

# Secure | Start

A Quarterly Newsletter for People with Ostomies

## Surf the Support

Meet, learn, and share on [C3Life.com](http://C3Life.com)

Where can I find information and support? Where can I connect with people who understand? Where can I share my experiences? Community-based websites are the newest way for Internet users of all ages to find all of the above. They exist for a variety of medical conditions including cancer, depression, and diabetes. Put the word "ostomy" into your search engine, and you'll now find a few sites for people with ostomies, their caregivers, and their friends and family. One exciting example is [C3Life.com](http://C3Life.com).



"It's a great way to keep in touch and get answers from those who really, really know. Cause they are there right along with you...been there...doing that or have done it," writes one C3Life Community member.

When you visit [C3Life.com](http://C3Life.com), you can read about a variety of lifestyle topics, including healthy living, family and relationships, travel, and work/life. You can also find information on ostomy-related health issues, products, news and events. And if you sign up you can pose questions through the "Ask the Clinician Panel" feature, share your thoughts and experiences with peers on an interactive forum, and submit personal stories, photos, videos and more.

The stories are the heart of the site. A woman writes about dating after her divorce; a mother reveals how she explained her daughter's temporary ostomy to teachers, school nurses, and friends; and a man describes how he found a whole new career after his surgery. You can read the stories that call to you, and consider submitting one of your own. Want to connect fast? Go to the interactive C3Life Community Forum and type in a question or comment.



"This forum is a great place for support, and that's the key to getting through this and learning how to adapt to the new situation," writes another member.

Go to [C3Life.com](http://C3Life.com) any time of the day or night to tap into the support. And remember—the community needs you too for understanding, friendship or just a smile.

"Ya know, I just love visiting this site," writes another member. "I always come away with a smile no matter what."

### Announcements/What's New

## The Hollister Photo Contest Reaches Out To You

Smile for the camera and win \$250 for your IOAA chapter! This year's photo contest theme is "Reaching Out," and Hollister wants to see just how you do it. Submit a photo of you, a colleague or your support group in action—hamming it up, vacationing, playing with your grandchildren—anything that shows you reaching out and living life to the hilt. We'll choose 20 winning photos from around the globe and award each of the photographers' IOAA chapters with \$250! Submit photos to Diane Dreis at [wod2009pc@hollister.com](mailto:wod2009pc@hollister.com) or Hollister Incorporated, 2000 Hollister Drive, Libertyville, IL 60048. The deadline is August 1, so say cheese! Questions? Call Diane at 1.847.932.3573.



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#### General Information

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**Resources**

**United Ostomy Associations of America, Inc. (UOAA)**  
1.800.826.0826  
info@uoaa.org www.uoaa.org

**Wound, Ostomy and Continence Nurses Society (WOCN)**  
1.888.224.9626 www.wocn.org

**Crohn's & Colitis Foundation of America, Inc. (CCFA)**  
1.800.932.2423 www.cdfa.org

**Personal Profile**

# Younger Every Day

*Living with a colostomy for over 50 years has taught Donna Doll a thing or two*



*Donna Doll at Mount St. Helens on her trip to the Northwest*

Donna Doll bet her son-in-law that she would dance in the Pacific Ocean with her shoes and socks on. At age 80, a colostomy reconstruction and Hollister **New Image** Two-Piece Pouching System finally gave her the freedom to venture cross-country to visit relatives in Oregon.

What's so amazing about this picture is that Donna had her original colostomy in the 1950s — before pouching systems were invented. She was told to go home and irrigate twice a week — period. Though it limited her gadabout spirit, it didn't stop her from being a wonderful mother and wife.

"You just have to accept it and go on from one day to the next," explains Donna. "I had a great husband and family that kept me going."

Much to her doctor's disbelief, at 45 years of age Donna became the first woman with an ostomy on record to have a baby. Her daughter Angie gave her more reason to survive, and at 91 Donna is still going strong. She lives alone, drives a car, counsels other folks with ostomies, and stays in touch with her 66 grandchildren via the computer.

"It keeps my mind going," says Donna. "I've sure had a lot of fun on it."

Donna won the bet with her son-in-law and had to be rescued from the tide. Her shoes and socks were drenched, but her heart was full of joy.

"God bless Hollister for coming up with this two-piece system; it's simpler and cleaner," giggles Donna. "I call it my Tupperware because it snaps together."

*Editor's Note: You spoke and we listened! From now on, each issue will feature the Personal Profile of a person with a different kind of ostomy — either a colostomy, urostomy, or ileostomy.*

**Laugh with Brenda**

# Log on to Laughter

*Brenda takes up blogging instead of jogging with hilarious results*



I used to think, "Who has time in their day to read blogs, let alone write them?" And now I'm one of those people! I have Google Alerts™ set on my computer to receive all articles that pop up concerning colostomy. You can set it for anything you want to know more about, such as your latest heart throbs (Tom Cruise and Richard Gere are mine). Some blogs are very inspiring, especially when the writer appears to be honest about his or her struggles with physical challenges.

I was a little shocked when I viewed a video of a guy changing his ostomy pouch, but I'm sure it was enlightening for many. Do a Google search for "colostomy" and most things that pop up are slanderous. It is an oft-used reference when someone deeply wants to insult another by calling him a colostomy bag. Often these writers will refer to a boring event as comparable to caring for an ostomy. Come on people; let's come up with something more original!

I have to admit all this ignorance irks me. Many of these writers lump old age and colostomies together as well and this shows their complete lack of knowledge. Many adults with ostomies were also children with ostomies. I was 39 when diagnosed with colorectal cancer, not quite a senior citizen.

I urge my fellow blog and article writers to be more creative when needing to insult someone. Ostomy humor can be effective, but unless you have an ostomy or love someone who has one, you might not really know how to do it well. It can be done...and can have its funny moments. My book *I'd Like to Buy A Bowel Please!* is filled with true humor about living with an ostomy from 80 different writers. Having an ostomy can be life enriching in so many ways...not to mention prolonging.

As intimidating as all this technology is, it has been lifesaving for people as well. I have heard stories where someone posts a concern about an unusual symptom or strange disease and

another person in another part of the country or world writes to him or her. Lo and behold, they compare notes and get a life saving idea! Even our United Ostomy Association of America has set up technology so people with ostomies can exchange information. This electronic reaching out may not be as personal as a face-to-face meeting, but friendships have bloomed, and marriages have been created via cyberspace.

Now Twitter, LinkedIn, Facebook, MySpace, and a plethora of other hosting sites allow people to exchange information or make business contacts. Some even connect to your phone so you can get instant messages all day long. It's hard to keep up and must we really? I talked to someone recently whose husband challenged the family to get through a week without using cell phones, TVs, or computers. After all, they were on vacation! He even threw \$1000 into the mix and the mom won. The young adults didn't last more than a day.

*"This is an exciting time to be alive, thanks to the speed of new technology."*

So hop on your favorite search engine, heat up the latest hosting site and blog away...we only have this moment and if that makes you happy, go for it. You can read my weekly musings at [C3Life.com](http://C3Life.com) or watch me do some comedy on my website at [www.livingandlaughing.com](http://www.livingandlaughing.com). This is an exciting time to be alive, thanks to the speed of new technology. We've come a long way from the days of the battery-operated calculator! Now if they could just invent a microchip implant for my tongue that would make me spit out food once I hit my 1500 calories for the day I'd be in business! Who am I kidding? Instead of jogging, I think I'll stick with blogging for now.

Brenda Elsagher is a comic, national speaker, and author of *If the Battle is Over Why am I Still in Uniform?* and *I'd Like to Buy a Bowel Please!* Her third book, *Bedpan Banter*, will be out in May. Order these books at [www.livingandlaughing.com](http://www.livingandlaughing.com). She also enjoys hearing from you at [Brenda@livingandlaughing.com](mailto:Brenda@livingandlaughing.com) or 952.882.9882.

## Talking Points

# A New Year Brings New Beginnings

*Updated Medicare fee schedule resolves to boost reimbursement for the ostomy community*



The new year has rung in a new president, new resolutions, and a new billing cycle for Medicare. The biggest change for this year is a fee schedule update. There has been a five-year freeze on reimbursement increases for all Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS) that was mandated by Congress in an effort to control costs for the Medicare program. 2009 marks the end of that freeze and, therefore, most products in this category were given a 5% increase in their fee schedule. The good news is that all ostomy billing codes realized this increase.

What does this mean for you? If you currently receive your supplies from a supplier that "accepts assignment" or accepts Medicare's fee schedule as

payment in full, then your supplier will see an increase in his/her reimbursement. If you, however, must pay for any portion out of your pocket, this increase may help. I say it may help because there are many other factors at play like, is your supplier raising his/her price? Hopefully, though, some of this increase will be realized by you as well.

As for the Medicare Policy for Ostomy Supplies, there was only one change and that was the addition of a Usual Maximum Quantity for a code that was added last year that does not affect Hollister-manufactured products. Therefore, let's review a couple of highlights from that policy.

Medicare's maximums are outlined in the Medical Policy by their billing codes. As a general rule, the published maximums include the following:

**60 closed pouches**  
**4 oz of stoma lubricant**  
**20 drainable pouches**  
**31 stoma caps**  
**20 urinary pouches**  
**4 oz of paste**  
**20 standard wear skin barriers**

There are some supplies that currently do not have a published maximum in the Medical Policy (extended wear skin

barrier products and pouch deodorant, to name a couple). In the event that a maximum quantity is not established, it will be up to the regional Durable Medical Equipment Medicare Administrative Contractor (DME MAC) to determine what is reasonable and necessary for the beneficiaries' needs.

Of note, if you require both drainable and closed pouches to effectively manage your stoma it is technically up to each regional DME MAC to decide what is reasonable and necessary. The maximum quantity in this situation will be some combination of the two maximums listed previously. In other words, the maximum quantity will NOT be 20 drainable AND 60 closed each month – the appropriate amount of pouches should be derived by what makes sense for your situation.



*New year, new resolutions, and a new billing cycle for Medicare.*

## Personal Profile

# Staying Sexy

*Nicola Dames refuses to compromise her femininity after ileostomy surgery*



*Nicola and Joseph Dames prepare to send their lingerie to the US*

Nicola Dames, a vivacious 31-year-old Irish Intensive Care Nurse couldn't leave the house without making sure her bra and panties matched. But after her ileostomy surgery in 2006 all that was available to her were oversized "passion killer" underwear (as her husband calls them).

"I realized that the problem was not my body but my underwear," explains Nicola. "I gave my promise, as a sexy woman in the name of promoting sexiness, that something would have to be done."

She took out a pair of her favorite underwear, placed them down on paper and designed her attractive prototype, which incorporated a pouch. Samples were tailored and Nicola began the agonizing process of finding a manufacturer. After a series of rejections, she met her angel, an agent for Eastern European underwear companies who was willing to take a risk.

In January of 2007, Nicola took four young sexy models with ostomies to a photo shoot in Glasgow and her website went live in February. The phones have not stopped ringing since Nicola's appearance on London's "This Morning Show." As if that excitement was not enough, Nicola and her husband were also expecting their first child.

"My message is simple; we deserve to continue to feel sexy and attractive despite our surgery," says Nicola. "I may have had my insides removed, but I have not had my confidence removed."

## Our Favorite Things

# Luscious Lingerie

*Vanilla Blush offers sexy stoma-friendly underthings*

Sexy is back and here to stay! The attractive cami and panties shown are just one example of an exciting new line of lingerie designed exclusively for people with ostomies. Vanilla Blush, a Scottish company, offers silky underpants, thongs, and even swimwear fitted with an inside pocket to discreetly accommodate an ostomy pouch. All are made of a sensuously silky microfiber and lycra or microfiber and cotton blend in a full range of sizes. All are priced from \$36.75 to \$41.30 for cami and \$18.22 to \$22.68 for panties and thongs. Swimwear runs from \$49 to \$69. And they haven't forgotten your man! Check out the Mlush collection of boxers priced at \$27.40.

### Available now:

- Camisoles
- Panties
- Thongs
- Swimwear
- Menswear
- Miss Attitude Teenwear

### To come:

- Bridal
- Maternity
- Fabulous Underwear for Intimacy

Go to [www.vblush.com](http://www.vblush.com) today to see this exciting new line modeled by people with ostomies!



*The Vanessa Camisole with panty or thong. Available in black or white.*

**Secure Start Book Club**

# If the Battle is Over Why Am I Still in Uniform?

*Humor as a Survival Tactic to Combat Cancer*  
by Brenda Elsagher

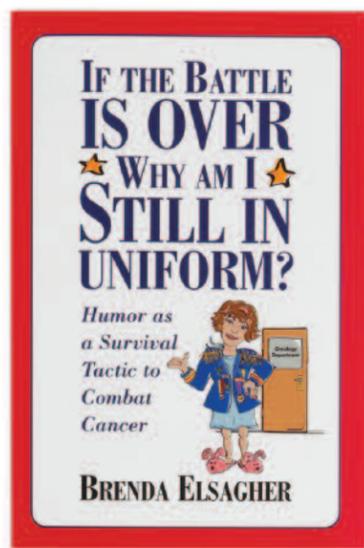
To most people, cancer is not a laughing matter, but comedian and professional speaker Brenda uses humor to heal battle scarred bodies and broken spirits in her first book "If the Battle is Over Why Am I Still in Uniform?"

Though irreverently funny, sometimes shockingly so, this book is no lightweight, rose-colored-glasses romp through recovery. Brenda invites the reader into the trenches with her to experience almost every detail of her battle with cancer of the rectum.

At 39 years old, this successful hairdresser owned her own business, was

happily married and the mother of two small children. Though often painful, Brenda's detailed accounts of her everyday skirmishes, from diagnosis and surgery to recovery, are riddled with no-holds-barred humor. For example, Brenda calls her surgeon "The Rear Admiral" and her stoma "Perry" after St. Peregrine, the patron saint of cancer.

Brenda ends the book with "Fifty Ways to Help a Cancer Patient," information about ostomies and colon cancer, a medical glossary, and information resources. This is a great read for patients, families, caregivers and friends. It's a life-changing story of triumph over not only cancer, but



everything that comes along with it. On the other side is Brenda's lifelong dream of becoming a stand-up comedian, and it's certainly obvious that she has earned her stripes.

Note: If you read this book while recovering from ostomy surgery, watch out for your stitches! To order this book and others by Brenda, go to her website at [www.livingandlaughing.com](http://www.livingandlaughing.com).

**Ask the Expert**

## Connection is the Answer

Hook up with a panel of expert clinicians on [C3Life.com](http://C3Life.com)

The "Ask the Clinician Panel" on the C3Life.com website receives questions concerning ostomy products and maintenance from people with ostomies every day and the questions and responses are posted on the site for all users to view. Below is just a small sample. If you have product-related questions of your own, please register for the site (if you haven't already) and visit the "Ask the Clinician Panel" section. Please be aware that information provided by C3Life.com is not medical advice and is not intended to substitute for the advice of your personal physician or other healthcare provider.

**Q:** I have a very hairy abdomen and when I remove the skin barrier I pull most of my hair and it hurts. Should I shave the hair off?

**A:** No. This is generally not a good idea, as the shaving can sometimes nick the skin (leaving it open to infection) or the hairs grow back underneath the skin (giving unusual bumps or pimples). Using a clipper would be better, as this leaves a small amount of "stubble" on the skin that still allows the barrier to stick but prevents unnecessary pain upon removal.

**Q:** I used to go jogging all the time before my surgery. Can I do this again now?

**A:** If your surgeon has given you the all clear, there is no reason why you can't go back to your usual routine. Just remember to start off slowly and build up gradually. Also, empty your pouch before you start any exercise and drink enough fluids to stay hydrated. Remember to consult your physician before you start jogging.

**Q:** Since I have gone back to work, I keep having periods where I just feel tired all the time. Is this normal?

**A:** For many, fatigue can be a real problem, even months after the operation. More often than not, people start back to work gradually (perhaps a couple of mornings a week at first) before going back full time. Unfortunately, it's not always possible to do this in all jobs. It's a good idea to check the employment rules at any place of work before requesting or receiving either time off work or reduced time.

**Q:** The paste stings when I put it on the skin around my stoma. Is this normal?

**A:** Pastes generally contain alcohol. If your skin is broken the paste will sting on application, but this usually goes away as the alcohol evaporates. Lower alcohol pastes are available, or you can try using a seal or ring instead of paste to fill in uneven surfaces. Generally, seals and rings are alcohol-free.

**Q:** Can a retracted urostomy stoma be corrected? How can I prevent leakage? I use a convex barrier.

**A:** The only true way a retracted stoma can be corrected is by having surgery. Leakage may be reduced by using a different type of pouching system or additional products. Adding an ostomy belt or trying a pouch with a thin, transparent dressing as the adhesive instead of a skin barrier may be helpful. A different degree of convexity may also do the trick. I would recommend meeting with an ostomy care RN or physician to get further suggestions.

## Announcements/What's New UOAA Conference to Spice Up New Orleans



Save the dates! You are warmly invited to the second annual UOAA National Conference August 5-8 in the "Big Easy." This year's theme, "Let the Good Times Roll," says it all. Educational workshops, ostomy product exhibition, and WOCN stoma clinic will keep you informed while parties, an early morning Fun Run, and nights on the town will get you hopping. Opening night festivities include "A Taste of New Orleans" sponsored by Hollister Incorporated and an appearance by veteran race car driver and person with an ostomy, Tim Mitchell. Register online today at [www.uoaa.org](http://www.uoaa.org). See you there with bells on!

**Announcements/What's New**

### It's Time to Get Your Guts in Gear

Start training today! The Ride for Crohn's & Colitis is a three-day, 210-mile cycling event on two coasts that raises funds and awareness for Crohn's disease and ulcerative colitis. The Hudson River Valley ride is June 12-14 and the Pacific Northwest ride is August 7-9. A new Midwest ride has been added this year! Riders will travel through Northern Illinois and Southern Wisconsin October 2-4. You don't have to ride to make a difference! You can become a crew member, sponsor a rider, or simply make a donation. For more information, go to [www.ibdride.org](http://www.ibdride.org).



**Take a Break**

### Word Search

O M G Q R A I N B O W S T H G  
 E N I H S N U S F Z Y P E S Y  
 J D A L V B N J C K S O K A S  
 G N I T L E M I P V T R C L P  
 E M I T G N I R P S O D A P R  
 G A D A F F O D I L O N J S O  
 G N L S E I Y W Z H B I M E U  
 R R I L P H Q A E T R A T C T  
 Z E O N E I I I L M E R A J E  
 F G W W E R L H T R B Z V J E  
 H E D O T D B U Y A B H F L G  
 U U Q V L H R M T W U M D R I  
 S E E D S F K A U O R D E J R  
 O R N D M C T Z G V U E A N F  
 Q F I Z W Y E Z Y P N A F Z P

Word Scramble compliments of [www.puzzle-maker.com](http://www.puzzle-maker.com)

- DAFFODIL
- FLOWER
- GARDENING
- GREEN
- GROWTH
- JACKET
- MELTING
- PUDDLE
- RAINBOW
- RAINDROPS
- RUBBERBOOTS
- SEEDS
- SPLASH
- SPRINGTIME
- SPROUT
- SUNSHINE
- TULIPS
- UMBRELLA

**World Ostomy Day is October 3**

**Hollister reaches out to you!  
See back cover for details.**