# Secure Start

## **Try a Little Tenderness**

### Love and intimacy go hand in hand after ostomy surgery

Let's face it — sex can be an embarrassing issue to discuss, even with a doctor or nurse. Throw that in with all the other issues surrounding having an ostomy, and it can seem like an impossible topic to broach. Wound Ostomy Continence Nurses Toni McTigue (MSN, APN, RN, CWON) and Janet Doyle-Munoz (BSN, RN, CWON) of Morristown Memorial Hospital break through the taboos with honesty and compassion.

"Once we find out if a patient is married or in a relationship, we let them know that we are trained and available to discuss issues related to intimacy at any time during the process," explains Toni.

Depending on how ill the patient was before ostomy surgery, questions about intimacy often come up before surgery or towards the end of the hospital stay. For women, these questions usually center around clothing and uncertainty about attractiveness, such as, "How can I possibly look and feel sexy again?" Men often ask questions about potential impotence or harming the stoma during sexual activity.

Toni leads a local support group for people with ostomies, and encourages them to bring their partners to these meetings. She often finds that the couples share stories and advice about intimacy, and end up developing an unconditional love for each other. Group support can be powerful. But for some, private couples counseling is the key.

"It's important to bring the spouse or partner into the treatment plan as soon as possible to discuss these issues, so that they can see there are many ways to be intimate," explains Janet.

Janet tells the story about a young couple that came to see her after the wife had a colostomy. She was devastated and embarrassed. Together, the husband and wife learned how to change her pouch, and by the end of the week he was changing it for her. He even made up a song about it to the tune of "My Sharona" with the words, "My My My Stoma!"

"We've seen some wonderful relationships blossom when couples work together," says Janet. "We learn as much from them as they learn from us."

There are many resources available to people with ostomies who have questions or concerns about intimacy. Support groups, your WOC Nurse, and online resources such as the UOAA website are great places to find support. Your Hollister **Secure Start** Associate Coordinator can also provide compassionate listening, and can direct you to resources that will provide the information and support you need. But good old-fashioned communication with your partner works wonders. When it comes to relationships and intimacy after ostomy surgery, a little tenderness goes a long way. Try it.

If you have questions about any of your Hollister products, call Hollister Consumer Programs at **1.888.740.8999**.





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**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.ccfa.org

### Announcements/What's New

## **New Catalogs Now Available!**



Ostomy Product Catalog (for people with ostomies)



2011 Ostomy Care Continence Care Rowel Care Tube Fasteners

Wound Care

As part of our continued effort to keep you informed of our products and educational materials, Hollister is pleased to announce that our new 2011 product catalogs are now available.

### **Ostomy Product Catalog**

For the individual with an ostomy, the Ostomy Product Catalog provides a listing of key Hollister ostomy products, including the Premier One-Piece Pouching System, the New Image Two-Piece Pouching System, and Adapt Accessories. The catalog is a great tool to help identify product options you may not have considered before, such as beige pouches, pre-sized barriers, pouch filters, and odor eliminators.

Clinicians will also find the Ostomy Product Catalog a helpful tool when sending patients home from the hospital. It can help identify products that may be appropriate later, after a patient's transition through the Secure Start Program.

### **Product Catalog**

Our more extensive, full-line Product Catalog is appropriate for clinicians who need a reference on all Hollister products for Ostomy Care, Continence Care, Bowel Care, Tube Fasteners, and Wound Care.

For more information on these catalogs, contact our Consumer Programs team at **1.888.740.8999**. For our Ostomy Product Catalog, reference MRP number 911263. For our Product Catalog, reference MRP number 911206.

# Laugh with Brenda Best Supported Comedian

Brenda gets by with a little help from her friends

There are unusual rewards that come with having an ostomy. You might say I have a "Pollyanna" attitude, but I can live with that. Life is good, and constantly changing. As my husband always says, "Life is never dull with you, Miss Brenda." I feel grateful to be around to keep torturing him.

At first, it was a tough adjustment as I tried to figure out which pouching system would work best for me. I had my trials of doo doo flying everywhere except into the pouch, and it caused me great stress in the beginning. After some research and development, I got through it with help from others and using better products.

One of the best things I did was seek help from my local ostomy

support group in Minnesota. I expected to see sad looking, perhaps smelly people, milling around (I may have been projecting what I felt inside). Instead I saw attractive, smiling people and I couldn't tell who had an ostomy and who didn't. I didn't feel isolated anymore; in fact, I realized I wasn't "special" anymore. There were people like me in Minnesota living life to the fullest and I intended to join them. They gave me tips and encouragement. From that moment on, I knew I was no longer alone.

### One perk of joining a support group was

meeting new friends. One evening, I invited Carol Larson out for dinner. As we talked, we realized we were both writing books about our experiences with colon cancer. The conversation has been nonstop ever since that meeting. We have written three books each, all different from the others.

I joined the support group board and eventually became the president. One year, Carol was elected president, and another year, we served as co-presidents. We even co-taught a class at the UOAA National Conference in New Orleans called *How to Make Meetings Fun*. I don't know if the audience had fun, but we sure did. While I got involved with GYGIG (Get Your Guts in Gear<sup>™</sup>), a three-day, 210-mile bike ride, Carol got involved with GYRIG (Get Your Rear In Gear), a 5K run that's held across the nation.

Later, Carol would win the Breaking Boundaries award for 3C,



award for GYRIG. As a result of our parallel lives, we have shared many dinners, visits with members of Congress, and lots of laughs. Our friendship is a blessed side effect of having an ostomy.

Before ostomy surgery, I was a hairstylist, business owner, wife, and mom. I was happy with my life and then along came an ostomy. Though I was challenged in many ways, I received many gifts, too. I discovered a love for comedy and telling stories. I have been unstoppable in letting everybody know that an ostomy is not shameful, gross, or the worst thing in the world. What's worse is when a small child who has been eating pizza and drinking orange

> pop suddenly projectile vomits all over your new white cashmere sweater. Okay, there are ostomy moments that are not too sweet, but overall, my ostomy has been a gift — the gift that keeps on giving!

> Hollister Incorporated has been a great supporter by allowing me to write this quarterly column. I've witnessed their sincere care and commitment to all people with ostomies. We are fortunate to have them in our corner. These days I enjoy relationships with people who have ostomies via Facebook, my blog on **C3Life.com**, the

UOAA Conference, various audiences, and my books. The riches that my ostomy has brought me include a longer life, great friends, creativity, and a forum to educate the general public about colon cancer screening. Thanks, dear readers, for being part of my life. You enhance it greatly with your phone conversations, lovely notes, book orders, and e-mails. Keep it up!

Brenda Elsagher is a comic, national keynote speaker, and author of three books: *If the Battle is Over, Why am I Still in Uniform?, I'd like to Buy a Bowel Please!,* and *Bedpan Banter.* Look for information about her upcoming fourth book, *It's in the Bag and Under the Covers,* in this newsletter.

Want to order your own copy of one of Brenda's current books? Call Brenda at 1.952.882.9882 or go to her website at **www.livingandlaughing.com**.



Two peas in a pod: Brenda Elsagher and Carol Larson





## Talking Points Ensure Your Insurance

The relationship between documentation and reimbursement is key

By Deanna Eaves, Senior Manager, US Reimbursement

While we're on the subject of relationships, let's take a minute to talk about the relationship we have with our physicians. With the health care industry's increasing emphasis on value and quality, comes an increasing demand for documentation to show that value. The time allowed for face-to-face communication with a physician seems to be dwindling as the time spent on charting and paperwork increases.

Since your time is limited, it's important for you to make sure that some key elements are recorded in your medical record by your physician or healthcare provider. This includes documentation for your ostomy supplies. When the initial order for your supplies is received, it should include not only the type of supplies you require, but also some indication of the *quantity* of supplies you need. Medicare and most other insurance providers now require that this information be supported by the medical record. This means the discussions between you and your physician about your supply needs must be documented in the physician's notes. This is not only true of your initial order. Each time you see your physician, you should talk about your ostomy supplies and whether the amount and type you are receiving is sufficient for your needs. Have this discussion with your physician (or at least the clinician who takes your vitals) and make sure they write it down in the notes. These notes can be reviewed by the insurer at any time and should reflect a continuing need for the supplies you are receiving.

Remember, your time at the physician's office is becoming more and more limited so you must make the most of that time. Don't be afraid to ask them to record information on your ongoing needs. Your ostomy supplier will need this information in order to keep supplying you without interruption.

Always remember the words of Mahatma Gandhi, "Nobody can hurt me without my permission." Make sure your documentation is in order and take the lead on this to ensure your supplies are not interrupted.

## Our Favorite Things Continuum of Care

How do I choose the best products for my lifestyle? Can I swim with an ostomy? Where can I order my supplies? How will I adjust to life with an ostomy? The complimentary Secure Start Program from Hollister Incorporated can help answer these questions with one-on-one support.

"What distinguishes us from other programs is that we mainly focus on support and relationship building," explains Luke Eimerman, Manager, Secure Start Program.

All it takes is a simple phone call to begin the process. Your Secure Start representative can help you find the right product(s) to meet your needs, provide you with information and education, help match you with an appropriate supplier based on your insurance plan/type, and provide compassionate support to help you get back to your life. Through the Secure Start Program, Hollister helps provide the bridge that will continue to "I want to thank the Secure Start team for your exemplary customer service, and your caring attitude. You are a great help in all matters, and I appreciate your fast and uncomplicated service." —Heike Van Pelt (Secure Start member)



guide you in the months and years to come. You can also find a wealth of information online. Logon to **www.hollister.com** and find a learning center, supplier network, and video diaries of real people with ostomies.





### **Secure Start Book Club**

### *It's In the Bag and Under the Covers: Stories of Dating, Intimacy, Sex, & Caregiving*

By Brenda Elsagher

Will my husband and I be able to make love again? When is the right time to tell someone I'm dating about my ostomy? Will my pouch be a turnoff? Questions like these come up at conferences, in Internet open forums, and when speaking to WOC Nurses and Hollister Secure Start Coordinators. After years of volunteering in a visitor program for people new to ostomies, Brenda Elsagher has heard them all. Now she uses her wit and wisdom to pull the covers off of this delicate subject, and share the stories of real people.

"I was not going for humor in this book as much as an honest telling of how people handle dating, intimacy, sex, and caregiving with their ostomies," Brenda writes in her preface. "I wanted the inside scoop so that we can understand the tension we may face, or the relief we may find, in knowing that we are not alone."

If you have read Brenda's other books, you know she is a master of mixing laughter and tears. This book is no exception. Stories from women include feeling attractive again, and finding the right apparel to add to the romance. For some men, the "mechanics" don't always work quite the same after ostomy surgery, and it can be disconcerting. There are a few stories in this book that address that.

What stands out after reading the stories in *It's In the Bag and Under the Covers* is that everyone reacts to a partner with an ostomy differently. Brenda concludes that more often than not, people that are in committed, healthy relationships experience no difference except for more compassion for one another, including gratitude for the caregivers.

This book is a must read for anyone searching for answers about intimate relationships, from people who have been there. Perhaps you just had ostomy surgery and are wondering how to tell your partner about your ostomy. Maybe after reading a few stories you will realize that it takes some time to adjust to your new situation, and that's okay too. This book may just be the launching pad for the story of the rest of your life.

*It's In the Bag and Under the Covers* will be available in June of 2011. Check Brenda's website www.livingandlaughing.com, for updates.

### Announcements/What's New 2011 Youth Rally to Rock San Diego

San Diego, California will never be the same after 100+ young people take the city by storm. The 2011 Youth Rally, a summer camp for adolescents age 11-17 with bladder and bowel dysfunction, will take place July 11-16 at San Diego State University.

This transformative experience is designed to provide a non-threatening environment where campers can receive education and psychosocial support that encourages independent living.

Activities will include swimming, softball, volleyball, skating, and other sports. Campers will also enjoy dances, picnics, crafts, and field trips to a fitness facility, beaches, and amusement parks. Educational sessions and discussion groups will focus on personal hygiene, self-esteem, sexuality, and self-care.

Counselors, many of whom are former campers, volunteer their time with the Youth Rally. They stress to the campers that the only thing limiting them is their attitude, not their medical challenges. All leave with new friends and an understanding that they are not alone.

"The Youth Rally allows you to form your own support group of friends who understand you and love you for everything you are," says Amy, a camper from Alabama.

Know a young person with an ostomy or continent diversion who is ready for a life-changing experience? Go to **www.rally4youth.org** and make 2011 a year to remember forever.



### Personal Profile Happily Ever After

With twins in tow, Lauren Kraly's fairy tale picks up momentum



Lauren Kraly was in her mid-20s when her bladder failed. Surgeons created an Indiana pouch — an internal urinary diversion — which later ruptured causing extreme infection. After 60 surgeries, including a urostomy, Lauren finally felt well enough to look at her life.

"It's a hard pill to swallow when you're that young," explains Lauren. "You think about going to the beach and what swimsuit you're going wear."

Toni McTigue, a WOC Nurse at Morristown Memorial Hospital in New Jersey, helped Lauren realize that everything was going to be OK. But when she and her longtime boyfriend broke up six months later, Lauren wondered how she would explain her urostomy to anyone else.

As fate would have it, she met her future husband John a month and a half later. After only a couple of dates, Lauren decided to tell him about her urostomy, in case it would dissuade him from pursuing a deeper relationship. John would not be dissuaded. "You have such a positive air," he told her. "I think you're more beautiful for going through a situation like that, and it would never scare me off."

Their relationship progressed quickly and they were married a year later. Lauren was told that creating an Indiana pouch would mean she couldn't carry a child. But she was thrilled when she learned that now with the Indiana pouch gone, and replaced with a urostomy, it would indeed be possible for her to have children. However, she never imagined twins in her future. Her boys came into the world via Cesarean Section, cheered on by a team of doctors, including Lauren's urologist.

Since then, life has been one adventure after another. Lauren, a Human Resources Manager at L'Oreal, found herself on a team-building wilderness weekend in Arkansas. Thanks to her Hollister Premier One-Piece Pouching System, she rock climbed, repelled, and even felt confident sleeping on the top bunk. Now, Lauren is ready for anything her fairy tale brings her way.

### Ask the Expert

## **Intimately Speaking**

Honest answers to delicate questions about sex and relationships

By Joy Boarini, MSN, WOC Nurse, Clinical Education Manager

Following ostomy surgery, you will likely have many questions and new skills to learn. Whether you have a new ostomy or have had one for years, living with an ostomy is an ongoing learning experience. Many people have questions that involve personal relationships and intimacy.

### Q. Does everyone need to know I have an ostomy?

**A.** You can tell who you wish about your surgery. However, when a relationship becomes more intimate, this can no longer be ignored.

### Q. Is it possible to be intimate with someone after ostomy surgery?

**A.** Many people have happy and fulfilled lives and relationships after their operation. It's possible to have improved sex after surgery, and many people go on to have children. You are a person with all sorts of characteristics, talents, and interests. Sex is only one part of your life.

### **Q.** How do I talk about my ostomy with someone I am interested in?

**A.** If a relationship is becoming serious, it's wise to discuss your situation before the relationship gets physical. Plan ahead by rehearsing a short explanation to yourself. It might be easiest to start with the fact that you had a serious illness that had to be treated surgically. The result is that you wear a pouch. Once you have decided what you want to say about your situation, finding the right time to say it will be easy.

### Q. How soon can I resume sexual relationships after surgery?

**A.** Recovery from a major operation takes time. People having stoma surgery are likely to have been debilitated prior to surgery. Unfortunately, this very often slows the recovery process. Do not expect to resume sexual relationships as soon as you return home from the hospital. It's a good idea to discuss with your surgeon when you can resume sexual activity. Once you start, it is important to proceed slowly and gently.

### **Q.** Are there resources available?

**A.** Check out the *Lifestyle Series* on the Hollister website. These booklets cover such topics as love and sex, personal and professional relationships, pregnancy and childbirth, and travel. Also, you can explore **C3Life.com** where you will find opportunities to connect with other people with ostomies, and clinicians who can provide suggestions and support.

Many people have happy and fulfilled lives and relationships after their operation





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