

*Portland Maine Ostomy  
Support Group  
Newsletter*

**The Visitor**

May/June2006

**Next Portland Meeting:  
Sunday, May 21, 2:00 p.m.  
Mercy Hospital**

**Program: Round Table Discussion  
(Or maybe an oblong table discussion)**

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**The Next Seacoast Ostomy Meeting:  
Sunday, May 21 - 2 to 4 p.m.**

**Ellis Conference Room  
York Hospital**

Contact Jerra Sullivan with Questions  
207-351-3456



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

**From the Editor**

After three meetings in a row with speakers, the May meeting looks to be all about us - when we have the chance to ask questions and discuss living with our various ostomy and other procedures. These meetings are often prove to be the most interesting, especially for those who are new to their surgery. If you have any questions or recent problems, or want to be a help to those who do, please come on Sunday, May 21st.

I recently attended a regional ostomy conference in New Jersey. It was fun and interesting, and worth the long drive. I may write up something about it for the next newsletter, but my deadline won't allow it for this issue.

In other news, the UOAA has contracted with a woman in Tennessee to be their "office." She will be the mailing address for inquiries that come into the organization, and she is answering the 1-800 help line set up for people with questions. It is the same 800 number the UOA used before it ceased operations. I met her at the regional conference, and we will be well represented.

Just a reminder, you will never receive dues reminders from the UOAA - it is not set up that way. Instead, the organization receives a lot of its funding from subscriptions to the new Phoenix Magazine, so be sure to subscribe. After twenty years of receiving the Ostomy Quarterly, I find I only read parts of it, but I am able to bring issues to the meetings for Peggie and Kate to distribute to new ostomates who get a lot out of it, plus it supports the new organization.

Also, the first UOAA national conference is being held in 2007 in Lincolnshire, Illinois, which I understand is outside Chicago. It will be held on August 15-19, 2007. Unofficially I have heard that instead of just in a hotel, it will be held at a facility with over 100 acres and that activities such as volleyball and (I assume) others of a somewhat less strenuous nature will be available. But we have plenty of time to get the details.

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**Evelyn's Story came from the Inside Out newsletter from the Winnipeg Ostomy Association and is continued from the last newsletter – Editor.**

In 1948, a year and a half after my surgery, my doctors decided to finalize my ileostomy as the Ulcerative Colitis was still active. I had my colon and rectum removed and the ileostomy made permanent. I took a long time to recover and had several surgeries before it healed properly.

This was another very frustrating time in my life. I wondered if the surgeries, pain and frustration would ever end. But it did! This ileostomy lasted over forty years, until 1991, when I had a revision - quite the life span!

Ten years after the ileostomy was made permanent, in 1958, I discovered that I could order Nu-Kumfort appliances from the United States. These appliances had a steel plate which attached to a regular plastic bag. The funny part about these appliances was that every time I went through security before flying, the metal detector would buzz! I wore a big belt, with metal hooks to keep the bag in place. It might still sound very primitive, but it had no bags to scrub and no "donut" to blow up. It was also much flatter than the Davol pouch, so it was not as obvious under my clothes. I liked these pouches much better and they made my life a lot easier.

My life just kept getting better. In 1967 I got married and moved to Thief River Falls in Minnesota with my husband. We came back to Winnipeg in 1971 when my husband retired from his Area Store Manager job and we lived in Winnipeg, working together as apartment caretakers until my husband died in 1991.

I wore the Davol appliances until joining the Winnipeg Ostomy Association (WOA) in 1972. It was at the WOA, with the institution of the Manitoba Ostomy Program by the provincial government through the WOA's lobbying efforts, that I discovered "modern" appliances. These modern appliances are super! No odour, no leaking, except on rare occasions, as we've all experienced. They are very flat and fit under clothes very well and they are very easy to change. They even look good with either the mesh covering on some pouches or a fabric pouch cover.

In gratitude for what the WOA did for me and because I wanted to help others in the same position, I have been an active member of the WOA ever since. I attend meetings regularly and was involved with the "New Horizons" group that was set up by the WOA especially for seniors. We would have a luncheon meeting every week. It

was a nice social event but the group is, sadly, no longer functioning.

I have been a Social Convener and served on the Refreshments committee for many years. I have gone to several conferences, have twice been a fashion model for special events and regularly volunteer whenever help is needed, whether it's World Ostomy Days, the WOA Christmas Party or the Annual Wine and Cheese. I really enjoy meeting people at the meetings, whether they are long-time friends or new ostomates. I think this is why I have been a member of the WOA for so long.

I am retired, but sometimes feel that I am more active now than when I was working. I certainly am a lot more active than when I suffered from Ulcerative Colitis as a teenager. This contrast shows how debilitating Inflammatory Bowel Disease (IBD) can be. As an octogenarian, my life is fuller and more active than it was when I was in my teens! In addition to my WOA activities, I joined the Optimists in 1993. I am on the South Winnipeg Optimist Club Board and keep very busy with our yearly events such as the Optimist's Band Festival, the circus, Buffalo Barbeque and other special events. I really enjoy staying active, meeting people and feeling useful. My volunteer work lets me do this and help others as well.

Despite the poor appliances and surgical problems with which I began, I strongly believe that my ileostomy has had a very positive effect on my life. I have lived a full, active life and enjoyed good health. I could not have done this without having my ileostomy surgery. My Ulcerative Colitis was totally debilitating and my ileostomy cured me and let me live again.

My experiences certainly demonstrate the medical advances made in ostomy equipment over the last fifty-nine years. From being discharged from hospital to an isolated Northern Ontario town swaddled in bandages, followed by years of primitive, but partially effective pouches, through the formation of the Winnipeg Ostomy Association bringing with it the Manitoba Ostomy Program and the availability of modern appliances, continuing on to my current very active life as an octogenarian. These advances have impacted my enjoyment of life in a very positive way allowing me to live life to the fullest. I like to think that I am a positive living example for ostomates, showing that ostomy surgery not only saves lives but greatly enhances quality of life as well.

*Evelyn Waldera celebrated 60 years as an ostomate on March 4, 2006. Source: Winnipeg Ostomy Association, Via Inside Out newsletter.*

## The Back Page (cont'd from page 4)

"Can you see how awkward that would be?" Michelle asked him. He seemed to give it some thought.

"Well, maybe," he admitted. "But this is a sacrifice for me. I liked being married to you. I'm just asking for a bit of a sacrifice in return."

"And here I thought being interviewed for the 6 o'clock news five years ago was my sacrifice." She seemed to be weakening, so I had an idea.

"We have to check with my father," I said. "We're staying at his place right now." I was pleased to say something that was the truth during this whole fiasco.

Michelle nodded. "Yes, we'll have to let you know what he says. It will sound odd to him, you have to admit."

"Well, be persuasive," Jake advised us. "No futon to crash on, no signature."

We left a minute or two later. Walking to the car, Michelle said, "That wasn't too bad."

Obviously her expectations had been even lower than mine. She paused before unlocking the car doors. "Did they really remove your sphincter muscles?" she asked me, which was a odd question when you consider what we had just gone through. I had a better question. I waited until we were in the car before asking it.

"Are you really considering letting that nut case stay under my father's roof while you and I pretend to be engaged? Is there any aspect of the idea that makes sense to you?"

She sighed. She didn't protest, or assure me that her husband wasn't a nut case, and she didn't claim that any aspect of it made sense. She just sighed. That spoke volumes for the scheme.

Life is a trade off. Having the surgery changed my physical self-image. It was inconvenient, but it brought normalcy to my health and my inner life. I didn't have to know where the nearest bathroom was all the time. I wasn't constantly sick. I could go back to work. But I could see that, living with my parents in my life, my life would never be normal.

**Next Issue: I Go Back to Work**

## Helpful Hints from Canada

(You may want to consult with ET Nurse or doctor)

=> Is it hard to manage a seal on your two-piece appliance? Try soaking the pouch in very warm water and the ring will become flexible and easier to handle.

=> **Urostomates:** Train yourself to shut the pouch valve as soon as you empty the pouch. Gallon bottles of white vinegar and cheap liquid detergent make the daily wash up inexpensive. Change your pouch first thing in the morning. A

five-gallon paint pail with a metal handle is a great night bottle and a safe way to carry to equipment the bathroom in the morning.

=> Some ileostomates have watery discharge and this is normal for them. This is not to be confused with diarrhea.

=> Try making a template of your stoma shape by making a paper one, tracing it with a felt tip on a white plastic container lid, cutting it out. No more measuring.

=> If you are looking for a mild soap to wash the stoma area, try No More Tears baby shampoo.

=> Try mixing your expensive liquid pouch deodorant half-and-half with water. Just as effective and you can use as much as you want.

=> Your loose stool may be caused by an antibiotic or other medication. Check it out.

=> A hernia belt especially made for ostomates can be a great help if you have a stomal hernia or just cannot avoid heavy lifting.

=> When you go swimming, make a little frame around your wafer with micropore adhesive tape if you are using a tapeless pouch for an allergy. This is a paper tape which causes few people problems.

=> Eat a little something before going out to dinner. It will help to control gas from an empty stomach.

**Source:** Ottawa Ostomy News

## Why Should I Come To Meetings?

[**Editor's Note:** I see these lists all the time, so I am including in *(parentheses)* my advice for those who haven't attended many meetings.]

1. No matter how many meetings you have attended, you can learn more.
2. Keep up on newer developments and hear the speakers (*Why should they be the only ones to give up a few hours on Sunday?*)
3. You may have questions and problems that can be asked and answered at the meeting (*and sometimes complaining just feels good!*)
4. Give support and encouragement to the more active chapter members (*but don't make eye contact or you'll be asked to help next!*)
5. Be a role model for new ostomates to show an active life can continue (*or even a great inactive life*).
6. Learn what's new in ostomy equipment. (*Can you say "Freebies?"*)
7. Experience a sense of accomplishment and renew a positive attitude for life and fulfillment. (*Oops, that is from the list of Why I Should Win the Lottery*)

**The Back Page- Fiction by Peter McGinn**  
(previous chapters available at uoaportland.com)

#### **Chapter 4 - Jake shows me his tattoo**

Michelle and I went to visit Jake on that sunny Tuesday afternoon. Dad was playing the British gentry that week, so he saw me off at the front door with a "Good luck old chap," as though I were going to hunt a fox rather than going to see a convict while pretending to want to marry his wife.

After serving four years of hard time, Jake was in a country club, as near as I could see. Anger management courses, a full gym, and long walks near a winding river - one quick tour and I was looking for a place to sign up. "What laws do you have to break to get in here?" I asked the social worker who looked us over before seating us in the visiting area. She smiled at my joke, or frowned - I wasn't sure which. Her face was pretty sour to begin with.

While we waited for Jake to put in his appearance, Michelle told me about him.

"He's not violent," she assured me. "He comes off seeming that way, because he shouts and makes threats when he feels threatened. But he never follows through."

"Who'd need to?" I asked rhetorically, remembering the hostage-taking adventure that had landed her husband in jail. "Waving a gun around like he did pretty much guaranteed that no one outside the police would dream of setting him off."

"I know," Michelle said. "He went off the track, like I said. But it turned out the gun wasn't even loaded."

I held up a hand. "Stop it. I'll be nominating him for sainthood if you keep talking about him."

She rolled her eyes. "All right, Dale. I'm just saying, don't worry, that's all."

I didn't bother pointing out that worrying is one of the things I do best, and I wasn't about to give it up on this ripe occasion. It was like asking a gambler to give up betting on Super Bowl Sunday.

Jake arrived a moment later, looking just as large and sturdy as I expected. He leaned down as if to kiss Michelle on the cheek or somewhere, but she shifted position and left his lips hanging in midair with nothing to do. So he spoke with them.

"You look pale."

"I've been in the hospital," I informed him.

"I was talking about her," he corrected my wrong impression. "You're not wearing make-up." I resisted the urge to respond again.

"What's it to you?" she asked, her thin lips pressed together, indicating that perhaps she might benefit from the anger management courses herself.

He shrugged. "You both look like crap. Quite a couple, you are."

"I've told you my excuse," I said. He looked at me. "Surgery," I reminded him.

"Yeah, did they remove all your muscles?"

"Just the ones that operate the sphincter," I said.

He looked puzzled.

"You're still working out," Michelle said, with a bored look that suggested she was only asking in order to butter him up.

"I've got to," he said, "for Betty. Okay, I'll show you," he said to me, as if I'd asked. He rolled up a sleeve and showed me a tattoo of Betty Boop. "Now watch the floor show," he said. He flexed his muscles, which had an invigorating effect on Betty's own cartoon physique.

"It's great at parties," Michelle observed. He shot her a look.

"You never thought so when we were together."

"I got tired of it," she said. "What would you have done if I had taken my blouse off at every party we went to?"

He gave it a bit of thought. "Got into a lot of fights, I guess."

"Not a good thing for a nonviolent man like yourself," I said, more for Michelle's benefit, as you can imagine. He looked at me but didn't respond. Instead he asked me, "Do you have any cigarettes on you?"

"No," I replied. "I don't have any cocaine either, if that's your next question."

Michelle looked at me. I was feeling reckless.

But Jake laughed. "Funny guy."

"Come on, Jake," Michelle said. "Cut the crap. Just tell us, are you going to sign off on the divorce or not?"

He sat back, his right hand fiddling with his shirt pocket, as if still looking for a cigarette. "Why not?" he answered. "He seems more your style than I was."

Dad would love that, I thought.

But Jake was no fool. He had a condition. "I have a small favor to ask for in return. I assume you guys are already living together. I have a home visit coming up in a few weeks, to test the waters of freedom. I need to crash with you guys."

A small favor? I was wondering what would constitute a big favor.

"I don't see that happening," Michelle said firmly.

"Come on, Michelle," he persisted. "Where else can I go? I just need a bed or a couch or something. You won't see much of me."

(cont'd on page 3, col. 1)