Where it Matters Most

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Request your trial sample at: **Hollister.com/en/ostomycare** 

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