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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: **Jan 19th**

Gainesville Support Group Contact info:

JoAnne Bell at 352-284-4214
 Meets the 1st Sunday of each month (except Holidays)
 at Hope Lodge 2121 SW 16th St
 Gainesville, FL
 Next meeting: **Jan 5th**

Ocala Support Contact info:

Lynn Parsons 252 337-5097
www.ostomyocala.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: **Jan 12th**

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 **Jan 19th**

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 Parkway Jacksonville, FL 32218 (Meeting Room 3-4)
 Free parking
 Next Meeting: **Jan 13th**

The Villages Ostomy Support Group
 We meet on the 2nd Tuesday evening of each month at 6:00 PM at (except July & August)

Saddlebrook Recreation Center
 3010 Saddlebrook Lane
 The Villages, Florida
 Linda Manson
 tvostomy@gmail.com
 865-335-6330
 Next Meeting: **Jan 14th**

Living with an ostomy: An 18-year old's perspective.

By Steven Berit

I fainted the first time I lost a tooth. Not from the actual pain of the removal, but from the sight of the blood dripping from my mouth. I also fainted during a health talk in the sixth grade. Most people would call me “squeamish,” and I would agree. The sight of blood or even the mention of anything related to the human body can easily send me into a spiral of emotions typically resulting in me waking up in the nurse’s office. So, you can imagine my apprehension when the doctors first suggested the idea of me receiving a colectomy.



Hi, I’m Steven Berit. I’m eighteen years old and I am a senior in high school. I live in Pennsylvania with my mom, my dad, and my sister when she is home from college. I live a pretty “normal” life. I go to school, play football, and hang out with friends just like anyone else my age would do. The only difference between me and everyone else is that I have an ostomy bag and they don’t. This small detail isn’t even noticeable for most, but at first, it certainly was noticeable to me.

I was sixteen when I was first diagnosed with ulcerative colitis. The next year and a half would be full of trial and error, and with each passing day the errors stuck out more and more. Mesalamine, Remicade, Entyvio, and Xeljanz were just a few of the never-ending drugs that I was prescribed. The only thing that seemed to be working was steroids, but both my doctors and my acne-ridden face agreed that this was not a permanent solution. Finally, in July of 2019 while in my latest stint on the 5th floor of the Children’s Hospital of Philadelphia, I made the decision to say good-bye to my very inflamed, friend- my colon.

I don’t remember much of the first night following the surgery, but the next couple of days stick out in my mind vividly. Well, I mean I clearly remember the restless nights. As for the actual stoma itself, this took me some time before I had my first encounter with it eye-to-eye or eye-to-intestine in this case. The second night was one of the worst nights of my life. I guess the anesthesia had worn off and with it came the regret. Yes, that second night I thought I made the biggest mistake of my life. There I laid in a hospital bed way too small for my eighteen-year-old frame contemplating if I could ever recover from this setback in my life.

Well, the sun rose and with it time for my first bag change. I remember screaming- a lot. They told me that the stoma couldn’t feel pain, but what they failed to mention was that I could still feel the pain of my hair ripping off my body as they pulled the adhesive off my skin. Trust me your average eighteen-year-old boy has plenty of hair to go around, but your eighteen-year-old boy that has been steroids for the last year and change has more hair than one would openly like to admit. But, as the bag came off, I got my first glimpse of my future in the form of a beautiful, red stump known as my stoma.

The next couple of weeks would come and go with relatively little struggle, but as summer came to an end my biggest challenge approached- going to school. I tried every possible combination of tucking my bag into my pants until I came to the realization that no one cared. Either people didn’t take notice of the bag of stool attached to my body or they too were busy and caught up with their own lives to care about what secret I kept hidden behind my shirt. It was my first time since being diagnosed with UC where I felt “normal” at school. Which was odd because to most this was the least “normal” I had ever been.

No, my journey with my ostomy was not one I would describe as love at first sight. But it has grown on me over time. Yes, I still need my parents help to change my bag every three days, but the once shrieks of pain have now subsided into murmurs. I now go to school every day like a new person. I no longer have fears of finding where the nearest bathroom is or if I am going to be able to take a test for thirty minutes without a wave of urgency



coming over me forcing me to drop everything and make a mad dash to the nearest restroom. Instead, most days go by without any thoughts of UC or stomas crossing my mind.

As I come closer every day to my reversal surgery in December, I begin to wonder if I would be able to live with this bag for the rest of my life, and after some thought, I honestly believe I would be able to. UC has taught me over the years that I can overcome anything and the ostomy bag was just the latest thing I had to overcome. If I can go from fainting over a loose tooth to conquering a disease that once bullied me then I can overcome any challenges that may come my way. The once terrifying ostomy bag has become a cherished friend of mine who I will never forget even when it is gone. I cried when I had my first tooth removed. I may also cry when I have my ostomy removed, but I think these tears will fall for a completely different reason.

The above article is reprinted with permission from the November E-News United Ostomy Association of American www.ostomy.org.

My Two Cents Worth...

Patricia McCray, RN, CWOCN University of Maryland Medical Center (via The Pouch)

Intimacy can play an important role as you take steps to resume the life you had before surgery. Your stoma does not limit or prohibit sexual activity. Here is my two cents worth on intimacy...

- Sexual activity will not hurt you or your stoma.
- Your stoma should never be used for sexual purposes.
- Empty your pouch before having sexual relations.
- Intimate apparel, specially designed underwear and pouch covers can be used to conceal your pouch and keep it close to your body. Return to your regular-sized pouch afterwards.
- Explore different positions to determine which one is most comfortable.
- Try kissing, cuddling and holding each other to enhance your sex life.
- Approach your sexual activity in a relaxed, non-pressured way. Maintain open, honest communication. How you feel is most important. Be confident. Being able to accept yourself will help your partner accept you as well. Together, the intimacy that you enjoyed before can be rediscovered.



Problems that can Occur With an Ostomy

Many people with an ostomy find that once their stoma has settled and they are in a normal routine, they are able to live their life with few ostomy related issues. However, as you are adjusting to life with a stoma, you may experience some problems that are quite common. We have put together a list of some common ostomy related problems and solutions so you can be well prepared if and when they occur.

Many ostomates continue to live with stoma issues and problems unaware that there are solutions available to them. Learning how to care for your stoma and understanding these common problems will help you to find normalcy and routine after your surgery. Access to this information will help you to take charge of your life and increase your confidence.

Before we get into the common problems and solutions, it might be helpful to mention proper cleaning and application. With proper care of your stoma and the skin around your stoma you may reduce the risk of the below problems. Proper care begins with proper application. Make sure your barrier hole fits tightly around your stoma, and that the skin is clean and dry for application. When removing your barrier, it is important to lift it gently off of your skin while using your other hand to press down on your skin. Ripping the adhesive off quickly can cause redness and irritation that can lead to other problems. To clean your stoma and the area around it, use a soft cloth or towel and warm water. Be gentle when cleaning, as aggressive rubbing or wiping can irritate the skin. It is not necessary to use soap, as soaps can leave residue and irritate the skin. When changing your pouching system, it can be helpful to use a small hand-held mirror to see all around it. If there is leakage, use the mirror to check all areas of your barrier and stoma for gaps and creases. Once you've identified the problem area, it will be easier to address.

Leakage

Two of the main factors of leakage problems are: how you prepare your skin before you apply your barrier, and your barrier size. You should make sure to clean and dry your skin completely before applying a new pouching system. If you are having trouble getting the area dry, an absorbing powder might be a good solution for you. If

your pouch gets too heavy and tends to pull away from your skin, or if your barrier does not fit correctly, a protective seal between your stoma and the barrier can prevent leakage and seal the pouching system.

Skin Problems

The skin that surrounds your stoma is called peristomal skin—it should be smooth and healthy and look like the rest of your skin. If it is red or irritated, you should address the problem immediately. If you have problems with adhesive residue or are unable to get the area completely clean before application, you may want to try to use an adhesive remover.

Odor

New sound and smells coming from your pouching system can be embarrassing and induce anxiety. Many new pouching systems have filters to neutralize the odors caused by gasses in your pouch. What you eat can have an effect on gasses you produce. It is recommended to avoid carbonated beverages and limit high-fiber foods. If the filter in your pouch gets blocked, you may experience ballooning. Ballooning happens when air from your stoma cannot escape the bag and it fills up like a balloon. Depending on the type of system you are using, you may want to release air from it throughout the day. If the odor is strong when you are changing your pouch, you may want to try a lubricating deodorant which can help mask the smells during a pouch change. Simply place 6-10 drops into the pouch when you change and empty it and spread it around inside the pouch by rubbing the inner sides together, avoiding the filter. This helps the output to make its way more easily to the bottom of the pouch.

Should you need more assistance dealing with a problem you are having with your ostomy, consult your healthcare professional. For more assistance and personalized support, check out Coloplast® Care, which is an ongoing comprehensive support program that gives people with an ostomy support throughout their life.

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