

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



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Jacksonville Contact Information: Patti Langenbach (800) 741-0110

(904) 733-8500 <u>patti@ostomymcp.com</u> Support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street Next Meeting: June 17th

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

Brinda Watson (352) 373-1266 Jean Haskins (352) 495-2626 Meets the 1st Sunday of each month (except Holidays) at Hope Lodge2121 SW 16th St Gainesville, FL Next meeting: June 3rd at 2pm

Ocala Support Contact info:

Shirley Gonzalez-Day 352-209-4986 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: June 10th

Citrus County Support Group

Meets third Sunday of each month at 2:00 PM in the Seven Rivers Regional Medical Center, 6201 N. Suncoast Blvd., Crystal River, FL 34428, in the Community Room of the Medical Office Building Next Meeting: June 17th

Amelia Island Area Ostomy Support Group (904) 310-9054 Meets second Monday of each month at 6:30pm UF North Campus UF Health North 15255 Max Leggett ParkwayJacksonville, FL 32218 (Meeting Room 3-4) Free parking Next Meeting: June 11th





"Gutsy's FAB Gab-About: Stories of Ostomy 'Glories/Gories'!"

"Speak Out and YOUR WORDS WILL Be Heard!" By Linda Blumberg AKA "Mrs. Lips"

SUZANNE'S STORY:

Hello there; my name is Suzanne; I'm a wife and mother of two. At 36 I was diagnosed with advanced stage colon cancer, having been misdiagnosed with IBS for many years. At the time my priorities revolved around treatment and survival. I had Chemotherapy, Radiotherapy and an AP resection (permanent colostomy).

Finding clothes to wear with my colostomy has at times been a challenge, and not always successful admittedly, but I'd say I've had more wins than losses, so I'm happy with that. My blog isn't going to appeal to those who prioritise comfort, there's plenty of sites for comfy colostomy clothes, and their offerings scare the cr*p out of me (if you'll pardon the pun). I'm not ready to swap to comfort yet, nor do I imagine many younger or young at heart ostomites are.

On trend, stylish or sexy clothes to wear with a colostomy - not colostomy wear, there is a difference.



I set up a website (www.gladragsandbags.org) not only to provide links to shops and online stores where I have had clothing success but also share hints, tips, and life hacks for wearing what you want when you want without any messy mishaps. This isn't a fashion blog by any means; I'm no guru; this is just plain and simple sharing of my experience with a hope that others will share theirs, too, an anthology of dressing for ostomates. This site is merely for sharing info, for philanthropic purposes; none of the products are sponsored by the manufacturers. I receive no kick-backs or payments in any form for recommending any products included on here. I founded it purely because I wanted to share the things I have learned over the years.

Others will more than likely have tips for me to use, which is what I'm hoping for, really. A sort of forum, not for discussion about having a stoma and all the "joys" that brings (there's plenty of places for that out there and it's not really my thing) but for looking good, feeling great, and making the most of our bodies that for the most part serve us well.

You may well notice a lack of clothing aimed at men or helpful hints for people with ileostomys. I can only go with what I know - being a woman and having a colostomy; all input is welcome, so in future there may well be a section on many aspects of bag life. If you have any tips and hacks to offer, please feel free to email me. Happy to add more info to the page with your name attached.

What makes you different makes you beautiful

Hints, Tips & Hacks:

Do I spend a lot on clothes? in all honesty - yes. But some of my best finds have been from high street stores; jeggings are a staple in my wardrobe as are some cropped, stretchy trousers I bought in Primark, in both cases I bought multiple pairs of all the colour options available. Once I get the trousers or skirt right I can add any top I like, and if all else fails buy fabulous shoes and no one will notice your clothes! Needless to say shoes are my passion and hobby. (I remember after a complication of my AP resection op I ended up with a catheter bag as well as a drain bag and the colostomy bag; one of my best friends quipped: "I thought you collect shoes not bags!") [hahaha!...]

TIGHTS: I quickly learnt that tights were not my friend anymore; but I love wearing skirts, even in winter. I had a lot of trouble with recurring *pancaking. So I decided to cut a hole in the tights for my bag to come through, meaning nice warm legs but no extra restriction on the bag. So far 4 winters later it's still working for me, if laddering is a problem, use a little nail varnish, I tend to only cut thick tights, which don't really ladder. ["Laddering" must be like having a "run" in stocking...good to conceal...because the "reveal" could be oh so "shocking!" hahaha]

*There is very little literature, which states how common a problem pancaking is for the colostomate but a problem it certainly is. Pancaking (or pattycaking as the Americans call it) occurs when the poo sits on or around the stoma and fails to drop down into the bag. As more poo comes out there is nowhere for it to go so often it pushes its way underneath the flange. This causes problems with sore skin (where the skin is exposed to the poo), unpleasant odour and leaks. This in turn can lead to a fear of venturing out in public due to potential accidents. Pancaking is believed to be caused either by the filter on the appliance being too effective, i.e. it lets all the gas out very quickly and leaves the bag flat against your body, or because your clothing is too tight which was my biggest issue.



This trick can also be used on Spanx or Spanx type control undies. It can't hold your tummy in much after you've cut a hole for the bag in fairness, but it can still trim a bit of your bottom and thighs.

SLIPS: Although usually associated with the older generation petticoats, slips, and camisoles, and I have become firm friends! I find that just by simply adding one of these to a dress I can smooth the edges of the bags meaning I can be a little more daring with the dress I choose. Often opening up more options of styles or fabrics to my wardrobe. Without a slip to smooth the bag's outline I couldn't wear flat fronted dresses.

BELTS: My most confidence-boosting dresses are ones with fabric belts that tie up. You could be forgiven for thinking this would draw attention to the bag; but I find the bow or knot disguises that area. I have many many dresses of this design, Hobbs and Micheal Kors being my favourite buys due to the fabric and design; but most stores do this style.









STYLES: The Peplum isn't my favourite design style but it is a very good way of disguising the bag. I have worn them a few times and I must say I feel confident in the knowledge that everything is hidden away.



DESIGNS: Ruching, ruffles & twists at the side is a godsend for evening wear and for dresses you'd wear for longer days like a wedding or a day at the races; every lump and bump in the bag hidden beneath cleverly placed folds of fabric can make for a far more restful, confident day out, without the worry of- "this dress looked OK before I left home while the bag was empty".

Ok, so I may have gone overboard with the ruffles on photo 3 and it's not for popping to Costas to meet the girls for coffee but its fabulous none the less!









DP Eden Legging

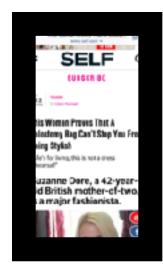
Top Shop Leggings

NYDJ

For a really long time now, I've been wanting to put some of my experience out there for people to use. Mostly I have found dressing with a colostomy an extreme case of trial and error. Thankfully I've had many highs along the way where outfits have surpassed my expectations, but also some very unfortunate real lows; for example, when my bag leaked in the Jimmy Choo department at Harvey Nic's, I could've just curled into a ball with the embarrassment and shame; I wanted the world to just swallow me up. Instead I picked myself up and dusted myself off, or in this case I dashed across town back to my car red faced for a quick change. Then straight back to Choo with my head held high to finish off my purchase - after all s*** happens; don't let that stop you!

Gladrags & Bags is about looking & feeling good whilst having to wear a colostomy bag, and I now know, many years on it's possible and achievable.

I don't belong to any stoma support groups. I've never felt any need. Having a colostomy doesn't define me; it simply makes me think smarter when it comes to shopping and dressing. That being said, I'm always up for new and inventive ways of hiding my bag and dressing without risk of leaks. Any tips and hacks would be gratefully received; email me via the contact info and I will add your hint attributed to you: email:"







WEBSITE/BLOG/EMAIL: Suzanne@gladragsandbags.org"



Incidentally...

by Marjorie Kaufman, Los Ileos News, Los Angeles; via Northern Virginia The Pouch

No one can tell me at a glance that I have an ostomy. Only those close to me know it for sure. Perhaps that is why it is difficult for me to recognize a curious fact; some people do not realize it's a BLESSING, not a DOOM!

One wonders whether this knowledge might have some value to the human race—at least that part of the human race that tends to look upon an ostomy as a disaster.

Acceptance is part of being happy. People need happiness as much as they need food; without it they're devoured by restlessness and discontent.

How many people who think they resent an ostomy would, if they were truthful, recognize it as the thing they most needed to enjoy life again? How many could, with a simple change in mental outlook, admit it's a BLESSING?

Many people never learn; they never achieve the peace of mind and contentment this knowledge brings. They spend their lives in a prison where an ostomy is the eternal punishment. An ostomy is not DOOM—that's a mental attitude.

Nothing is a joy or a burden; only thinking makes it so. How can we avoid that feeling of compulsion that makes an ostomy a burden? We don't disclaim it. There's no use kidding ourselves about that.

Nevertheless, there are things we can do to take the edge off the feeling of compulsion and make things more pleasant. We need to expend our mental and physical energies.

If these energies are not expended in a constructive fashion, they turn inward and poison our minds and bodies with resentment and dissatisfaction. We need that warm sense of accomplishment, to be needed, wanted and useful. We need it to give balance to our livesContentment depends not so much on the BLESSING as on the attitude of the person who has it.

World Ostomy Day 2018 OCTOBER 6



https://www.ostomy.org/event/world-ostomy-day-2018/



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