

*Portland Maine Ostomy  
Support Group  
Newsletter*

**The Visitor**

March/April 2006

**Next Portland Meeting:  
Sunday, March 19, 2:00 p.m.  
Mercy Hospital**

We will welcome the Hollister Rep,  
Andrew Peck  
Come hear about what is new at Hollister



**The Next Seacoast Ostomy Meeting:  
Sunday, March 19 - 2 to 4 p.m.  
Ellis Conference Room  
York Hospital**

Contact Jerra Sullivan with Questions  
207-351-3456

<b>Portland Support Group Contacts</b>	
Paul Brady, Treasurer	934-4055 pbrady@maine.rr.com
Sally Hinckley, Secretary	799-2235 Hhinckl1@maine.rr.com
Peter McGinn, Website/Newsletter	854-1741 narrator@maine.rr.com
Peggy Delparte, Mercy Hospital	879-3190
Kate Hill, Mercy Hospital	879-3190
Barbara Gardner Visiting Nurse	780-8624
Jerra Sullivan York Hospital	351-3456



[www.uoaportland.com](http://www.uoaportland.com)

Sounds Like a Real Bargain



Is this the Installed Price?

We had a double program for the January meeting, sort of. First we watched a short video concerning the Friends of Ostomates Worldwide, and the work they do sending ostomy supplies to nations who can't even purchase it locally. If you couldn't make the meeting but have some supplies you won't be using and would like to donate, you may still bring them to the next meeting. I will ship them with a chapter donation to help cover their shipping costs.

For the March meeting we will welcome the Hollister Rep to talk about new products and changes since the last time we heard from them.

My ostomy fiction continues in this issue. If you haven't read the first two installments, they can be found on our own uoaportland.com website. Past newsletters are also located on the site. If you are interested in attending a regional ostomy conference in New Jersey April 21-23, go to uoaa.org for more information.

## Tips for all Ostomates

### Internet Sources

The following are some tidbits of advice. If you have questions, contact your ET nurse.

- When you wear a two-piece snap-on appliance, take the extra second to make sure the pouch is snapped to the flange securely. Start snapping it together at the bottom and work your way to the top. Give a little tug straight down on the pouch to test its lock, but make sure you hold the faceplate/wafer so you don't break the seal.
- Don't shove that parsley aside. It's one of nature's best deodorants. Use parsley in cooking fish to reduce odors for colostomates and ileostomates.
- Store appliances away from warm, humid places. "Melt-down" can render equipment less effective.

Pouches can leak for a variety of reasons. Find out why, and correct the cause.

- Make a note of the day you change your appliance so that you know when it is time to change again. Some use a ball point pen and write the date and time on the tape around the flange. This is an easy method for always remembering your change date.
- Don't keep a lifetime supply on hand. Shelf life may be limited. Let the stores stock up on your appliances.
- Do not apply a double coat of adhesive. A second coat rewets the original coat, and results in an inconsistent adhesive layer with unpredictable results.

Chicago N. Suburban

### Here are some humorous stories I ran across:

- 1) I am 11 years old and have had an ileostomy since November 29th, 2000. Some of the things I have learned are:
  - I cannot do belly flops on a gym mat. It has a tendency to blow apart your ostomy bag.
  - My bag leaks if I am in a hurry and forget to put it on.
  - I can't lay on the same side as my bag is on when I sleep at night, because I have a

filtered bag and at night it plugs up. If I let it fill up with air it blows off real quick.

- And, in the winter it really does keep my hands warm.
- And the very last one is that my dad can always tell where I've "burped" my bag last.

2) A friend of mine with UC has come to the end of treatment and was recently told she will need an ileostomy. Because she considers me an expert, due to personal experience, she asked about the "bags". I told her it might be a good idea to wear one for a few days to get used to it. She wore it and said when her sister came to take her to the dentist, she removed the bag. She was afraid that if they got into an accident, the emergency room staff would remove the bag, and not seeing a stoma, they would send her to the psychiatric ward because they would think she was a "stoma wannabe!"

3) Having had my ostomy surgery in high school, I was extremely terrified of swimming class and having to undress in front of the rest of the guys. I took a deep breath and said, "Here goes nothing," when one of the guys turned he said "I heard you had surgery and what a nasty scar, but why do you carry your money like that?" I let out a laugh and said, "You just don't know these days, so I keep my money as close as possible." I had survived. The rest of the times I undressed with my butt pointing towards them.

4) I had a temporary colostomy for 4 months following surgery for perforated bowel. When the colostomy was repaired, I told the surgeon: "I certainly will be glad to have that behind me."

### Evelyn's Story

#### A Life Lived Half-full! (from WOA Website)

On March 4, 2005, I had my fifty-ninth anniversary of living with an ostomy and it was certainly a celebration. Having an ostomy has unquestionably improved the quality of my life! It rescued me from a debilitating chronic illness and has allowed me to live a full, active life. I am very happy that I had my ileostomy surgery, even though the early days were certainly challenging. I have never let challenges get in the way of my life as my story below will show.

I grew up in the town of Redditt, Ontario, nineteen miles north of Kenora in Northern Ontario. When I was a teenager, I developed chronic diarrhea. As a result, I experienced six years of severe illness, missing my schooling for three of those years. I went to a doctor in Kenora who was unable to diagnose or resolve the problem. I was referred to Winnipeg where wild strawberry extract was recommended as treatment for my diarrhea. I also tried several diets, all to no avail. These were very hard times for me. I was young and my life was restricted, painful and downright miserable. In 1945, my father, frustrated by the lack of effective treatment, called the Mayo Clinic in Rochester who referred me to the Winnipeg Clinic where I have been going ever since. At the Winnipeg Clinic, I was finally diagnosed with Ulcerative Colitis. One of my original doctors there was Dr. Paul Thorlakson. When he stopped practicing I came under the care of his son, Dr. Robert Thorlakson, who I still see today.

I had a temporary ileostomy on March 4, 1946 at the Winnipeg General Hospital, to allow my colon to rest. I weighed only 79 lbs after my surgery and I was very weak from years of being ill. I was sent home from the hospital with no supplies, just a big binder and cotton wool, which was piled up over the stoma and strapped on with the binder. No pouches were available at this time and this system was the best they could offer! It didn't work very well, as you can imagine. The pain was gone, but now I was an invalid in a new way. I wondered what kind of life I could have wrapped in bandages and needing messy changes every few hours?

A month after my return home, my father had had enough of watching me suffer. He contacted a medical supply company in Winnipeg and they got hold of some Davol pouches for me. These were made of rubber and were sealed with an inflated rubber donut which was pumped up at each fitting. The pouches had an inch and a half wide elastic belt which was quite uncomfortable. The bags had to be scrubbed once a day and after a few months, the donut would expand to such a size that a new one was required. Compared to having no appliance at all, they were a massive improvement - no bandages and no mess (usually). I had my life back again!

**Evelyn's Story came from the Inside Out newsletter from the Winnipeg Ostomy Association and will be continued in the next newsletter – Editor. Page 3**

### **The Back Page – Cont'd from page 4**

"It won't be like that," Michelle explained. "Before he signs off on the divorce, he wants to meet the man I'm marrying. Jake is your father's age. When I told him I wanted the divorce, I didn't want to tell him about your father, because Jake can be a loose cannon."

"That's another term for psychopath, I assume?"

She ignored me. "You see, I cited our age difference when I talked about the divorce, and here with your dad I have the same age difference. That and what we don't have in common."

"He goes on rampages," I pointed out, "and you don't. He takes hostages and you don't. I agree."

"Dale, let me finish. The point is, your father and Jake won't like each other."

"Hold on," I kept up my protest. "I'm not sure I care for the implication that he might like me. I don't want to be liked by him. Who knows what new tricks he has learned in prison?"

"You forget, Dale, he never actually hurt anybody. He just made threats.

There's a difference."

"Tell that to the judge," I muttered. "So you're not wearing make-up in order to look less attractive to him, is that it?"

"I have to use everything at my disposal."

"Including me?" I suggested.

She rolled her eyes. "You don't have to come, of course, Dale." She took hold of my arm and squeezed it gently. "I'm not going to twist your arm. Will you help me, Dale? Please? Your father knows about it."

That didn't shock me. Before the skies opened up and wads of money fell into his lap, Dad used to send me to the landlord when he couldn't pay all of the rent.

Michelle looked up at me, her pale unpainted face shining in the sun streaming in through the window. "I'll be ever so grateful, and so won't your father. Don't worry about Jake. He's all talk. He said when he gets out, he's going to Texas. He won't even be in Maine. Will you help me?"

I felt a sudden kinship with Fred and Ethel Mertz. Was this what it was like to have Lucy Ricardo as a friend? But like Fred and Ethel, I felt myself being drawn into the scheme. Oh, I fought the impulse. Sure Dad approved: it would be my teeth flying out of my head, not his. But when a beautiful woman squeezes your arm and pleads sweetly to help her, the word no doesn't come easily. Maybe it's a guy thing. So against all my screaming instincts, I agreed to do it.

**Next Chapter: Jake Shows Me his Tattoo.**

## The Back Page by Peter McGinn

### Chapter 3 - Home from the Hospital

My doctor told me that hospital patients are the most optimistic people in the world. Once they can hobble to the bathroom, they assume they can manage alone at home. HMOs are just as optimistic, and they pay the bills.

So even though he wanted to keep me longer, he allowed me to leave two days after the visit from Dad and Michelle. I worked for the hospital, of course, but I was exempt, which meant I didn't get benefits, so I was covered under Dad's insurance until such time as I turned 21. Which wasn't too far off.

I have alternated living with Mom and Dad ever since the divorce. As a kid, I worked one off the other to get what I wanted. I had it down to a science. The secret was not to actually ask for anything but rather explain with patient sighs how I didn't mind not having what I wanted. I try not to do so much of it nowadays, since I have some of the lottery winnings in a bank account of my own.

It was decided I would convalesce in Dad's house. Mom didn't take offense. She worked for a living still, didn't live in a twenty-room house, and couldn't afford the visiting nurse Dad hired. It was generous of him, I suppose, but it was more a matter of him following his new habit of throwing money at problems rather than rolling up sleeves and pitching in. I suppose it is better than his old habit of ignoring problems completely. I gathered early on that he didn't want to hear about my medical progress and setbacks.

The nurse was to fill that need. I was assigned the word "fine" while I stayed there. "How are you, son?" "Fine, Dad." Our roles were set.

So I settled in with Dad and his girlfriend while Mom awaited the return of her touring pianist. It hardly seemed fair that my middle-aged parents were giddy in love like teenagers (but not with each other!) while I hobbled around like an ancient. Dad had won the lottery, and Mom had toured Europe twice with the maestro. What had happened to me? Couldn't I use a little excitement in my life? Of course, the only problem with wishes is that once in a while you get what you ask for.

I didn't see much of Dad and Michelle my first few days there. Dad keeps strange hours, ramming around town, as he called it, until 2:30 a.m. or so, and then sleeping until 10:30 or later. I don't know how he spent his time, but he didn't strike me as someone about to settle down calmly into parenthood again.

On my fourth day there, Michelle sought me out. She was wearing no make-up, not even the bright

red lipstick that Dad seemed to stare at sometimes until he was in a trance. She was still pretty, but the difference was startling.

"I never let your father see me like this," she confided. "But today I have a mission to perform, and I need a big favor from you."

I tried to imagine a favor that had anything to do with her not wearing make-up. I have a pretty good imagination, but it failed me. So I just screwed on an encouraging look and waited for it.

"I'd like you to come with me to visit my ex-husband. The thing is, technically he is still my husband." I opened my mouth to say something dumb, no doubt, but the words were pouring out of her as if she'd waited years to say them.

"Back when he went off the track, I didn't want to aggravate the situation by pushing for a divorce. Besides, there was no one steady in my life then. Finally I started divorce proceedings about a year ago, and it has reached the point where I more or less just need him to sign off on it. Will you come with me??

"What do you mean, went off the track?" I asked her. Her eyes widened slightly in surprise.

"You mean your father hasn't told you?" She pursed her now pale lips prettily for a moment. "Okay, my husband - well - he went on sort of a rampage at the local zoo, and then we had this hostage situation. It was blown way out of proportion by the reporters."

A memory fell into place. "I remember," I said. "Didn't he tell the judge that she could give him the death penalty if she'd just give him one more crack at the arresting officer?"

"He was just putting on a show."

"It was a convincing show," I said. "So he's in prison now?"

"Not exactly. He has served his time and is in a halfway house. Will you come with me?" It almost made sense. How wise would it be for her to bring her current lover along when completing the final breakup with the estranged husband?

"Okay, I said, "I can give moral support with the best of them."

"I don't know how moral it will be," she said, "I want you to pretend to be my fiancé."

I felt an urge to reach down and pick up my lower jaw. "Wait a minute," I said, "I saw this in a sitcom once and I'm trying to remember how it turned out."

"Dale..."

"I think a black eye came into it before the laugh track kicked in."