



WEB SITE: [www.ostomysolano.org](http://www.ostomysolano.org)

# SOLANO OSTOMY NEWS

**EDITOR: DAN BRUCE**  
**OSTOMY ASSOCIATION OF SOLANO**  
**P.O. BOX 5142, VACAVILLE, CA 95696**



**DATE: February 4<sup>th</sup> and February 18<sup>th</sup> \*\*VIDEO METINGS\*\***

**HOSTS: February 4<sup>th</sup> at 7:00 pm – Peggy Terry & Dan  
February 18<sup>th</sup> at 7:00 pm – Peggy Terry & Dan**

**REFRESHMENTS: BYOB (Bring Your Own Beverage)**

**WHERE: In Your Living Room, Kitchen, Dining Room – You Pick It**

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## Just a Few Comments

**February Already?** We have finally had the first real winter storm of this year. It is a good thing as we can use the rain and snowpack in the mountains. With the arrival of the first vaccines, I am looking **positively** toward 2021 as the beginning of the end of the pandemic. I received my first Covid vaccination on Wednesday the 27<sup>th</sup>. My wife Kathy gets her first vaccination on February 3<sup>rd</sup>. I am looking forward to when we can have unrestricted family and friend interactions, begin to travel again and have at least a somewhat normal life (whatever that turns out to be).

**As you know.** Mary Ann Chico, CWOCN has moved on to a new position with Kaiser at the hospital in Vallejo. Peggy Terry, CWOCN has graciously volunteered to cover for Mary Ann until her replacement is in place. According to Peggy, as of last week, they have not even posted the position yet, so it may be a while.

**At the Next Online Video Meeting** on February 4<sup>th</sup>, I am hoping to have some new ostomates join in the meeting. I have been reaching out to the other support groups in the area, who are not having any physical or online meetings. I have also been in close contact with **Brenda Elsagher** who is the new national **Director of Affiliated Support Groups** for UOAA. Brenda may join us at the next meeting. She is also actively involved in the Ostomy Association of the Minneapolis Area. It should be an interesting meeting. I also have several guests in the works for the next few meetings.

**Like Old Photos?** If you missed the online link to view the ostomy group photos, here it is again. I thought some of you may be interested in seeing them. I still have the original photos, but at some point, I am planning on discarding them unless someone would like to have them. Click on this link to view the photos: <https://photos.app.goo.gl/ELo6TkM7VpeYUyEd9>

Be sure and get your **vaccinations** as soon as possible. It may literally save your life. Please be safe out there and remember that even though we need to isolate ourselves for a bit longer this year, we can hopefully look forward to a **great new year**.

**Don't forget Your Favorite Valentine!**

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### Upcoming Meetings – Add to Your Calendars – Details to Follow

**February 4<sup>th</sup>** - Online Video Meeting - 7:00 PM –Roundtable Discussion and Support  
Tentative Special Guest – Details Forthcoming

**February 18<sup>th</sup>** - Online Video Meeting - 7:00 PM – Roundtable Discussion and Support  
Tentative Special Guest – Details to Forthcoming



## Why I Decided To Make My Ostomy Permanent

"Coltrane" is here for life.

[Karin Camposagrado](#)

When the surgeon and I were talking about my [colectomy](#) in the hospital, she mentioned leaving a couple of inches of rectum partially because it was so inflamed she wasn't comfortable operating, but also so that I'd have the possibility to have my ileostomy reversed and go the [j-pouch](#) route. I told her I wouldn't be doing that but she didn't believe me. The doctors didn't feel like I was mature enough to make such an important decision as to taking my colon out, especially not while on steroids.

At my follow up appointment, she told me I'd need to either get my stump (the 4 inches of rectum and anus they left) taken out or do the j-pouch sometime in the next 2-3 years. I figured, great, I have time to think about it, and boo, now all of my decisions will be based upon when I'll get that surgery done. Boy, do I not enjoy surgery. Oh wait, who does??

I'm not sure how Coltrane ([my stoma's name](#)) feels. If he's happy seeing the world through my clothes? Or if he'd prefer to be back inside my body? But I've made my decision, I'm going to make him a permanent part of my external body by having them take out my "stump". It was never really a question for me. My reasoning is that the couple inches they left of my rectum is still affected by ulcerative colitis and reminds me of that almost every day, multiple times a day, often with urgency. Having a j-pouch requires just a little bit of rectum to be left, but what's the point if you still get flares? Also, still having a little bit of my anus and rectum means still being a prime candidate for colon or rectal cancer — no thanks!



**“But you’re so young, are you sure you don’t want to give the j-pouch a try?”**

I can't even tell you how many people questioned my certainty of wanting a permanent ileostomy. The fact is, in addition to the logic above, I've met a number of people over the last nine months who had j-pouches and had a lot of complications, or that had one that worked fine for a long time but then had to be reversed, so I'm not confident in the j-pouch science yet. If I went the j-pouch route and ended up with complications (now or down the road), I'd have to have a reversal surgery and worry Coltrane #2 won't be nearly as awesome as Coltrane #1 is. This is just my thought process and what my "gut" tells me to do, so I'm listening. I do know a number of people who are happy and healthy with their working j-pouches and encourage everyone to do their own research and talk to their surgeons before making such a big decision.

I hope Coltrane continues to be a contributing member of my body and that we get along, until death do us part.

Article credit: [Newbie Ostomy](#)



## Revision for Stomach

### Inspire.com - Community Forum for Ostomates

[LisaClark 811](#)

Has anyone had a revision on their stoma? If so, how was the recovery. Also have a [parastomal hernia](#). Both will be repaired at the same time. I have a new Colon and Rectal surgeon and new WOCN. The stoma I have is flush since surgery. Help for advice. Thank you!!!

**Reply 1** - Hello, It depends on a lots of factors. If you have a lot of scars tissue, adhesions, how much of your bowel your surgeon would need to mobilize (pulling out), your health status, the list is long, and you should talk with your surgeon. My experience was 3 ileostomy revisions/reconstructions. For first one, a week (not too bad) at the hospital and the second and third (last year) one month hospitalized each. They had to do open surgeries both times because of my specific condition. Not fun... but very happy of my new stoma, it was worth it.

Take care

**Reply 2** - I had a stoma revision on the same site as my original stoma. The surgery and hospitalization were quite brief, but your surgery will be more complicated than mine was. I wasn't prepared for how swollen my stoma would be, and it was a bit disconcerting. I had ordered some larger cut to fit wafers prior to my surgery so I would be prepared. It may be difficult, however, to predict what type of supplies you'll need until you see what your new stoma looks like. You might want to talk to your WOCN prior to your surgery about what to expect in your particular situation. They'll know exactly what's going on with you, so they should be your best resource. Wishing you the best!



**Reply 3** - Hi Lisa, I had two revisions last year. Both surgeries were done with a vertical incision on my stomach under my belly button. I was inpatient for 5 days after each surgery. Typically with revisions they want to keep you a few days to ensure you are able to advance your diet and that your intestines "wake up" after being under anesthesia. The site will obviously be tender and your stoma will be swollen! This is totally normal and will take about a month or so to return to normal size. Keep up with your pain meds and rest rest rest! Best of luck to you with your procedure

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## What to do when you feel overwhelmed with ostomy life

Expert advice for ostomates when it all feels like too much.

[Stephanie Brenner, LCSW](#)

Oct 10, 2019

The experience of managing an ostomy or chronic illness can be a lot to handle. Add in the demands of family and work from our busy lives and it all feels totally overwhelming. Nowadays, "stress" seems to be a normal part of life. It might seem like there's nothing you can do about it but you have a lot more control than you might think. Here are eight tactics to help you deal with ostomy overwhelm.

**1. Know how long things take** - I'm notorious for assuming tasks take much less time than they actually do. For instance, I'll block out 15 minutes for a pouch change and then my stoma decides it's going to take 30 minutes. I've learned this simple rule: whatever time you think a task will take, double it. That way, when your stoma suddenly acts out, you'll feel prepared because you know there's extra time to apply the wafer properly. We all know that rushing a pouch change = leaks = more stress!

**2. Simplify your life** - Is your life too complicated? Take a few minutes and look at everything you do in a day and ask yourself if there's a better, easier way. This may involve saying "no" to things you've planned. Your to-do list is probably making you anxious and stressed and overwhelmed. Technology can help us organize our lives when it comes to ordering ostomy supplies. Many [medical suppliers](#) offer automated reordering and there's also a handy app called [Ostobuddy](#) which alerts you when you're running low or when to refill a prescription.

**3. Start daily habits** - One of the most important things you can do for yourself is self-care. As soon as I wake up, I start each morning with a hydration routine. Next, I might take vitamin supplements if I'm not eating well. Then, I'll pack healthy snacks for the day ahead and always carry my water bottle. I make sure to change my pouch prior to eating breakfast and make sure I carry extra supplies in my purse. These daily habits allow me to feel prepared for the day. If you're not a morning person, you can plan these things the night before.

**4. Allow for Murphy's Law** - No week is complete without something going wrong, just plan on it. Take for instance that terrifying feeling of your ostomy appliance coming loose and the [bag splashing onto the floor](#), or a very inconvenient [leak at the shopping mall](#). Allow time in your schedule to prepare an emergency kit with extra clothes and ostomy supplies — always carry it with you! You're better off knowing these things are readily available just in case you need them.

**5. Be kind to yourself** - If you're having ongoing issues with your ostomy, this kind of overwhelm can lead to feelings of depression and anxiety. This is not the time to beat yourself up. It's extra important to pay attention to your mental radio and turn down the volume on your inner critic station. Practice self-compassion by giving yourself some credit for everything you've been through. Read [inspiring stories](#) about ostomates who've been through similar things. Self-love is so important.



**6. Lean on others for support** - The first step is being honest. If you're living with chronic illness or an ostomy, and it's a lifelong condition, then you need help. Brene Brown found through her research that people tend to feel shame around the idea of "never being enough" ... at home, at work, never smart enough, never good enough ... it's no wonder so many of us don't bother to ask. Do not feel guilty about asking for help. When you ask in a considerate way and understand they may need to say no (see #2), there's no hurt feelings. It can be something as simple as a friend bringing a meal over if you're tired, or [help with ostomy supplies](#) if you're paying out of pocket. Never let your pride get in the way of asking for help when in desperate need.

**7. Dump all your feelings onto paper** - When you're fed up with your ostomy, sometimes taking time to write down your frustrations can help. I give my patients journals to help with this. One of my favorite assignments is having them [write a letter to their ostomy](#), expressing all their truest emotions and thoughts — the good and the bad. [Ranting](#) is welcome but including gratitude and appreciation is the key to acceptance.

**8. Connect with others who understand ostomy life** - There are many ostomates who have gone before you, and many yet to come. It's very helpful to connect with others going through similar experiences because we can all learn from each other. If you want a pen pal friend, [Girls With Guts has a program](#). UOAA has over 300



local support groups. There are private Facebook groups for [online support](#), and of course many ostomates are on [Instagram](#) and [Twitter](#). Don't underestimate the power of peer support.

THE RULES: Just pick ONE (maybe two) of these tips to try today. I don't want you to become overwhelmed using them all!

by  
[Stephanie Brenner, LCSW](#)

Stephanie is a Licensed Clinical Social Worker in Evanston, Illinois.



## Interesting New Product

If you use **skin barrier rings** under your wafer, this may be a useful product to reduce skin irritation from the affluent getting under the ring and burning your skin. It looks like it might be most useful for Iloestomates that have a more liquid output. Also, maybe for Urostomates?

Here is the link to their website. They will also ship you a free sample.

<https://ostofrom.com/>

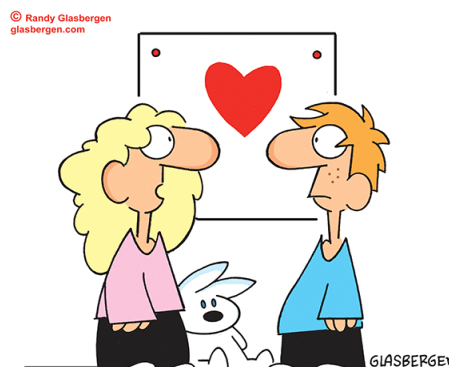
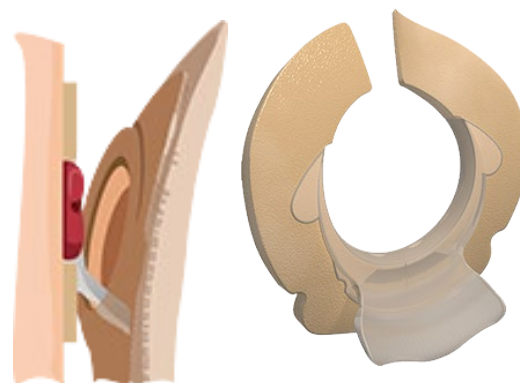
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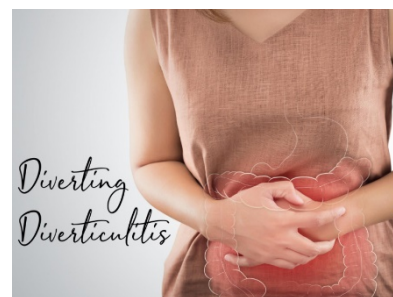
"Valentine's Day is the holiday where men give presents to the woman they love to make up for the way they screwed up at Christmas."

## DIVERTING DIVERTICULITIS

**OstomyConnection.com**

From the time I can remember, constipation was always an issue for me. I assumed I was doing something wrong to cause it. It turns out that I was born, like so many, with a redundant foot of bowel, which in layman's terms, means that my colon was not only oversized but a portion of it went in the wrong direction. Here is what I mean...the colon or large intestine ascends on the right side (ascending colon) and goes across the abdomen (the transverse colon) and descends the left side (the descending colon.) That is exactly the path that stool takes in its journey to leave the body. My redundant foot of bowel meant that the transverse colon actually went up at the connection to the descending colon, for a foot, before heading downward, so stool had to travel against gravity before leaving my body.

My first barium enema was when I was 10 years old, and although we didn't know what the problem was I was always told at that time, and every subsequent test, that my sluggish bowel would be an issue for me, (and it truly was, until my ileostomy 6 years ago). So, it came as no surprise that I was also told, each colonoscopy or c-t scan, that I had severe diverticulosis, which could become diverticulitis, a problem that often requires medical intervention.



The diverticula are small sacs that form along the mucosal lining of the colon, often due to straining to move stool through the intestinal tract, which puts pressure on the intestinal wall (which causes the bulging). This issue can worsen with age, medications and other causes of constipation. If the diverticula are inflamed or rupture, serious infection can result, which then is called diverticulitis.

While diverticulosis doesn't cause discomfort, diverticulitis can be terribly painful, cause fever, constipation or diarrhea, nausea and fatigue. Several in our Ostomy Support Group have had resections of their colon and ostomies due to diverticulitis. Some choose to be reversed after the several weeks of healing necessary to allow the connection in the intestine to do its job. Others choose, instead, to live with their ostomy, which offers them freedom from constipation.

There are ways to avoid diverticulitis, and they are manageable for most. Eating a high-fiber diet rich with fruits and vegetables and whole grains is a great place to start. You may remember that I have also mentioned that is a smart way to enhance our immune system, which may help fight Covid-19. Add more fluids, and if possible, pitted watermelon, for an extra kick of fluid. These tips will soften waste and help it pass more quickly through your colon. That may reduce the risk of diverticula becoming inflamed. Also, exercise and maintaining a healthy weight are very helpful.

Many physicians recommend reducing red meat; some used to say avoid nuts and seeds, although that restriction seems to have been eliminated. As I tell Ostomates, if you eat nuts and seeds and fresh fruits and vegetables, which are healthy and filling, please chew, chew, chew, since that is the best way to avoid inflammation or a blockage.

Many medications can impact motility of the bowels, so be mindful to changes when you add or delete medications, and please address with your physician any concerns. And most importantly, if you notice any changes, pain, distention, nausea, vomiting, or generalized discomfort in your abdomen that has you concerned, do not wait. Speak with your physician or go to the Emergency Room. Much can be done to not only make you feel better but to prevent a manageable situation from becoming extremely serious!

- Comments Off
- by Ellyn Mantell

## Ask Nurse Anita

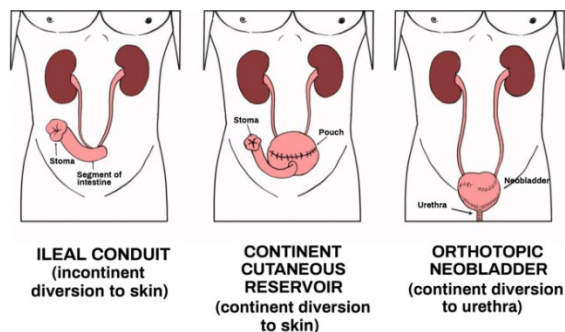
### Neobladder Incontinence

*I am a woman with a neobladder for 18 years and am experiencing urinary incontinence, especially at night or during the day when I cough or sneeze. I also get frequent urinary tract infections, including a kidney infection this year and now have chronic kidney disease. I currently catheterize about 12 times per day because I'm so afraid of getting another kidney infection. I've had so many surgeries and am littered with staples and scar tissue so that surgical repair is not an option for me. Is my neobladder worn out? What can I do?*

**M.R.**

**Dear M.R.,**

I don't think your neobladder has worn out, but perhaps your urethral sphincter has been damaged from years of catheterizing. As you know, urinary incontinence is a frequent occurrence in women with neobladders. Reports show up to 50% experience night-time incontinence. Nocturnal incontinence is thought to occur due to pouch overdilatation, physiologic increase in urine production and relaxation of one of the urethral sphincters during sleep. I would suggest decreasing your fluid intake before bedtime and set a clock to wake you up to catheterize during the night. The daytime leakage you experience when coughing and sneezing is called stress urinary incontinence (SUI). Pelvic floor muscle exercises known as Kegels may help. Physical therapists may be able to assist you with retraining these muscles accompanied by biofeedback. If the sphincters are not closing completely, urethral bulking agents such as botox are the least invasive intervention. Success rates vary, but overall are not very promising. Anatomically, research has shown that sparing the vagina and uterus has been shown to decrease urinary incontinence in women with neobladder. If the uterus and vagina are left in place this provides increased support to the neobladder and reduces the risk of



pouchocoele formation and kinking of the neobladder-urethral angle, both of which may contribute to urinary retention. Urinary continence has been shown to be better when the uterus is spared during surgery.

**Nighttime incontinence has been shown to have a marked negative impact on Health Related Quality of Life (HRQoL) during both day and night.** Most people with neobladders do clean intermittent catheterization (CIC) every four hours and can hold 300 to 500 mL of urine. More often than this can

cause injury, irritation, increased mucous production and infection. Using sterile catheters with water-soluble lubricants are vital for anyone who has had frequent UTI's. Adjust catheterizations to have an output of at least 300 mL. **Urinary retention or incomplete emptying of the bladder is another frequent cause of UTI's. There is a chance that you are not completely emptying your neobladder.** It is possible your neobladder is prolapsing which is preventing you from emptying completely. Women may benefit from using a pessary to mechanically correct the neobladder position. The device is placed in the vagina and helps to reposition the uterus and/or bladder. A pessary placement is the least invasive and inexpensive method that may work for you. Talk to your urogynecologist about this option.

**Bladder stones are fairly common in patients with neobladders (10-20%) and even higher in patients that have staples in their construction.** Stone formation is more probable in the presence of UTI and alkaline urine. When patients have stones, they are more susceptible to getting UTIs. When urine has an alkaline pH, bacteria thrives. Taking vitamin C can acidify your urine and help reduce the risk of UTI's. Some women report that cranberry juice also helps. Regular emptying of the neobladder, combined with routine irrigation, may reduce the incidence of stone formation.



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TYPE OF OSTOMY: COLOSTOMY \_\_\_\_\_ ILESTOMY \_\_\_\_\_ UROSTOMY \_\_\_\_\_

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# Happy Valentine's Day

