

Secure | Start

A Quarterly Newsletter for People with Ostomies



Caregiving 101

New caregiver's booklet from Hollister offers compassionate support

Secure | Start

General Information

Hollister Consumer Programs
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www.C3Life.com

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Announcements/What's New

Our Photo Contest Winners Continue to Reach Out



Last August, about 600 people from 19 countries entered the Hollister Photo Contest, and nine Americans each won \$250 for their IOA Chapter. This year's theme, "Reaching Out," yielded so many inspiring winning photos, we just have to show you a few more. Enjoy!

It's a given that adjusting to life after ostomy surgery is challenging for the patient. But how does it affect the caregiver? How does a wife, husband, parent, son, daughter, or partner cope with the changes ahead? Jane Ellen Barr, director of Ostomy and Wound Healing at Long Island Jewish Medical Center, asked these very questions and approached Hollister with the idea for a booklet geared exclusively to caregivers.

"As a nurse, I have always felt that I care for both the patient and the caregiver," says Jane Ellen. "Loved ones are experiencing many of the emotions and needs that the patient has, and this booklet acknowledges and addresses them."

Inspired by her family's reactions to a past illness of her own, Jane Ellen, together with Hollister, developed the booklet from a series of interviews with caregivers. The result, *Caring for a Loved One with an Ostomy*, is an informative booklet with a compassionate twist. It kicks off with step-by-step, how-to ostomy basics, much like the Hollister *Understanding Your Ostomy* booklets. Hands-on tips range from ordering ostomy supplies and dealing with insurance to communicating with doctors and visiting nurses.

The booklet also delves into ways to emotionally support a loved one, including listening, touching, and communicating openly. It goes on to address self-esteem and intimacy issues, as well as recognizing when to let go and foster independence. Caregivers will also find a list of support groups and information on the Hollister **Secure Start** Program.

But who cares for the caregiver? An entire section of the booklet is dedicated to helping the caregiver jump emotional and physical hurdles, such as balancing caregiving, work, and child support.

"Get a good night's sleep, exercise, and most importantly learn how to ask for and accept help," explains Jane Ellen. "Above all, be good to yourself."

Go to www.hollister.com to download your copy of the caregiver booklet today.

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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.ccfa.org

Personal Profile

Never Give Up the Battle

Dave Paca joined his father in the trenches after colostomy surgery

Dave Paca and his father, Felix.



Ruth and Felix Paca always took time to enjoy the flowers

Felix Paca, a World War II veteran, faced one of the biggest battles of his life in 2008 when doctors found a mass blocking his lower intestine. After emergency colostomy surgery, his oldest son David enlisted as main caregiver and comrade.

“Dad said to me, ‘Mom is too old to do this, please help me! I know that we can get through this,’” recalls Dave. “It was at that moment I realized that this veteran had faced larger problems during the war and was not giving up this immediate battle. How could I refuse him?”

Dave was frightened at the thought of accidentally causing his father more pain, and watched intently as the nurses in ICU changed the pouching system, hoping to pick up a few tips. Ostomy nurse, Terry Renteria, Pam Achabal (a Hollister **Secure Start** Program Coordinator), and other family members became his support team. And the Secure Start Starter Kit got them off on the right foot.

“Every link in this chain gave us strength during the recovery period,” says Dave. “The combined years of knowledge, training, and tools produced amazing results.”

Soon the sparkle was back in Felix’s eyes and his wry sense of humor kept both father and son amused. Dave remembers assisting his father in an airplane washroom. Just as the two grown men crammed into the tiny closet, Felix decided to reminisce about a previous airline washroom disaster. They laughed so hard that Dave’s rear hit the door handle and the light went out.

Felix passed away unexpectedly a year later, leaving Dave with memories he will treasure forever. The caregiving experience not only strengthened the bond between father and son, but it taught Dave many valuable lessons.

“I not only learned to lovingly and respectfully care for my father,” shares Dave. “But that the task given me was not something that I had to go through alone, and success was achieved through patience and a knowledgeable support team.”

Laugh with Brenda

The Tenderness of Caregivers

Even illness can be a laughing matter when caring for Brenda



My #1 caregiver came in the form of a dark-haired, good-looking, short, Egyptian, Muslim man. I grew up blonde, not bad looking, short, in a predominantly white, Catholic neighborhood and never knew anyone from Egypt before I met the man who would become my husband. We were married six years when I started complaining of a relentless pain in my butt that the usual remedies wouldn’t relieve.

We all went to the clinic — multi-tasking our appointments. We were spending the day at the clinic; some people take their families to the zoo! When everyone else was done, mine was just finishing. My husband checked in on me and together we heard the doctor say, “I’m almost 100% sure, even without the biopsy results, that you have cancer of the rectum.” We were devastated. We had only been married for six years, and our children were too young.

My parents were my next set of caregivers. I talked to my father, the financial planner, and went right into, “Do you think we have enough money for Bahgat (my husband) to make it without me?” After he let me carry on he said, in his fatherly wisdom, “You know, Brenda, you just might live!” Soon, siblings and my godparents had gathered to hear the details. Extended family caregivers.

The next day I went to work at my hair salon. At my request, my sister who worked with me had already told my co-workers. As each one came into work, they’d squeeze my hand, blow a kiss or give me a hug as they walked by me. Co-worker caregivers.

My #1 caregiver tried to keep my spirits up by joking a lot. The night before my CAT scan, I couldn’t sleep, worried that the cancer had spread to my liver. He woke up and just said, “Liver alone.” It was such a stupid pun that it made me laugh and soon I was fast asleep. After surgery, with the tubes and wires hanging all around me, he told me, “You look like the

back of my stereo system!” I laughed while still groggy from surgery. My #1 helped me with awkward pouch changes and accidents while going to work and taking care of the kids.

A schedule was started by friends to help with the children and me after I arrived home from surgery. My husband would leave the door open when he went to work; a friend would show up early, come in, and do what needed to be done for us until Bahgat got home. Other friends delivered nice meals every other day for weeks. My husband was almost sad when I got better! Friend caregivers.

I was complaining about not being able to sit down comfortably one day when my #1 caregiver told me his father had died while I was in the hospital and he didn’t feel he could leave us to go to the funeral back in Egypt. I didn’t realize until that moment how much Bahgat was suffering. Up to this point, it had been all about me. My caregiver now needed care-giving big time. I immediately called my friends and started talking about ways we could nurture him. Cards and visitors came for him. His mother died six months later. He quit making puns for almost two years while he grieved.

I was fortunate to have so many caregivers who now also extended care to my husband. In many ways, I feel that to be the caregiver must have truly been more painful. As a result, in my talks around the country, I try to acknowledge those who care for others who are ill. Their task is enormous. My #1 is doing fine these days, the puns are back big time.

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 recently released *Bedpan Banter*. Her books can be ordered online at www.livingandlaughing.com or by phone at 1.952.882.9882. Brenda also writes a blog on www.C3Life.com. Check it out!



#1 Caregiver, Bahgat and Brenda Elsagher

Talking Points

Prepare for Take-off

Steps for Security Simplicity

Body Scans

The newest technology to increase airline security is the development of full-body scanning, which allows TSA (Transportation Security Administration) personnel to see a detailed image of your body under your clothing, as well as anything you may have attached to your person. For people with ostomies, the thought of someone viewing their ostomy pouching systems, catheters, urine leg bags, and other devices is embarrassing to say the least. Unfortunately, this invasion of privacy cannot be avoided, but there are steps you can take to minimize your discomfort:

- Cooperate and explain that you're wearing an ostomy device
- Make sure your pouch is emptied
- Ask to be searched in private by someone of the same sex
- Send complaints to TSA if you feel your privacy or rights have been violated in any way

Carry-Ons

The good news is that flying with your ostomy pouching system and supplies has gotten much easier. Gone are the days of tight restrictions on medications and gels. Familiarize yourself with the following points before you pack for your next trip and

check www.tsa.gov before you leave to make sure requirements haven't changed:

- Scissors of four inches or less are permitted when they are accompanied by other ostomy supplies
- If you need bottled water on the aircraft to irrigate your pouch, simply purchase the water in the boarding area after you go through the security checkpoint
- You may carry on liquid medications, gels, and pastes; however, if they are greater than three ounces you must declare them separately for further inspection
- It is recommended, but not required, for passengers to bring along any supporting documentation (ID cards, letter from doctor, etc.)
- If the name on the prescription medication label does not match your name, you should be prepared to offer an explanation to security officers

Knowledge is power. Know the restrictions and your rights, and prepare for takeoff! More questions? Email them to tsa-contactcenter@dhs.gov



Personal Profile

Like Mother, Like Daughter

Gretchen Watson and Linley Dunn share a two-stoma household

Linley Dunn, a gifted thirteen-year-old basketball player was about to enter an international baccalaureate program when she was diagnosed with Familial Adenoma Polyposis (FAP). A month later, her mother Gretchen was tested to determine if she carried the mutated gene that causes the syndrome. She did, and was placed on the ileostomy fast track ahead of her daughter.

"I was able to change my pouching system in the hospital, but at home it was a different story," explains Gretchen. "It was just 'Stella' my stoma, a cold bathtub, a pair of scissors, and some very expensive ostomy equipment that wasn't working."

Luckily, an ostomy supply catalog representative suggested the Hollister **Secure Start** Program. Secure Start Program Coordinator, Roxanne was extremely helpful and explained how all the different pouching systems worked.



Gretchen Watson & Linley Dunn

By the time Linley's surgery rolled around three months later, Gretchen was a pouch changing pro (or so she thought). Because of her own journey with her Hollister **New Image** Two-Piece Pouching System, she knew that her daughter would need a convex skin barrier, but she wasn't prepared for the caregiving detours ahead.

"I realized that I had never had training from the perspective of looking at the ostomy from the front rather than from above," exclaims Gretchen. "I would never have believed that the self-care and caregiver experiences would be so different."

Linley's stoma, "Stewie," was shaped differently from her mother's, her wound was larger and Gretchen couldn't "feel" when the pouch had a good seal. Roxanne came to the rescue again, and soon Gretchen became confident in her caregiving role. Linley continues to be a star on the court and is being scouted for basketball and volleyball scholarships.

Gretchen's advice to other caregivers is simple: "Depend on your support, and never be afraid to call or feel like there are any dumb questions. If I didn't have Roxanne to talk to, I really don't know if either Linley or I would have kept our sanity!"



Linley Dunn shows off her backhand

Announcements/What's New

QuietWear Pouch Material Now On New Image Closed Pouches



New Image Closed Pouch with AF300 Filter

Hollister Incorporated, a trusted leader in ostomy innovation, knows that when it comes to ostomy products, details matter. That's why Hollister introduced **QuietWear** Pouch Material on **New Image** Closed Pouches with the **AF300** Filter. The combination of bonded film and fabric reduces embarrassing pouch noise and is one of the closest things to natural fabric found in your most comfortable clothing. This allows people with ostomies to live their lives with comfort, confidence, and discretion. Click the following link for additional details: www.hollister.com/us/products/product_series.asp?id=1&family=10

For a trial sample of the New Image Closed Pouch with the QuietWear Pouch Material, with the AF300 Filter, go to the following link: www.hollister.com/us/news/news_display.asp?id=1&newsid=68

Our Favorite Things

Prints Charming

Tell your own story with Gus Gear prints and solids

Are you a football fanatic? Animal lover? Gardener? Now you can express yourself right down to your pouching system with Gus Gear ostomy bag covers and wraps. Originally developed by Sarah Palya for her young son Gus, these handcrafted creations quickly caught on with friends, nurses, and doctors. The result is a line of super soft cotton, satin, flannel and fleece covers, wraps, and other accessories designed for both kids and adults. Covers have an envelope wrap in front for easy emptying, and an adjustable elastic

opening in back provides security. All are available custom sized to your pouch, in two lengths, and in prints and solids that range from the whimsical to the understated. Cotton/Lycra® wraps with Velcro® strips secure bags in a horizontal position and are available in black, beige, and white. Gus Gear can also custom order prints and team logo fabrics. For more information and to order, go to www.gusgear.net.



Ostomy Bag Covers
Prints in all cotton.
Short, \$17.95 ea Long, \$19.95 ea

Hollister Incorporated is not responsible for products and services provided by Gus Gear.

Secure Start Book Club

The Immeasurable Spirit

Lessons of a Wounded Warrior about Faith and Perseverance by Latoya Lucas



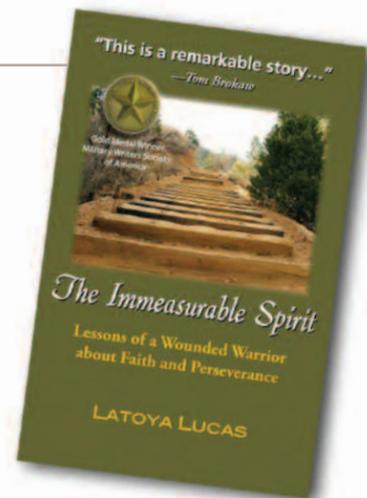
As Americans, we are bombarded by statistics about the war in Iraq. We hear of the number of wounded and killed, some of them from our own communities. But how often do we get to walk in their sandy boots, hear the missiles rush past their ears and lie in the dirt with them bleeding as they wait for a medic? Soldier Latoya Lucas gives us that opportunity in her book, *The Immeasurable Spirit: Lessons of a Wounded Warrior about Faith and Perseverance*.

It is the no-holds-barred account of her life-changing experience after an RPG (rocket-propelled grenade) exploded under the Humvee she was driving on a routine supply mission in Iraq. Not only was she severely burned and all the bones on her left side broken, but her pelvis was shattered, necessitating a colostomy. And to top it off, she sustained a Traumatic Brain Injury. At age 24, this could have left her scarred and bitter, but from page one of her book, her optimism, patriotism, and faith shine through.

Latoya takes the reader through her 5-month rehabilitation at Walter Reed Army Medical Center in Washington, D.C., and with each painful step, she shares the insights she learned along the way. Almost every chapter begins with a word and its

definition, such as: resilience, encourage, self-esteem, confidence, desire, attitude. Latoya uses each as a jumping off point to teach a powerful lesson about rising above adversity and finding one's true calling in life. Her prose is peppered with inspiring quotes from not only the Bible, but also military leaders, writers, and scholars.

Affectionately known as "The Purple Heart Lady," Latoya now serves her country in another capacity, inspiring other wounded warriors as well as church groups, corporations, and conferences. *The Immeasurable Spirit* is the next best thing to experiencing Latoya in person. It ends with a call to action, to look inside for ways to use our circumstances to inspire others. Latoya beautifully blends the inspiration of a self-help book with the gritty truth of a memoir, and the result is a novel that will inspire anyone who has fought on the battlefields of disability of any kind. Tom Brokaw writes on the back of the book, "This is a remarkable story of patriotism, courage near death, recovery and inspiration. We should all be proud to share our citizenship with Latoya — and thank her for her service."



Ask the Expert

Caregiving Made Simple

The how-to guide to caring for a loved one with an ostomy

Joy Boarini, MSN, WOC Nurse, Clinical Education Manager

If you have a loved one in your life who is scheduled to have or has an ostomy, you may have many questions. You are not alone! The following are some things that may help you during the planning and recovery.

Q: Should I be asking questions of the doctor?

A: Yes. You are a part of the team. Knowledge and accurate information can be very helpful in quieting fears and anxieties. Before each doctor's visit or when you go to the hospital, write down your questions. If time is limited, ask your most important questions first.

Q: There is so much information. How do I keep track of everything?

A: It's helpful to have a blank journal or notebook for this purpose. You can record key information, like insurance, current medications, and allergies, as well as your questions and the doctor's and nurse's answers.

Q: How can I be involved in my loved one's care?

A: That will vary. Each person's previous relationship will influence this. For example, if you are usually someone who easily provides physical support, it may be natural for you to be involved in the care of the stoma. If not, the emotional support and encouragement can be just as valuable. As time goes on and your loved one is further out from ostomy surgery, your role may change as they experience different emotions during the adjustment and recovery. It is also not unusual to see them progressing well and then suddenly become disheartened.

Q: Sometimes I feel overwhelmed. Is that normal?

A: As a caregiver, you may be experiencing your own physical and emotional struggles. You may have feelings of disbelief, shock, fear and/or anger. These are all normal. By caring for yourself, you will be better able to care for your loved one. Some ideas to consider for your own self-care might include a good night's sleep, planning a break for yourself, learning how to ask for help when you need it, and trusting your own instincts. Remember, both of you are adapting to a new "normal."

Q: Are there other resources I can turn to when I need them?

A: There are many resources available today for someone who is undergoing ostomy surgery. Depending where you and your loved one are in this journey, you will find you need or want different information. There are ostomy support groups as well as online communities. There are educational resources in print or online websites that can help you with specific information and topic areas. Often you do not think of all the questions you may want to ask while in the hospital. Your WOC Nurse and **Secure Start** coordinator can also be sources for specific questions you may have on products and living life with an ostomy.

Announcements/What's New

Videos from the UK: Living with a Stoma

Hollister announces a new addition to the Ostomy Educational Theater — *Living With a Stoma: The Patient Perspective*. These beautifully produced videos feature people with ostomies from the UK and their Stoma Care Nurses sharing a wide range of experiences and triumphs. Videos include: Life Before Stoma Surgery, Getting Back to Normal, What Can I Eat, Can I Still Travel, Love and Sex, Sports and Fitness and more. Check them out at www.hollister.com/us/ostomy/learning/theatre/eng_livstoma_patexpuk.html

Introducing Secure Start Program Video Diaries

The **Secure Start** Program from Hollister is focused on improving patients' outcomes throughout their continuum of care. We created video diaries from people with ostomies, caregivers, WOC Nurses, and Secure Start coordinators as a way to share experiences first-hand. These new video diaries demonstrate how, from the time a patient is enrolled in the program, the WOC Nurse and Secure Start coordinator partner to help improve that patient's outcomes! Get ready to be inspired yourself! Get comfortable and go to: www.hollister.com/us/ostomy/ss/video_diaries.asp



Caregivers are a part of the team...