

THE JOURNEY

Sept. 2011

Sorry this is so long in getting finished. This newsletter has been started several times and not finished for many reasons. Normally I try to keep this informative, upbeat and interesting (I hope). This one will be a little different in that I am taking you with me on a Journey I have had the last 6 months, which I just found out the other day is not as settled as I thought it was. This past March I decided I had to get my humongous hernia repaired. I went to Dr. Rehnke in St. Pete to have it done. The surgery went well and I even got an unexpected tummy tuck because I had lost a bunch of weight and got rid of a bunch of extra skin in the closing process. That was an unexpected bonus I was very happy with! I also went home with two drains on either side of my lower stomach I did not expect and that were a little scary, bothersome and another new experience to deal with. I found myself dealing with a lot of things that were scary, depressing, but still somehow manageable. We always seem to plow on ahead when we have to and really have little alternatives. After the 3rd week of stitch removal, long trips to St. Pete and one of the drains falling out on the floor (very scary), nurses coming most days to check and make sure things were ok, things started to go downhill very fast. I started oozing fluid and blood from a couple of areas in my incision. We had a trip in the ambulance to Seven Rivers and a long trip by car down to Palms of Pasadena where Dr. Rehnke opened up a 2 inch line in my incision and I helped him push out 2 large towels full of blood that had collected in my abdomen. My body had decided it was not going to absorb the blood and I wound up with a large hole that had to be repacked, bandaged and treated every day, sometimes twice a day. There was infection they couldn't culture that got better enough that they finally sent me home after about 10 days with an intravenous line in my arm, antibiotics for 10 more days, twice a day, that I learned how to do myself. It was another totally scary and awesome experience with new "things" I never knew existed!

The infection finally left and we spent the next 3 months with trips to St. Pete usually at least once a week, daily visits by the nurses to repack the hole which was not closing as quickly as hoped. The Dr. finally opened the cut again slightly and stitched it closed in the hopes it would finish healing. Of course it did not work completely and we were still leaking but not as badly. More frustration, depression, long trips, but finally another incising and stitches that finally seems to work!! We even got to go on the cruise in July we had been planning for a year with some of our best friends. One of them would not be able to go because she would up having a tumor removed from her colon. Ironically I was finally getting done with one thing and she had to start on her own journey. Thank God she is ok right now. The cruise was amazing. I could not do a lot of things I would have liked to do, but it was quite fantastic in many ways. We came home totally exhausted, but glad we went. Two weeks later the last weak spot was no longer leaking and just left me with a little scab that finally came off a few weeks later. Through all this I was lucky enough to have many angels to encourage and help me. I really needed them because I had many days and weeks of being scared, exhausted and depressed. I thought the worst was over but just found out our journeys are never as easy as we would like. A month ago I had some blood come from my rectum with the usual mucous discharge I have once in a while. Needless to say, I was really scared and all I could think of was "you've got to be kidding me". It only lasted a couple of days and stopped, but did it again a couple of weeks later, less than before and only for one day. I knew I had to get it checked out and made an appt. to see my gastroenterologist which I did last Fri. I had only had one more spotting of blood one day and wanted to cancel the appt. and hide my head in a blanket, but knew I could not do that. I found out 2 things that did not make me happy-I may be getting a new hernia back and I probably have something called "Diversion colitis" I was told Dr's don't usually mention this probability because it is not a common aftereffect of colostomy surgery so why worry someone needlessly. He still wants to "look" and make sure that is "all" it is. He does not seem to feel concerned or worried about it and says I will be fine. I have no idea what it may mean in the future and I know I don't want to have to deal with it in any way, shape or form. I know I will, but this is starting to feel like things are never going to be ok again. There are days I have no energy, am really depressed and do not care about anything. Still in

a lot of pain from all this and don't feel able to do anything but just make it through another day. Sometimes I really don't care about doing anything. I guess my new "normal" is going to be anything but that. I know that there are many of us with worse problems and I totally sympathize. We all have stuff to deal with but I had to share some of my stuff to try to sort some of it out. I am going to include the last month's minutes of the meeting and the last Bd. Meeting we had. Some changes My be made to our group which will upset some who like me just Want things to stay the same so we don nit have anything else to "deal with" I hope I can keep muddling through all the "stuff" changing in my life and our group and try to smile and laugh.

Minutes from Stormy Support Group Meeting--Aug. 20, 2011

The meeting was opened by our President, Steve Spielman, at 2:00. We had the Salute to the Flag and a moment of silence for departed members and armed service people. The members who were present voted to keep the Flag Salute and Moment of Silence as part of our openings.

Old Business: We had received a \$50 donation from the VFW Auxiliary a couple of months ago and I sent them a Thank You card. One of our members, Lester Green, passed away and his wife brought his leftover supplies for us to distribute. I sent her a sympathy card.

New Business: Steve stated he paid the \$100 fee to have a table at the Citrus County Chamber Business Women's Alliance show on Sept. 24th at the Armory in Crystal River from 9-2. Anyone who could stop by and help for awhile would be greatly appreciated. This is YOUR group and you can help educate others about Ostromies.

Steve and his wife attended the UOAA convention in Reno and brought back a great deal of information and samples. He met Paul Hastings, the CEO of the Youth Rally camp program. Steve decided to donate the money he could have used to pay for his trip and help sponsor an ostomy youth to the camp. It was agreed that we could try to sponsor a young person to the Camp next year.

Steve also purchased an "Apron" that is an AV aide for use by groups or wound care nurses to help explain and educate others about Ostromies. We will use it as possible and are giving it to Laura McCarthy to use as a teaching tool for nurses and patients. The cost was \$160.00.

We will be having a Yard Sale on Oct.30th at the VFW in Hernando. Please label all items with prices and bring to the storage site by the 29th, Call Steve(465-7290) if you need help getting items there.

All of us who are able are asked to help on the 30th.

Oct. 15th, Bonnie from "Friendly Flora" pouch covers will be at an Ostomy Fair in Charlotte County. If you are interested in going, talk to Steve.

A reminder that the next UOAA Convention will be in Jacksonville in 2013!!! We can ALL go!!

We are trying to find a new venue for the Christmas Party this year. One good possibility is Frankies in Inverness on Rt. 31. Any other suggestions are welcome. Help with planning is also needed.

World Wide Ostromates can only take products that are "fresh" because of new laws and the time it takes to get to other countries.

Gerry Brummer (head of CERT in Citrus County), gave a timely talk about preparations for Hurricanes and other disasters. It was stressed how important it is to have a battery weather radio when electricity is no longer working.

We still have a need for a secretary from April-Oct. when Sally is not here. It does not involve too much work to attend Bd. Meetings (and get to have lunch with friends) one a month and take notes at the meetings and occasionally send a thank you note or sympathy card. Everyone in this group needs to step up and take responsibility for making YOUR GROUP the best it can be!!!!

There is \$2100.00n in our treasury at this time.

Meeting was adjourned at 3:10.

I did not formally write the minutes from our Bd. Meeting last Wed. There were only 4 of us the-myself and Gerry and Mel and Betty. Steve was in Orlando and Sue Penner was in the Hospital dealing with problems she was having. She is home again and plans to be at the meeting Sun. Mel & Betty said

some members have complained of some of the meetings being too long and we will try to make sure to keep close to the hour time frame. Mel wants to keep the Bd. Meeting and Christmas party at Rexall Drugs out of loyalty to them. This will have to be discussed by the membership. I have found out the last 6 months that changes can be upsetting and sometimes good or sometimes bad. We will all have to discuss these things. We did decide to be a little more cautious spending money unless we find ways to get more income in the treasury. The yard sale can certainly be a way to do this if everyone helps out. If you cannot be there to help out the day of the sale, donating items will certainly help!! Steve will help get things to the sale if you need help. I know I will! We will continue to have meetings in the summer but not have any speakers since so few people come in the summer months. People do still take supplies to Rexall sometimes and they let Mel know to pick them up. We will have refills of the group flyer if anyone wants to refill the Holders they took to Dr. offices, etc. We need to find out who the Ostomy contact at Citrus Memorial is supposed to be. We have not had any contacts from there in many, many months. Laura has been asking for visitors to several patients in Seven Rivers. Thank you, Laura. Edwina has resigned as Secretary. It is too much for her to do anymore. I think it is terrible that she had done so much for us for most of the Group's existence, and she did not even have an ostomy!! She even continued to act as Secretary after her husband, Paul, passed away! My husband, Gerry, does not have an Ostomy but volunteered to be our Treasurer when one was needed not long after I got my ostomy 8 years ago!! Everyone in this Group needs to decide if they want to continue to have a group and step up to help out with running it or we may wind up having to disband it. The same 5 or 6 people cannot continue to do all the work. All of the other Ostomy groups that are around have people or committees to try to find speakers, to find new members, to find ways to raise funds, to arrange for fun stuff like trips or dinners. PLEASE look in your hearts and try to support this group before it is gone.

As usual, I have a few things I hope you find interesting or helpful and maybe a few laughs. Remember to go to the UOAA website and OUR website for other information.

The factors below put you at risk for stroke

High Blood Pressure You are at high risk for stroke if your blood pressure is anything over 140/90. If you don't know your blood pressure, your doctor will assume that you are at high risk.

High Cholesterol Your LDL cholesterol (the bad type of cholesterol) should be under 100 and your "good" cholesterol, HDL cholesterol, should be over 50. High cholesterol can result in plaque that travels down your arteries, potentially blocking off blood flow to your brain.

Diabetes Your blood sugar should be under 100. If your number is larger, you have too much sugar percolating around that can damage the arteries. Additionally, excess sugar increases risk of plaque formation and narrows blood vessels in the brain.

Smoking tightens blood vessels and increases blood pressure. It is a major cause of stroke, as it makes your blood more likely to clot.

Sedentary Lifestyle Not exercising is a major risk factor. Exercise helps to minimize other risk factors by reducing blood sugar, cholesterol and blood pressure.

Family History along with your gender and race are important risk factors. African-Americans and Latinas are up to twice as likely to have a stroke as a white woman.

If 3 or more of these factors apply to you, you should talk to your doctor immediately about your risk for stroke.

BROKEN EGGS If you drop an egg on the floor, generously sprinkle salt over it and let it stand for 5 to 10 minutes. Sweep the dried egg into a dustpan.

When tomatoes are plentiful in the garden and my time is limited, I just wash the tomatoes (whether cherry, roma, or regular large tomatoes). I core them and just plop them in a freezer bag whole. Once the bag is full, I then freeze the tomatoes. When I want to use the tomatoes, I take the tomatoes out of the freezer and add them frozen to the soups, stews, or slow cooker foods I am making. Or you can make the frozen mixture into sauce. I just let them cook slowly down. The skins look like thin transparent paper. I don't remove them. You can if you want.

—*enjoy nature, Hints and Tips Forum*

Sally's article to the Chronicle=====

OSTOMY SUPPORT INFORMATION

Over 115,000 people of all ages undergo ostomy surgery every year in the United States. Ulcerative colitis, Crohn's disease and colorectal cancer are the most common reasons. Many ostomies are temporary, some are permanent. Either way, having an ostomy is a life-altering experience that affects individuals physically, psychologically or both. Healing from an ostomy takes time and patience. Living life with an ostomy is a personal journey.

Becoming an ostomate, as I did in 1979, due to ulcerative colitis can be scary, but with all the information available it makes decisions easier.

There are hundreds of thousands of ostomates just in our United States. Colostomy, Ileostomy, Urostomy, BCIR (Barnett Continent Internal Reservoir), Kock Pouches, are just a few and each of those are diverse.

For those without computers, most local libraries have them, where you can get started gathering information. A call to your health care provider can be helpful.

All ostomates or ostomates to be, family, friends, caregivers and other interested persons can use the following websites to help you become more educated toward making a decision or learning more about yourself.

The United Ostomy Association of America is a hub of information at <http://www.uoaa.org>. This is an easy site to use. You can just search thru the site, or log in and ask questions on their message boards.

Associated with the UOAA is a quarterly magazine called The Phoenix. It includes true stories, ostomy care, supplies, suppliers and clotheslines, etc. You may subscribe to the magazine by calling 1-800-826-0826 or www.phoenixuoaa.org.

A worldwide chat room is available at www.ostomyland.org. Here you can chat with others, use Facebook, Twitter or message boards.

I came to Citrus County, read the Citrus County Chronicle, and joined an ostomy support group. It is for Citrus and the surrounding counties. The ostomy Support Group of Citrus County is a 501(c)3 group, and meetings are held on the third Sunday of every month at 2:00 PM, in the Citrus Memorial Health System's Office Building, the old schoolhouse at 131 S. Citrus Avenue, in Inverness. Visit this website at www.osgocc.org. A meeting may consist of a speaker or two, an informative short movie,

and personal discussion time. Any questions about the support group, please call Steve Spielman at 352-229-4202, Sue Penner at 352-560-7918, Sharon or Gerry Brummer at 352-382-4446, or Betty or Mel Shipley at 352-726-3802.

The starting point for all medical information should be your medical professional. There are nurses that are specialized in treating ostomy and skin care problems. They are ostomy nurses, ET nurses or WOCN (wound care) nurses.

Through sharing my story and supplying you with different avenues to explore for information to help all ostomates in their life changing experience is my goal and those of the Citrus County Ostomy Support Group.

Thank you,

Sally A. Borland
Winter Secretary of the Ostomy Support Group of Citrus County

Great job!! Thank you Sally.

The 5 Foods for Better Health

Changing your eating habits can do more than trim your waistline. With the right ingredients you can lower your cancer risk and potentially increase your lifespan. Learn more about the 5 foods from alternative health expert [Dr. Andrew Weil's ultimate eating plan](#).

1. Cooked Asian Mushrooms (Serving size: Unlimited)

Mushrooms contain immune system boosting compounds, helping to prevent illness. At less than 100 calories per cup, they're good for your diet too. But be careful, you'll lose the benefits if they're not cooked well. Here are some varieties to try: shitake, maitake, oyster and enoki.

2. Whole Soy Foods (Serving size: 1-2 servings a day)

When you're shopping, look for whole soy foods over isolated soy protein powders like fake meats with soy isolate. Try eating tofu, tempeh, soy milk, edamame and soy nuts. They're good sources of protein and help guard against hormonally driven cancers, such as prostate cancer and breast cancer.

3. Cruciferous Vegetables (Serving size: Unlimited)

Cruciferous vegetables belong to the cabbage family. What's great about these greens is that they protect against cancer. Look for cabbage, cauliflower, broccoli, bok choy, kale and brussels sprouts.

4. Healthy Fats (5-7 serving a day; 1 serving is equal to 1 teaspoon of oil)

Not all fats are bad for you – some types actually protect your heart, like omega-3 fatty acids. If you're looking to increase your intake of good fats and cut out the bad ones, make sure you add these to your grocery list: hemp seeds, flaxseeds, walnut oil, olive oil, hazelnut oil and omega-3 eggs.

5. Whole and Cracked Grains (3-5 servings a day; 1 serving is 1/2 cup cooked)

The good types of whole grain products are ones where you can actually see the grain or large chunks of grain. These foods won't raise blood sugar the way products made with flour and sugar do. Stock up on basmati rice, wild rice, brown rice, buckwheat, barley, groats and quinoa.

Opening Medicine Bottles with Ease

By Heather Larson

Struggling to open bottles, specifically childproof tops on prescription and over-the-counter (OTC) medicine bottles, can be maddening. When getting to the medicine that's supposed to relieve your pain causes additional pain, it's tool time.

Look for an opener that requires minimal grip pressure and is easy to figure out, says Cathy Dow Royer, director and associate professor for the division of occupational therapy at American International College, in Springfield, Mass.

"You'll also want a rubber nonslip coating on the grip points, so that your hand doesn't slide," she says.

Here are tools that work well when you want to open bottles:

[Dycem Bottle Opener](#). This dome-shape opener fits in the palm of your hand and provides a stable grip to open childproof twist tops. Use it also to open doors and cupboards, and to turn on taps and oven dials. \$7.

[Multi-Grip Twist Cap Opener](#). The opener gives you increased leverage to remove stubborn twist caps from any size bottle. \$6.

[PurrFect](#) and [DogGone Openers](#) with Pill Extractor. Different parts of this cat- or dog-shape tool can be used to flip off caps and remove cotton from the narrow openings of OTC medicine bottles, twist open prescription bottles, push pills through foil containers, split pills and open cans that have tabs. \$10.

On the Importance of Being Part of a Group

"No man is an island entire of himself."

We sure like to pull things out of context sometimes. We also like to pull people out of context. This quote is pulled out of context. It has a deeper meaning than you probably know. I never knew the full quote until just now and it goes perfectly with what I want to say.

My point is that groups and communities are some of the most important things in our lives. Maybe they are the most important.

It isn't right for us to be alone. We live in community. We thrive in community. We are born alone and we die alone, yet while we are on this Earth we are in community.

Community helps bring meaning to our lives. Working and playing with our fellow human beings is what brings the most meaning to our lives.

We seem to be preoccupied with what group we are in too. Some people feel like they can't belong to a certain group because they aren't good enough. Many people come and go in organizations because they are too "clique-ish". Meaning that they are too well defined and tend not to let new people in without first having them pass the often unspoken test.

We use groups to exclude but we also use groups to include. It is a good feeling to be part of a group. To define yourself in a way you feel comfortable with and enjoy.

We define ourselves by race, creed, nationality, occupation, religion, abilities, hobbies, skills, etc. There are many ways to define ourselves and surprisingly, if we think about it, it mostly has to do with grouping.

This can't be understated or underestimated. As much as some of us hate being "labeled" we do it to ourselves all the time. When asked what we do we answer our occupation. You are labeling your own self by your occupation and thereby defining a large part of yourself. This is how humans operate. And it is perfectly acceptable.

Why is this important?

To quote a famous song, "Everybody needs somebody, sometimes..."

Although Thoreau's idea of Self-Reliance is a worthy objective, it is something that is achieved over time and not in totality. We are meant to rely on our fellow human beings from the day we are born. No baby can take care of itself. Although we are much more self-reliant as adults we still have to rely on others.

This is important to think about and realize because it comes down to acceptance and love.

We learn to accept each other for who we are, limitations and all. This opens up the chance for us to help each other and not let pride get in the way. I openly accept that I need help in some areas. I also accept that I excel in areas that other people need help in. When you accept this you can begin to realize that it is not prideful to accept help or to give it. It is just how we live best in community.

So you can click the author to read the full quote, but I will give you the end of it to make the final point. Maybe you will find it interesting to know that two oft-quoted quotes are actually one...

"...any man's death diminishes me, because I am involved in mankind; and therefore never send to know for whom the bell tolls; it tolls for thee." – John Donne

Find the communities that you can best belong to. Learn to both give and take graciously. This is what helps make the world go round

Common Myths & Misconceptions

by Barbara Skoglund of Maplewood, MN

I had ulcerative colitis for 14 years before I became so ill that my colon had to be removed. I was so afraid of having an ostomy that I postponed treatment and nearly died. Knowing my feelings about ostomies, my Doctor performed a rarely done straight ileoanal anastomosis when he couldn't make me a j-pouch.

I lived 3 years of hell with that “straight shot” and had an ileostomy installed in December 1996. It was the best Christmas gift I ever gave myself! I had many misconceptions about living with an ostomy and I frequently encounter others with those same misconceptions. After one person too many told me that it would be better to be dead than to live like me, I decided to start a series of short articles for the internet newsgroups alt.support.ostomy and alt.support.crohns-colitis covering the facts and fiction of ostomy life.

Myth #1 – People with Ostomies Smell Bad

Modern ostomy appliances are made of light weight odor proof materials. No one has ever walked up to me, sniffed and said, “Boy you smell terrible. You must have an ostomy.” I spent the first year of living with an ostomy thinking everyone could smell me. Every time we drove past one of the many Minnesota cow pastures, I was sure it was me—it wasn’t.

Some ostomates worry about the smell when they empty. Our stool isn’t any more toxic than other people’s—we just empty up front—where are noses are. A touch of the flush handle and away goes the smell. The roots of this smelly myth probably stem from old time appliances. Early ostomy supplies were made from non odor proof materials. Many ostomates had trouble controlling the odor from these old time appliances. Thank goodness for modern technology!

Myth #2 – New Clothes Optional

While the shop-a-holic ostomates among us, myself included, may harbor thoughts of having a perfect excuse for buying an entire new wardrobe – it’s really not necessary. I have only had to make one change in my attire as a result of my ileostomy.

I used to wear French cut undies and now wear briefs. It’s just more comfortable for me that way. There are some men whose stomas are poorly placed at the belt line. They frequently find suspenders easier to deal with than belts. If you have an experienced ET nurse who pays attention to such things—stomas at the belt line can be avoided. What about spandex, skin tight leather, and bikinis? None of these items were in my wardrobe to begin with.

But I do know a young woman from alt.support.ostomy who still wears a bikini—she just found a new style. I’m sure every ostomate has stories to tell about folks who stared and stared and still couldn’t see our pouches through our clothing! So—if you find yourself facing ostomy surgery, don’t waste time worrying about wearing muumuus or overcoats. At the most you may have to buy a new swimsuit or some new undies. Though feel free to be like me and use it as an excuse to buy more clothes!

Myth #3 – Somebody to Love

A couple of times during my single days, I placed personal ads as a way to find potential mates. Before I’d write my ad I’d sit down and list all the qualities I was looking for in a mate. I wanted a partner who was smart and funny, someone who shared my interests, who shared my values, etc. NO WHERE on that list did it mention “my partner must not have an ostomy.”

But I used to think that no one out there would be interested in me if I had an ostomy. I was convinced that ostomates sat home, stinking in baggy clothes (see myths one and two) lonely and friendless. You’d think I’d still harbor this myth considering my first fiancé took a walk when I had my temporary ileostomy while my ileoanal anastomosis was healing. But it was pretty clear that we didn’t split over how I went to the bathroom.

We split because we weren't right for each other. I've since found my soul mate and life partner and he couldn't care less how I go to the bathroom. What he cares about is that I'm healthy! You see he loves me, not my body or my bowel.

BUT, BUT, BUT don't single ostomates have a hard time with dating. Some do and some don't. However, what I've found is that those who don't date are too afraid to get out there and try. And yes, I wouldn't be surprised if an ostomy limited someone's casual exploits. But—If you are interested in finding a life partner who loves you, not your shell- then an ostomy won't stop you.

If anything it's a good test of really what a potential mate is interested in. I never think to myself, "Will you still need me when I'm 64." I know my husband is with me for the long haul.

Myth #4 – Let's Talk About Sex

Warning — *these are the frank comments of an adult* — though less racy than recent US news stories. Ok, ok, perhaps ostomates can find a life partner out there. But what about sex? This is actually one of the top questions people ask me when they find out I have an ostomy. "Can you still have sex?" Of course I can. Reasons why my sex life has improved since installation of my permanent ileostomy:

1. I am no longer in pain. Once I got healthy I no longer have those times when I just don't feel up to making love.
2. When I had ulcerative colitis and when I had a straight ileoanal anastomosis, I often had perianal pain that made sex uncomfortable at the least and painful at times.
3. I no longer waste time worrying about having an accident during sex.
4. I no longer have to excuse myself to go to the bathroom "just one more time." There can be some challenges. It's always wise to empty your pouch before sex. While my dangling bag isn't a problem for me, some folks find wearing cummerbunds or crotch less panties helpful. Some who wear two piece pouches switch to a smaller pouch during intimate moments. I do have a lovely lace pouch cover I wear for some special occasions. Though I don't feel the need to wear it every time I make love.

A very small percentage of men have sexual dysfunction problems after j-pouch, ileostomy or colostomy surgery. The type of problems range from total impotence to those who continue to have erections, but do not ejaculate. The odds for trouble are dramatically reduced if you have an experienced surgeon. These problems don't come from the ostomy, but rather from sloppy snipping around the rectum. Those who have their rectums and anuses removed can no longer receive anal sex (not that I've found too many UC/CD folks who do anyway.)

I think the biggest impact an ostomy has on one's sex life is in the area of self image, not in terms of physical functioning. I've had my ostomy for almost 2 years now and I still have days (though they are few and far between now) where I look in the mirror and cry. Where I feel ugly and damaged and very unsexy.

Then my husband will walk up behind me and kiss the back of my neck and tell me and show me how he feels about me. I know that I'm so lucky to have him. He has helped me deal with the self image issue and picks my spirits up on those days when I feel so low. As I said before, over time I have fewer and fewer problems with the impact of my ostomy on myself image. I am able to feel sexy and act on those feelings without the pain and worry I often had when I was sick.

Myth #5 – Limits? What limits?

Whew, my legs sure hurt. I just spent the day at the Minnesota Renaissance Festival—the largest and most popular of its kind in the world. What fun! We grazed on tasteless, over priced festival food. I found a beautiful Celtic necklace and bought 3 pairs of earrings. We saw jugglers, magicians, comedians, dancers, jousters, jesters, and much more.

My favorite were the Scottish dancers. Oh! I suspect you are wondering what my Sunday activities have to do with Ostomy Myth Five. Well—before my ostomy I wouldn't have dared to go to such an event. I avoided any activity where bathroom availability was unknown- or known to be a problem. I just couldn't risk it. I'll never forget the time I went to the Wisconsin State Fair when I was in college. I went with my aunt and spent much of the day worrying—waiting for—expecting trouble.

Trouble hit in the dairy building. I rushed into the women's room only to be confronted by the long, long, long line to the bathroom. Frankly, I didn't make it. By the time I got into the stall I had a mess. So there I sat crying, trying to clean myself, my bowels still pouring out. Then the pounding on the door started. "Hurry up. Don't you know there's a line out here." There I sat, my eyes filled with tears, desperately trying to deal with a horrid situation and this woman was pounding on the door, yelling at me. Only one thought pounded in my head... "I wish I were dead, I wish I were dead, I wish I were dead." Well, I don't have experiences like that anymore. I used to think that an ostomy would limit my life — I've already shared my misconceptions about love and sex.

Well the opposite is true. I spent so many years tied to the bathroom. In the last 21 months I've got to live life to the fullest for the first time. I can do ANYTHING I want to now. There are many things ostomates enjoy doing—swimming, sitting in a hot tub, sports. There have been professional football and golf players among our ranks.

Let's not forget the actress and political leaders among us. One of the active members of alt.support.ostomy participates in martial arts and another is an adventure athlete. Believe it or not—there is even a stripper in Florida with an ostomy. Those of us who spent years ill, find living with an ostomy to be a joy compared to what we endured as a result of our disease. Limits? HA! My ostomy opened that bathroom door and set me free to do anything I wanted to do.

Myth #6 – Time, time, time

Whew! Is life hectic. My job is busy, busy, busy. My grad school class starts next week and I need to somehow get over to the U to buy my books. (Their concept of evening hours for adult students is staying open to 5 pm.) I'm also trying to get a different job in the same agency, but I've got to get a teaching license first, and I had to fill out paperwork, and then send it to my undergraduate school to get them to fill in their part — it's weird having to get a license for a job where I won't be teaching, but since the job is doing professional development for teachers and they usually recruit teachers for the job, it's one of the requirements.

That reminds me, I've got to revise my resume. Meanwhile winter is coming soon to Minnesota and we have tons of leaves to rake up in the yard. We just moved into our first house this May and still have quite a list of house things to do yet. Boy to houses take a lot of work. I've got to get the roses covered and the lawn furniture put away. Not to mention the laundry. My husband's in a wedding on Saturday and we have to get his suit cleaned.

I'm also trying to redo our Web Pages. I just learned how to use FrontPage, and am excited to be able to make my homepage much nicer. Tons to do and not enough time — Ah! Life. "What does this have to do with ostomy life?" you ask. My life is busy and hectic. I'm involved in a lot of things that take up time. Dealing with my ostomy isn't one of them. I empty my appliance 5-7 times a day- usually when I urinate. I tend to empty more often than necessary.

According to my ET nurse, as time goes by, I'll be less self conscious and empty less often. I spend far less time in the bathroom than I did when I had ulcerative colitis, or when I had a straight ileoanal anastomosis. I change my appliance every 4-5 days. It takes me about 10 minutes. Because of my allergy situation, I have to change my appliance more often than most. It also takes me a bit longer because of the system I use. Most folks use a much simpler appliance system than I do. The two times I tried to switch to a different appliance were the only two times I've ever had a leak—so, I've decided to stick with what works for me. The experiences of other ostomates will be a bit different.

Many colostomates choose to take time to irrigate so they don't have to wear an appliance. Although most ostomates have a longer wear time than I do, some have to change their appliances more often. When I hear horror stories of ostomates who have to change their systems hourly or daily—the first thing I ask is “When did you last see an ET nurse for a proper fitting?” Their answer is always the same...”never” or “years ago.” An experienced ET nurse can help an ostomate find a properly fitting appliance.

My wear time is considered short at 4-5 days. If you are getting less than 3 days then see an ET nurse ASAP. Odds are you are not using a properly fitting appliance. Managing an ostomy-emptying it and changing it—does not cut into my time. Actually since I spend so much less time in the bathroom and doubled over in pain—my ostomy has expanded my available free time.

Myth #7 – Misconceptions

This one is more of a misconception than a myth;

Nurse – “How long have you had a colostomy?”

Barbara – “I don't have a colostomy. I have an ileostomy.”

Nurse – “What's that?”

There are many different types of ostomies and continent ostomies and internal pouches. Yet some people seem to call them all colostomies. Doctors, nurses, ostomates themselves seem to lump ostomies together. One type of ostomy isn't inherently any better than another (except the loop— anything is better than a loop) but they are all a bit different. Colostomy, Ileostomy, Loop ileostomy, Urostomy, Continent Ileostomy, Koch pouch, BCIR, Indiana pouch, J pouch, S pouch, W pouch, kangaroo pouch—What are the differences?

OSTOMY – The word ostomy signifies a type of surgery required when a person has lost the normal function of the bladder or bowel due to birth defects, disease, injury or other disorders. Such operations include colostomy, ileostomy and urostomy. The surgery allows for normal bodily wastes to be expelled through a new surgical opening (stoma) on the abdominal wall. Most persons with ostomies must wear special appliances over the stoma.

COLOSTOMY – The most common type of ostomy is the colostomy. Depending on location and nature of the individual's problem, a stoma may be constructed in any of the parts of the colon. While there was a time when most colon cancer patients ended up with a colostomy, today they rarely do. The key is location, location, location. If the cancer is in the anus or rectum then a colostomy is probably part of the cure.

Other diseases often resulting in colostomy, are diverticulitis, inflammation of small pockets in the wall of the colon that become inflamed, and sometimes cause obstruction, bleeding or perforation. There are also accident and gunshot victims who have temporary and permanent colostomies. Birth defects can also require a colostomy. Some colostomates can “irrigate,” using a procedure analogous to an enema. This is done to clean stool directly out of the colon through the stoma. Folks who irrigate can avoid wearing an appliance.

ILEOSTOMY – An Ileostomy is a surgically created opening in the ileum. The ileum is surgically cut into two pieces, usually as close to the end of the ileum as possible. The proximal portion of the ileum is brought to the surface of the abdomen and a stoma is created. In most cases, the distal ileum and the entire colon are then removed. The greater the length of small intestine removed, the greater the loss of nutrient absorption. Over time, the remaining ileum will adapt and take over part of the absorptive capabilities of the colon. Ileostomies cannot be irrigated and the flow of stool cannot be controlled. We must always wear an appliance.

LOOP ILEOSTOMIES are temporary ileostomies where a loop of small intestine is pulled through the abdominal wall to create a stoma. From my experience it can be very difficult to find a properly fitted appliance for a loop ileostomy.

CONTINENT ILEOSTOMY – Here a reservoir pouch is created inside the abdomen with a portion of the terminal ileum. A valve is constructed in the pouch that is brought through the abdominal wall. A catheter or tube is inserted into the internal pouch several times a day to drain feces from the reservoir. Koch and BCIR are the most commonly performed continent ileostomies. They are named after the Doctors who designed them. The BCIR is a revision on the Koch, and is only performed in a few facilities in the US. Continent folks don't wear an appliance.

UROSTOMIES result when the bladder is removed or the normal structures are being bypassed and an opening is made in the urinary system to divert urine. A piece of ileum is used to create a urostomy stoma from which urine flows. Birth defects can also require a urostomy. Urostomies cannot be irrigated and the flow of urine cannot be controlled. They must always wear an appliance.

CONTINENT UROSTOMY – There are two main continent procedure alternatives to the ileal or cecal loop (others exist). In both the Indiana and Kock Pouch versions, a reservoir or pouch is created inside the abdomen with a portion of either the small or large bowel. A valve is constructed in the pouch and a stoma is brought through the abdominal wall. A catheter or tube is inserted several times daily to drain urine from the reservoir.

In the Indiana Pouch version, the ileocecal valve that is normally between the large and small intestines is relocated and used to provide continence for the pouch that is made from the large bowel. With a Kock Pouch version the pouch and a special “nipple” valve are both made from the small bowel. In both procedures, the valve is located at the pouch outlet to hold the urine until the catheter is inserted. Continent folks don't wear an appliance.

J POUCH, S POUCH, and W POUCH are internal pouches formed from the terminal ileum and connected to the anus. The j-pouch has become the surgery of choice for people with severe ulcerative colitis or familial polyposis. These procedures are not done on folks with Crohn's Disease since Crohn's disease can pop up anywhere.

This procedure is done in 1, 2 or 3 steps. Folks who have the 2 or 3 step procedure have a temporary loop ileostomy while their internal stitches heal. These internal pouches are named for their shapes. They are also called ileoanal anastomosis, pull through, endorectal pull through, pelvic pouch, or a combination of these terms. I lived for 3 years with a straight ileoanal anastomosis—I also frequently refer to it as a straight shot. Straight shots are rarely performed (because they rarely work.)

KANGAROO POUCH – where baby kangaroos nourish and grow.

(Thanks to UOA and ConvaTec's Web Sites for some of the more technical definitions.)

Myth #8 – “I’ve never met anyone with an ostomy.”

HA! That’s what you think. There are only two ways you can “tell” if someone has an ostomy:

1. They tell you.
2. You see them in the nude.

Believe it or not you have met many ostomates in your lifetime. You just don’t know it because they haven’t told you. I used to think I’d never met any ostomates. The week before my surgery to install my permanent ileostomy, I was in a union meeting at work. I was sitting next to the president who was also taking leave during Christmas for surgery. She was having glaucoma surgery, and asked me what I was going in for. Although I’d made up my mind to have the surgery, I wasn’t going to tell anyone. So I mumbled something about intestinal surgery.

She said, “Oh. Do you have Crohn’s?” I said, “No, colitis.” “Oh, are you having an ileostomy?” asked Susan. “Umm. Yes,” uttered honest Barb. “Rob (her partner) has Crohn’s. He’s had an ileostomy for years.” OH, my. I’d outed myself for the first time, lo and behold it was to a woman whose partner had an ileostomy. I still wasn’t going to tell anyone.

Well—I told folks on the internet, but it’s a lot easier to tell people via a computer than in person. It was nice that Susan understood, but I sure wasn’t going to say anything to anyone else. Then my health insurance company told me that my ostomy supplies were unnecessary convenience items. Mind you, if I was a man who needed a penile implant, or if I wanted a bed pan they would pay for it.

So out I came in full force. I told everyone—my legislators, all of the state employee unions (I’m a state employee), the newspapers, any and everyone who might be able to put pressure on my insurance company. It worked, and after 5 months, I won ostomy supply coverage for all State of Minnesota employees—no matter what insurance company they had chosen. Four of our six plans cover supplies. Just mine didn’t. I’m now very OUT about my ileostomy. No, I don’t walk up to strangers and say, “Hi, I’m Barbara and I have an ileostomy.”

But I don’t hide it. I mentioned it in my annual holiday letter when I had my surgery. When a co-worker lost her dad to colon cancer, I offered my condolences, and noted that I understood a bit how difficult it was since I had started developing cancer, and had to have my colon removed. “Oh, how can you live without your colon?” I said, “I have an ileostomy.” When it’s appropriate I discuss it. I’m open to share my experiences with others, and share how much better my life is now.

I’d speculate that I’m much more “out” than many of my fellow ostomates. I felt forced into that situation, when I had to fight my insurance company, and I’m also a very self disclosing person to begin with. Some ostomates only tell intimate family members. Others are out like me. Most probably fall somewhere in between. I’m sure they have met an ostomate—they never even knew it. We are everywhere.

Myth #9 – Only “OLD” people have ostomies

I’m going to be 36 in November. I’m not “old” despite what the teenagers on alt.support.ostomy think. I was 30 and living in Fargo, ND, working as the student organization and Greek adviser at NDSU, when my ulcerative colitis got so bad my colon had to go. My ET nurse arranged for four friendly visitors to see me before my surgery. I was going in for a j-pouch and temporary ileostomy, but as we know came out with a straight shot.

Anyway, there I was—lying in my hospital bed...depressed and feeling sorry for myself. In walks one of the most beautiful young women I’ve ever seen. Even though it was late September, she still had a tan and sun

bleached hair. Young and perky, she wore tight jeans and strut into the room as if she owned the world. She was carrying a lovely plant and said she was looking for Barbara. “That’s me I said.” She sat down and asked, “How are you doing?” “Been better I said.” I thought she was delivering the plant as a gift from one of the sororities or student groups I worked with at NDSU.

Boy was I shocked when she said, “Your nurse Jill asked me to stop by to chat with you.” “Huh?!?” I gasped. She said “Well I was born without a bladder and I’ve had a urostomy since I was an infant. I’m 23 now. What kinds of questions do you have?” My expectation of an elderly, grandmother ostomate was blown right away. Two of my other visitors were in their 30s and the fourth was in her early 40s. Two of them had had their ostomies for years. Just as ostomies are needed to deal with a variety of medical problems, ostomates are represented in all age groups.

Granted, UOA (United Ostomy Association) studies have shown the average age of ostomates is increasing. Innovations like the j-pouch and better cancer treatments have reduced the number of ostomy surgeries. But there are still many of us, of all ages, who live with ostomies. I was surprised to learn about kids who have ostomies in childhood, but who are able to have reconstructive surgery, or for other reasons are able to be reconnected later on.

When one of my former coworkers learned I had an ileostomy she said, “One of my sons had an ostomy when he was a little boy.” Some people, like my friendly visitor in Fargo, spend their entire lives as an ostomate.

Myth #10 – Mysterious Contraptions

When my ET nurse in Fargo walked in and showed me an appliance, I was shocked! Not shocked at how it looked, rather shocked at how it didn’t look. I envisioned a large, thick, rubber bag similar to a hot water bottle. Well– it wasn’t large– just a bit bigger than my hand. It wasn’t thick–the thickness and texture was a tad thinner than a Ziploc freezer bag.

It wasn’t red rubber either. I also didn’t know what to call the thing– ostomates use a variety of names–appliance, pouch, bag, prosthesis. Depending on your insurance company, it can also be labeled a durable medical product or a convenience item. Appliances are produced by a variety of manufacturers to meet a variety of needs. Some are one piece–where the bag and the adhesive face plate/wafer (I think face plate is a more descriptive term–but most folks call this a wafer) are one in the same.

Others are two piece–a face plate/wafer and bag that connect together with a Tupperware type seal. One piece or two–the opening that the stoma fits through can either be precut or cut to fit. Face plates typically have built in skin protection called a wafer and are approximately 4”x 4”. Pouch sizes vary. Some pouches are closed end, and others are open ended.

Most of us use open ended pouches that close with a plastic clip. Others prefer to use a rubber band or a twist tie. (I’m a diehard clip woman myself.) Colostomies, ileostomies, and urostomies are all a bit different and there are appliances specifically designed to meet their specific needs. There are also different designs and options to fit the contours of your body–convexity is a word you may hear a lot–in simple terms a convex appliance helps to hold the tummy down and make sure the stoma sticks out so the stool or urine stays as far away from the wafer as possible.

And as I mentioned in Myth One–modern appliances are odor proof. Many folks just peel off the paper backing on the face plate/wafer and stick it on. However, there are also a variety of other ostomy supplies that some of us use. Many use paste or a seal (looks like a thick O ring) to give us some extra protection around the stoma.

Many use a skin barrier to add an extra layer of protection. Some of us wear a belt that goes around the waist and clips to the face plate/wafer. Some folks “window pane” their appliances–by taping down all four sides with

fabric or paper tape. Those of us who use these “extras” do so to extend our wear times or to give some extra protection to our skin. (It’s very important to keep the stool or urine off the skin around the stoma.)

If you are curious—one of the leading manufacturers has a web site at www.convatec.com with photos of appliances. There are still some ostomates out there who use older appliance systems that indeed were made of rubber. My ET nurse told me of the patient he met who used bread bags and duct tape! If you run into someone who hasn’t modernized, encourage them to see an ET nurse. There have been many appliance innovations over the years.

Myth #11 – Birthing Babies out my Anus

As I shared in “Let’s Talk About Sex,” the number one question I get is “Can you still have sex?” Guess what number two is? “Well, you can’t have children now can you?” HUH?!?! Since when do women give birth via their anus? Babies grow inside a woman’s uterus, not her colon! Many female ostomates give birth after their surgery.

Many male ostomates father children after their surgery. Can ostomy surgery cause infertility problems? Yes. So can other abdominal surgeries, so can other issues, so can Crohn’s disease. As I indicated in an early myth posting, some men have impotence problems after surgery. When I say “some”, I’m talking about a very small percentage.

Studies have shown that the less experienced the surgeon, the more likely the problems. It isn’t the ostomy that causes any physical problems, but rather sloppy cutting near the rectum. Patients can reduce the odds of these problems by finding an experienced surgeon.

Women may also have problems resulting from surgery. There may be fertility issues caused by adhesions, the internal scars from surgery. If an adhesion appears near the opening of the fallopian tube it could block sperm from finding their way to eggs and/or eggs finding their way into the uterus. There are surgical procedures to help clear away problematic adhesions. In-vitro is also an option.

Infertility rates are higher for women with Crohn’s Disease than women with ulcerative colitis or healthy women. However, in some cases an ostomy could improve the fertility of a woman with Crohn’s disease—especially if she suffers from vaginal fistulas and surgery puts her into remission and clears away the fistula problem. I want to be a mother and was quite concerned about adhesions since I had 5 abdominal surgeries.

I recently asked for feedback from other ostomates. I received many notes from female ostomates who have and who have not been able to have children. Most women reported they had no fertility problems as a result of their ostomy. Of the women who discovered they were infertile, most were infertile for reasons unrelated to their ostomy. I am looking forward to the day when I can bust this myth for myself.

Myth #12 – Just a Few of Us

Many ostomates think they are all alone. This myth is fueled by comments like “I’ve never met an ostomate.” Intellectually we know we aren’t alone, but somehow we think there aren’t very many of us. According to the WOCN (ET nurse professional association) web site, “There are an estimated 500,000 persons with ostomies in North America, and more than 50,000 new ostomy surgeries are performed annually in the United States and Canada.”

Of that number, less than 25,000 are members of the UOA (United Ostomy Association – a support group in the US.) Mind you, our numbers in North America are declining because of improved surgical procedures like j-pouches and cancer resections, but there are far more ostomates than most people realize. According to the IOA,

“They don’t even count people with stomas in the US, let alone Burma, BUT an estimate developed from among the 70 member countries of the IOA totals about 2.5 million.” You are not alone...

Myth #13 – Leaks

I saw a puzzling post one day on the alt.support.ostomy newsgroup. The poster asked, “other than leaks, what problems do you have?” Everyone, myself included, seems to presuppose that all ostomies leak. Well folks, I hate to burst your bag but—ALL OSTOMY APPLIANCES DO NOT LEAK!

I cannot say I’ve never had an accident. I have had four in the nearly two years I’ve had my ileostomy. Three of the four was during a brief period of madness where I decided I knew better than my ET nurse, and I ordered a bunch of sample appliances to try. I’d heard all about the wonders of the two-piece so I wanted some Tupperware of my own—lo and behold they leaked on me. They just aren’t built for my body shape.

I also tried lightweight pouches that didn’t have convexity. Guess they didn’t fit me right either. If I’d stuck with what my ET prescribed, I’d never have had these leaks. Now I stick with what works. The fourth accident wasn’t due to appliance failure, but rather due to my own stupidity! I lifted a heavy suitcase, leaned it against my abdomen, and let it slide down my body onto the bed. The suitcase became hooked onto my pouch clip, and snapped it open. Ostomates—it’s not a good idea to slide heavy objects down your tummy. It can lead to a messy situation.

So, all four of my accidents were of my own doing. If I’d stuck with what my very competent ET nurses told me would work for me, and if I’d not been silly enough to slide a suitcase down myself, I could say with confidence...I’ve never had a leak. BUT, what if I got a leak again?? I’d deal with it. Two of the four accidents I had were at home and two were not.

Actually, the first one took place at Murphy’s Landing, a recreation of a 19th century farming village, over an hour from my home. Luckily that had a bathroom with running water, but it sure wasn’t private. I had to stand before a sink in a public restroom and change my appliance in a bathroom filled with other people.

AND I DID IT! I know I could do it again. So I do carry my emergency kit—but I haven’t had to use it once since I decided to stick with the appliance that was prescribed for me. Whenever I see ostomates post about leaks the first thing I ask is “When is the last time you were fitted by an ET nurse?” They always respond, “Never.” or “Years ago.” Phone ET, and get a properly fitted appliance.

Myth #14 – Bread and Water

What’s for Dinner? I’ll just be having a piece of dry toast and a glass of water. Maybe I’ll have a saltine for dessert. Ostomates have a special diet you know. HA! That’s what you think. Actually, that’s what I thought until I had my ileostomy. From my personal experience, my diet has expanded since I had my ileostomy put in. I’m slowly trying to add things to my diet that I avoided when I had UC.

OK, OK, I admit—I added ice cream real quickly, it’s the vegetables I’m adding slowly. I still remember when I had ulcerative colitis how I’d have one ice cream cone a summer. My mom would take me to the Dairy Queen, and then rush, rush home so that by the time I had to go, I could make it to the bathroom. Now I can eat ice cream and pizza and other dairy without having to break any land speed records getting to the bathroom. Some of the things I eat fill me up fast, but it’s my own fault, and I choose to deal with the consequences.

I’m a cola drinker, and the caffeine does make things flush through pretty quickly. I also know some particular foods (Panino’s – yummm, yummm) fill my appliance up quickly. So when I choose to eat these things, I plan accordingly. No dinner and a movie...just dinner and home. Some ileostomates have difficulty with

dehydration. I've experienced it myself sometimes, usually when I'm not paying attention. i.e. I walked around the Minnesota State Fair for hours in the sun without drinking anything. Dumb move.

One of the two main functions of the colon is water absorption, and although our small intestines do learn to absorb water, it is recommended that we drink a lot of water. Urostomates are also encouraged to drink a lot of water. On the plus side, I don't have to watch my salt intake at all. My husband rarely sneaks my French fries anymore. They are way too salty for him. Some ileostomates and colostomates experience blockages with some high fiber foods.

I've only had a blocked feeling once—when I ate a raw apple without drinking anything at the same time. Most blockages can be freed without a trip to the Doctor. Rarely does a blockage lead to more surgery. Participants on alt.support.ostomy frequently post diet suggestions and home remedies to release blockages. However, everyone is different. Just as with ulcerative colitis and Crohn's disease, the impact of diet varies from individual to individual.

For example, on the top of the standard list of ileostomy no-no's is popcorn. Well, I love popcorn, and have no problems eating it. The bottom line is ostomates are just like everyone else. There are foods we can tolerate, foods we can't, and foods we can't tolerate but eat anyway. What those foods are vary from person to person. Just as with non-ostomates.

Myth #15 – Doctors Know

An ET is my friend. This one isn't really a myth, but rather a description of the health care professional I trust more than any other. My ET (Enterostomal Therapy) nurse! GI doctors may know when to recommend surgery, and colo-rectal surgeons may know how to make ostomies, but neither know a damn thing about living with an ostomy.

I've been misinformed by many doctors over the years. I read post after post from non-ostomates quoting their doctors spreading misinformation about ostomies and ostomy life. While good doctors are willing to admit they don't know how to manage an ostomy, arrogant ones pretend they do. They don't. They just aren't trained in ostomy management- ET nurses are. For more information about ET certification, see the Internet site: www.wocncb.org.

ET nurses do many things »

- » They mark the proper spot for ostomy placement, paying attention to factors like belt lines and belly folds.
- » They determine the appropriate appliance for patients.
- » They help patients deal with any problems they are having. For example, it was an ET—three years after it happened—that figured out it was a paste allergy that caused my severe rash with my temporary ileostomy. A rash so bad that it caused me to have to have my ostomy moved to the other side.
- » They provide counseling and advice for patients dealing with ostomy life.
- » They coordinate friendly visitors so new ostomates can ask questions and find out what to expect.
- » ET nurses also deal with open wound patients.

Most ET nurses are RNs who have additional training in ET nursing. There are a few LPNs who have gone through ET training. There are a few major programs around the U.S., and I'm lucky enough to live in an area where ET nurses are plentiful since one of the schools was located in the Twin Cities. The first ET nursing program was in Cleveland, Ohio at the Cleveland Clinic. I know there are some parts of the U.S., and the world where ET nurses are not available.

If you are living in one of those areas and are having trouble with your appliance system, I suggest you try to find an ET to see. The UOA national and regional conventions typically have stoma clinics where you can see an ET nurse during the convention. Most supply companies also have ET nurses on staff to answer your questions—a phone consult isn't the best, but it's better than nothing—and it's FREE.

The professional association for ET nurses is the WOCN. The Wound, Ostomy and Continence Nurses Society (WOCN) is a professional, international nursing society of more than 4,000 nurse professionals, who are experts in the care of patients with wound, ostomy and continence problems. Wound, Ostomy and Continence (WOC) Nurses manage conditions such as stomas, draining wounds, fistulas, vascular ulcers, pressure ulcers, neuropathic wounds, urinary incontinence, fecal incontinence, and functional disorders of the bowel and bladder.”

The WOCN Internet site is www.wocn.org. Check it out to learn more about ET nursing. The Internet site features a search engine that can help you find an ET nurse near you. I encourage anyone contemplating ostomy surgery to find a doctor who works with an ET. If your surgeon doesn't work with an ET nurse, then your cutter isn't cutting edge.

Myth #16 – Ouch

“Ohhh. Doesn't that hurt?” No.

OK...surgery wasn't a picnic. But when is any surgery totally pain free?

Recovery wasn't a walk in the park-though I sure had to walk a lot!

But day to day life with my ileostomy is pain free.

Peeling off my appliance doesn't even hurt. Though I do admit, I'm not hairy around my stoma. I'm sure some folks feel a bit like screaming. Imagine pulling a band aid off a hairy body part. Some ostomy products have made my skin burn and itch– I was allergic to them, and now I avoid them. Many ostomy skin barrier wipes and pastes have alcohol in them and can sting. Recently, 3M invented a wonderful skin barrier wipe whose name says it all–”sting free.”

99% of the time, I don't even feel myself passing stool. When I do, it doesn't really feel any different than passing stool through an anus. Take that back. With no hemorrhoids, fissures, or perianal tenderness passing stool through my old anus was pretty painful. But what about the burning and itching?

If you are having pain, burning or itching–then something is wrong and you should see your ET nurse to find the cause. Perhaps you are allergic to an ostomy product. Perhaps you are using an ill fitting appliance. Perhaps you have developed adhesions or a hernia. Ostomies should not hurt–get yourself checked out if yours does.

Myth #17 – “Yuck! What a totally gross idea.”

This one is by request. I'll be the first to admit I thought this myself. But when I really think about it, I see things a little differently. How is wiping the tail of my pouch any different than wiping my bottom? At least I can see what I'm doing now.

When I change my pouch, I have to wipe stool off my stoma. It's a lot easier and a lot less gross than pulling down messy underwear and washing the feces off my legs from UC accidents. Ostomates may carry a bag of urine or feces. Non-ostomates just keep theirs inside. To paraphrase a wonderfully funny article on the

Winnipeg Ostomy Association Internet site—So stomas aren't real pretty. Well your anus doesn't look like Miss America either.

Nothing that I live with now is grosser than my colon. When they pulled that damn thing out of me it crumbled like hamburger. Talk about gross! You know what else? NOTHING is grosser than death. I'll take this kind of "gross" over that any day.

Myth #18 – All Colon Cancer and UC Patients Need Ostomies

I was 18, when I was first diagnosed with UC, and I was sure I was going to be dead before I was 28. Why? Well, I was bound and determined to die rather than have an ostomy and ileostomies were routinely performed on UC patients after 10 years of disease—hence dead before 28.

Times have changed. Although we still haven't found a cure for UC or CD, we have gotten closer. Asacol wasn't even around when I was first diagnosed—let alone all the other drugs that are now available. Proper treatment can keep UC and CD in remission for many people. Research has shown that although UC folks are more prone to colon cancer than healthy folks—the odds of developing colon cancer are not high enough to merit the preventative colectomies doctors once mandated at the ten year point.

New surgical procedures for UC patients have further reduced the odds of someone with UC needing an ostomy. J-pouches are now the surgery of choice in the U.S. There was also a time when colon cancer was an automatic ostomy. Not so these days. Improved treatments and surgical techniques can now cure early detected colon cancer pretty easily.

Most colon cancer patients do not need an ostomy. As Jim Rice is fond of saying—"location, location, location." Rectal and anal cancers patients are more likely to need an ostomy.

You may be thinking to yourself, "Why after 17 myths telling us that ostomy life isn't so bad are you now saying most folks won't ever end up with an ostomy?" Well –

1. This is a big myth. Since I started posting my myth series, I've gotten a few notes from folks saying, "I don't have an ostomy yet but." That "Yet" most likely will never even come.
2. Many folks avoid necessary medical treatment out of fear of an ostomy diagnosis. This is particularly a problem with colon cancer. This is one of the leading killers in the U.S. even though it is one of the most easily treated and curable cancer. I also avoided doctor visits, as a UC patient, because I was mistakenly convinced that death was better than life with an ostomy.

My point in debunking these myths for UC/CD folks is that if—worse case scenario—you end up with an ostomy, it isn't the end of the world. It is the beginning of health. UC folks will be cured. Colon cancer folks are likely to be cured if caught in time. Most CD folks enter remission, and even if they flare again, their flares will be without many of the traditional effects. i.e. no rectum = no vaginal/rectal fistulas; lack of bowel control isn't an issue with an ostomy, etc. If you end up joining our little club, it's likely ostomy life isn't the way you imagine it to be.

Myth #19 – Just me and my TV and lots of bills to pay

As I laid in my hospital bed, fighting to get strong enough for surgery one of my many fleeting thoughts was, "Well, if I end up with an ostomy, I can stay home and watch television all day." I worried and fretted over how I was going to be able to pay my bills. Of course I couldn't go back to work. Ostomates can't hold down jobs can they? Here are a few of the many ostomates in the world. Notice the wide variety of occupations we hold:

- » Paul Ashley – management consultant
- » Fred Astaire – actor/dancer
- » Barbara Barrie – actress
- » Rolf Benirschke – professional US football player/game show host/ConvaTec spokesperson
- » Napoleon Bonaparte – world leader and military conqueror
- » Marvin Bush – financial adviser and son of former US president
- » Earl – Dutch retired Air Force officer with 30 years of service in WWII, Korea and Vietnam
- » Al Geiberger – professional golfer
- » Bob Hope – entertainer/comedian/actor
- » Robert James – I.T. Consultant
- » Bob Lee – police sergeant
- » Tip O’Neil – US Speaker of the House and Ambassador to Ireland
- » Kevin McHugh – owner of research consulting company-McQ Research Services, coordinator of the CCFC IBD Research Network, educational/inspirational speaker, etc.
- » William Powell – actor
- » Queen Mum (colostomy since 1966)- British royal
- » Suzanne Rosenthal – CCFA founder
- » Red Skelton – comedian
- » Barbara Skoglund – government communicator
- » Ed Sullivan – TV host
- » Loretta Young – actress
-

“Happiness is always a by-product. It is probably a matter of temperament, and for anything I know it may be glandular. But it is not something that can be demanded from life, and if you are not happy you had better stop worrying about it and see what treasures you can pluck from your own brand of unhappiness.”

5 BOYFRIENDS!!!

I am seeing 5 boyfriends
every day.

As soon as I wake up,

Will Power

helps me get out of bed.

Then I go to see

John.

Then

Charlie Horse

comes along,

and when he is here, he takes
a lot of my time and attention.

When he leaves,

Arthur Ritis

shows up and stays the rest of the day.

He doesn't like to stay in one place very long, so he takes me from joint to joint.

After such a busy day, I'm really tired
and glad to go to bed with Ben Gay.

What a life! Oh, yes, I'm also
flirting with

Al Zymer!

I am thinking of calling

JACK DANIELS

or

JOHNNY WALKER

to come and keep me company.

Now remember:

Life is like a roll of toilet paper...

the closer it gets to the end,

the faster it goes ... so have fun,

think good thoughts only,

learn to laugh at yourself,

and count your blessings!!!

**Being happy doesn't mean everything's perfect. It just means
you've decided to see beyond the imperfections.**

Protect Your Eyes!

Wear sunglasses outdoors, even in the winter. This is the best way to minimize eye damage from ultraviolet (UV) light. Consistently wearing sunglasses that block UV rays will halve your risk for cataracts and macular degeneration, which are the leading causes of vision loss in adults.

Drink more water. The body's blood supply does not feed the lens of the eye, so drinking lots of water to flush toxins can reduce the risk for cataracts.

Eat cold-water fish three times weekly. Salmon, tuna, mackerel and sardines are the best dietary sources of docosahexaenoic acid (DHA), a long-chain fatty acid that rebuilds damaged cell membranes in the retina and may improve night vision.

If you don't eat fish, take a fish oil supplement containing 500 milligrams (mg) of supplemental DHA daily, or consume 500mg of supplemental algae, which is also rich in DHA. - Robert Abel, Jr. MD

Supplements for Your Symptoms

Use the list below to find dietary supplements and other substances that might be useful for symptoms of specific types of arthritis and related conditions.

Cartilage Degeneration

[ASU](#), [Chondroitin](#), [Glucosamine](#), [Sam-e](#)

Decreased Mobility

[Chondroitin](#), [DMSO](#), [Flax](#), [GLA](#), [Glucosamine](#), [Indian Frankincense](#), [MSM](#), [SAM-e](#)

Depression

[St. John's Wort](#), [Sam-e](#)

Inflammation

[Bromelain](#), [Cat's claw](#), [Chondroitin](#), [Devil's claw](#), [DMSO](#), [Fish Oil](#), [Flax](#), [Ginger](#), [GLA](#), [MSM](#), [SAM-e](#), [Stinging nettle](#), [Thunder God Vine](#), [Turmeric](#)

Pain

[Bromelain](#), [Chondroitin](#), [DMSO](#), [Devil's Claw](#), [Ginger](#), [GLA](#), [Glucosamine](#), [Indian frankincense](#), [MSM](#), [Sam-e](#), [Stinging Nettle](#), [Thunder god vine](#), [Turmeric](#)

Sleep Difficulties

[Melatonin](#), [Valerian](#)

I think I have made this long enough for his time. Have to leave room on the website. Thanks to my hubbie for getting this put on the website to read. I may have a hard copy for the next meeting for anyone who does not have computer access. Will probably leave some jokes off since it is so long. See you all tomorrow!!

Sharon Brummer