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.
Personal Profile

Never Give Up the Battle

Dave Paca joined his father in the trenches after colostomy surgery

Dave Paca and his father, Felix.

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 Holllister 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 make it without me, “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?”

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**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

### Announcements/What’s New

**QuietWear Pouch Material Now On New Image Closed Pouches**

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

### 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.

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,” explains 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” if either Linley or I would have kept our sanity!”

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!”
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 encourage, self-esteem, and desire, 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 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.

Caregivers are a part of the team...