



Vancouver Ostomy

# HIGH Life

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A non-profit volunteer support group for ostomates. Chapter website: [www.vcn.bc.ca/ostomyvr/](http://www.vcn.bc.ca/ostomyvr/)

## INSIDE

Letters, News	3
Continent	
Ileostomies	5
Our stories	6
New Patients'	
Corner	8
Eakin Seals	9
Pouchitis	10
Book Reviews	11
Visitor Report	14
Internet Sites	14
Contacts	15

## UOA ANNUAL CHRISTMAS PARTY!



Once again we will be hosting our Annual Christmas Luncheon to be held:

**Sunday, December 4, 2005**

**at the Holiday Inn, 711 West Broadway, Vancouver, BC**

**Doors Open: 12:00 Noon • Lunch Buffet 12:45**

*The Buffet includes:*

*Waldorf, Caesar and potato salads • Roast Turkey, potatoes, dressing • cranberry sauce, glazed carrots and green beans • Chef's Dessert Table  
Coffee, Tea, Orange Juice and Wine*

### Admission

Member	\$18.00
One Guest per Member	18.00
Additional Guests	19.00
Children (4 to 11 years)	10.00
Children (under 4 years)	free

*Please make your reservations no later than November 28 by contacting Nora Turner in the evening at 604-738-7065. In order to decrease paperwork at the door we prefer that you mail your buffet and raffle ticket money; however you may pay at the door as well.*

*Please make your cheque out to UOA Vancouver Chapter and mail your cheque to:*

**Nora Turner**

**#110 - 1551 West 11 th Avenue  
Vancouver, BC V6J 2B5**

*RAFFLE TICKETS are included in this newsletter. CASH PRIZES!! Six for \$5, or one for \$1. Complete these and mail them, along with a cheque, to Nora. We've had many out of town winners in past years! If you are able to, we ask that you bring a small gift for the door prizes. All donations will be acknowledged in the newsletter.*

### Next Meeting:

**FEBRUARY 4, 2006  
(NOTE NEW LOCATION)**

Collingwood  
Neighbourhood House  
5288 Joyce Street  
Vancouver  
1:30 pm

Executive meeting November 19  
1:30 at Joan Williams'

**2005 Xmas  
Luncheon  
Sunday,  
December 4,  
2005**

**RESERVE NOW!**





## President's Message

Hello to you all.

Well autumn is with us again, I do hope that you all had a really good summer?

We had a really good meeting at our new venue on September 18th 2005, if you missed the new address I shall give it to you again.

Collingwood House 5288 Joyce Street Vancouver, B.C. V5R 6C9, all that attended thought that the centre was acceptable. Julia Zeelenberg who has been our secretary has had to stand down, this is because of ill health, and we do wish Julia well and thank her for all her hard work. We were very lucky to have a new volunteer for this position; Martin Donner has kindly agreed to be our new secretary, welcome aboard Martin and thank you.

More sad news Jim Degeer will be resigning as District Support Services Rep at the end of the year, if there is anybody out there who would like to volunteer for this position, here are a few descriptions of duties.

**POSITION TITLE.** – District Support Services Representative (Pacific Region – BC & the Yukon)

**MAJOR FUNCTION** – Supervise Chapter Coordinators, Coordinate activities and provide resources to DSS personnel and Visiting Management Team members.

**REPORTS TO** – DSS Chairman

**TERM OF ASSIGNMENT** – Minimum requested 2 years service. Contact Jim on 604-464-1960 or e-mail – jigdegeer@shaw.ca or write to #446 – 920 Citadel Drive Port Coquitlam BC V3C 5X8.

The Christmas Party will be held on December 4th 2005 at the Holiday Inn. I hope to see many of you there.

I wish you all and your families a very happy Christmas.

Ron.

### IMPORTANT NOTICE

Articles and information printed in this newsletter are not necessarily endorsed by the United Ostomy Association and may not be applicable to everybody. Please consult your own doctor or ET nurse for the medical advice that is best for you.



## From the Editor



First of all, thanks to all who disregarded the address I gave for the September meeting!! The correct address is 5288 Joyce Street NOT on Euclid. My bad!

Our library and resource collection is developing well with the purchase of new books and the acquisition of videos and CDs from manufacturers. Several members at the September meeting took out selections from the new material. We look forward to expanding our resource library and making it a useful and appealing feature at meetings. If you have any requests or suggestions for titles/topics that would enhance our library please let us know and we'll find them for you. This ostomy 'lending library' is free and on the honour system, so if you take materials home, please bring them back at the next meeting!

Thank you to my crew from the Visitor Program for your excellent work this year. 2005 saw an increase in referrals as well as an increase in volunteer visitors. Perhaps the most encouraging result of the program's success are the number of new chapter members who were patients in 2005. Well done, everyone.

See you at the Christmas Luncheon!

### MEMBERSHIP RENEWAL

**As this is the first year of the new once a year annual dues program please remember that your membership is good until the end of 2005. Our head office in Toronto will be sending out renewal notices in the fall for 2006. So if you previously renewed in July you don't need to send in a cheque until you get your renewal notice.**

### DONATIONS AND BEQUESTS

We are a non-profit volunteer association and welcome donations, bequests and gifts. Acknowledgement Cards are sent to next of kin when memorial donations are received. Tax receipts will be forwarded for all donations. Donations should be made payable and addressed to:

UOA OF CANADA LTD.  
VANCOUVER, BC, CHAPTER  
Box 74570, Postal Station G  
Vancouver, BC V6K 4P4



## KIDS' OSTOMY SUMMER CAMP

Thank you for paying for me to go to camp. I really appreciate it. This was my first time going to camp and I really had a fun time.



Thank you  
Tyler, Logan.

To Ron Dowson and All Supporters,  
A GREAT BIG THANK YOU! Tyler had the time of his life. He is still talking about it every day. Since his coming home he has had a whole new outlook on himself. He has never met other kids with the same problems. This was a big eye opener for him. This trip has really been a great experience for Tyler. He can't wait to get back there.

Thank you again,  
Diane Logan

## ANOTHER TYLER!

Dear Ron,  
I would like to thank you for giving me the opportunity to attend Easter Seals Camp Horizon. I have been attending camp every year for 4 years, and it is a continuing source of inspiration from which I draw great strength. Without your help, none of this would be possible for me. I offer my whole hearted thanks to you and your organization.

Sincerely,  
Tyler Hall

## CANADIAN DEVICE HELPS DRIVE CANCER FIGHT

*Sheryl Ubelacker, Canadian Press*

TORONTO -- In what's being hailed as a world's first, a Canadian-made device is allowing doctors to target radiation therapy for prostate cancer with pinpoint accuracy, thereby avoiding damage to surrounding organs and ensuring all malignant cells are destroyed.

The device, which marries CT and 3D-ultrasound imaging technology, allows radiation beams to be directed only at the walnut-sized male sex gland, which can move position from day to day, said Dr. Gerard Morton, a radiation oncologist at Sunnybrook and Women's Health Science Centre.

Men undergoing radiation for prostate cancer usually have almost daily treatment for five to eight weeks. Side effects from the beams striking other tissue can include bladder and rectal difficulties and impotence.

"This enables us to give a large dose of radiation to the cancer within the prostate while sparing the surrounding organs," Morton said.

Researchers at Sunnybrook and Women's are in the midst of their second study using the device for prostate cancer treatment, and the Toronto hospital is planning trials of the computerized imaging system for women with breast and cervical cancers.

The B.C. Cancer Agency's Vancouver Island Centre in Victoria has also begun a patient trial to test the system.

To set up for prostate cancer radiation, technicians begin with a single CT scan of the man's abdomen. A 3D ultrasound image is then taken before each radiation session. On a computer screen, the latest ultrasound picture is superimposed over the CT image, which allows them to see if the prostate has moved.

The radiation beams can then be fine-tuned to strike only the gland, leaving surrounding structures untouched.

"Most internal organs tend to move around a bit, so it's a great advantage to be able to see, at the time of treatment, where the organ is that we're trying to target, where the tumour is and where the normal tissues are around it," Morton said during a demonstration of the technology at the hospital.

Radiation damages both cancerous and healthy cells in the prostate. But while the cancer cells die, healthy cells are able to repair themselves, he added.

The \$310,000 RESTITU system, which is not yet approved for routine use in Canada, is manufactured by Montreal-based Resonant Medical.

An estimated 20,500 Canadian men will be diagnosed with prostate cancer this year; about 4,300 will die.

*cont. next page*

## TSA ALLOWS OSTOMY SCISSORS ABOARD AIRCRAFT

WASHINGTON, August 30/PRNewswire

TSA (United States Transportation Security Administration) is modifying the interpretive rule to exempt ostomy scissors from the prohibited list. Ostomy scissors with pointed tips and an overall length of four inches or less are permitted when they are accompanied by an ostomate supply kit containing related supplies, such as collection pouches, wafers, positioning plates, tubing or adhesives. There are an estimated 750,000 ostomates in the United States. While specific data on the number of ostomates who use air transportation is not available, TSA has heard from individuals with ostomies who say they avoid air travel in part because they cannot carry these particular scissors. Allowing this limited exception to TSA's prohibition on metal pointed scissors removes a barrier to ostomates travelling by air without negatively impacting aviation security.

## KELOWNA APPLE TRIATHALON

Seven Summits Challenge athlete Robert Hill (guest speaker at the Vancouver UOA meeting \_\_\_, 2004) and competitive triathlete John O'Shaughnessy competed in



Stephen O'Shaughnessy and Robert Hill

this event August 21, 2005. Both men have ostomies -- Robert an ileostomy due to Crohn's/colitis and Stephen a urostomy due to cancer -- and are well versed in the need to manage hydration issues.

Weather on race day was fantastic with an enormous field of over 900 athletes. Robert finished in both good spirits and time while John came within 20 seconds

of his personal best at this distance. Both Robert and John would like to express their sincere appreciation to Paul Miese of Cooper Medical Supplies who was instrumental in bringing the two athletes to race in Kelowna this year.

**We would like to extend a warm welcome to new members:**

**Mark Dupont  
Robert Copps**

## ANN, IVOL Chair, SASO Committee Spring 2005

It is encouraging to see that interest in SASO is increasing. Personal stories, not only from spouses, but from significant others such as a parent of a child with an ostomy and a friend of an ostomate, have been published in chapter newsletters and Ostomy Canada.

Another example of increased interest is that more newsletter editors, across the country, regularly include a SASO column or feature in their chapter's newsletter. Rap sessions are being arranged by SASO Chapter Contacts to offer welcome support to spouses and significant others in their area.

The spouses and significant others in Brantford organized a very successful yard sale to raise funds for their chapter. The group received welcome help from members of the chapter who are ostomates.

In one notable case in Alberta, advice from a trained medical person was not appropriate for an ileostomate, especially when advised to eat more fibre and take a laxative to relieve a blockage. In this particular situation, the spouse understood that her husband needed to drink fluids instead to relieve his symptoms.

The message of SASO and its supporting role to spouses and significant others and ultimately to ostomates is being heard. Our thanks go out to those chapters who are helping to advance the objectives of SASO.

**Thanks to Lancaster  
Medical Supplies and  
Keir Surgical for their ongoing  
donations of F.O.W. ostomy  
products!**



The Vancouver UOA Chapter would like to thank the following individuals for their kind donations to the chapter:

**E. Pearl Schmuck  
George and Vi Puhl  
(in memory of Muriel Edgar)**

**Martin Donner  
Margaret & Bill Palagain  
Robert Copps  
Paris Tomei**

## CONTINENT ILEOSTOMIES

### What is a continent ileostomy?

A technique known as the Kock pouch was developed in the late 1960s by Swedish surgeon Nils Kock. The colon and rectum are removed and the last segment of the small intestine (ranging from at least several inches up to about 18 inches) is looped to form a pouch or reservoir with a valve, inside the abdomen. A segment of the intestine extends from the reservoir to the abdominal wall. The end part forms the stoma. Waste matter can then accumulate in this pouch, within the body, rather than flowing out through the stoma. After a period of time, the reservoir within the abdomen gradually stretches until it can eventually hold at least a pint of waste.

**So why is it called a continent ileostomy?** Medically, continent means being able to retain waste until an appropriate time for release. For example, someone in a coma who has no ability to control excretion is said to be incontinent. If we do have that control, we are continent. With a continent ileostomy, waste is retained in the reservoir. The valve in the reservoir prohibits the passage of waste material or gas out through the stoma, until a tube (catheter) is inserted. A few times each day, the ostomate inserts a tube to catheterize (or trigger the release of waste in) the reservoir. This procedure is called intubation. The waste drains out through the tube, into either the toilet or a receptacle. If the stool is too thick when the reservoir is catheterized, water may be inserted through the catheter to thin it. The reservoir is usually emptied three to five times a day.

The main advantage of the continent ileostomy is that you don't have

to wear an appliance. Usually, all you have to wear is a patch or bandage over your stoma for protection. As a result, the stoma doesn't need to protrude the usual three-quarters of an inch to an inch, as in conventional ileostomies. The stoma is still necessary for drainage, but it doesn't work nearly as often as stomas through which waste passes regularly. Because of this, the continent ileostomy can be placed on your abdomen in a more desirable place. Since appliances are not required, one has more choice in clothing.

**If continent ileostomies are so great, then why aren't all ileostomies of this type?** Why don't individuals with conventional ileostomies have surgery to change to the internal continent ileostomy? There are three reasons. First, although some may decide to convert from one to the other through new surgery, others may feel that they have grown accustomed to what they've got. Therefore, they have chosen not to convert. Second, and even more important, continent ileostomies are not advised for all ileostomates. In order for the continent ileostomy to be successful, the pouch or reservoir must remain disease-free. Evidence indicates that Crohn's disease may continue to attack portions of intestine that remain in the body. Therefore, because the small intestine is used to form the reservoir, Crohn's may affect the pouch or valve controlling the flow of waste after surgery. If you have Crohn's disease, therefore, you really shouldn't have a continent ileostomy. But if you've suffered from ulcerative colitis or familial polyposis, your surgeon may suggest the continent ileostomy. Although many surgeries for continent ileostomies are successful, some

may not be due to a variety of complications. As a result, appliances may have to be worn even with the continent ileostomy, or surgery may be necessary to return to a conventional ileostomy.

### What are the complications that can cause a failure of continent ileostomy surgery?

Your internal pouch may leak or there might be a malfunction in the valve (the valve could slip or not be able to prevent stool and gas from exiting the body). These are two of the more common complications. Other problems include difficulties with intubation, or the formation of fistulae or scar tissue within the pouch of the intestines. In some cases, another operation (maybe even more than one) may be necessary to correct the problems.

Approximately half of today's continent ileostomies are being done as original surgeries. The other half are revisions of the conventional ileostomies.

*Source: Coping With an Ostomy, A Guide to Living With an Ostomy for You and Your Family, Robert H. Phillips, Ph.D.*

### What I've Learned Department:

99% of the time, if something isn't working in your house, one of the kids did it.





## FAP and Me

by Peter McGinn

### **Age: Zero - Born with it**

Like the title of Dicken's David Copperfield states: I am born. My mother has told me that it snowed all through the night leading up to my birth. What she didn't know, what she had no way of knowing, was whether I had microscopic agents of Familial Adenomatous Polyposis (FAP) swimming in my veins (I did). My father had it and he passed it along to me along with his sense of humor. If you

are a parent with Familial Polyposis, there is a 50% chance your children will have it. (In my family, out of six kids, three of us were born with it, statistical perfection.) It seems to be caused by a mutated gene. You don't have to have a parent with it to get it, but it sure helps.

FAP plants polyps in your intestinal tract. It can strike anywhere, north to south, but early on it hits the colon hard, and that is the most dangerous place for developing cancer. So there I was, just barely born, and the disease was already biding its time and plotting its strategy.

### **Age: Thirteen - The Wrong Disease**

When I was young, I could read about a medical condition and become convinced I had it. I don't succumb to it much anymore, maybe because I have now lived longer than my father did, or else because I figure I have already received my fair quota of rare diseases.

When I am thirteen, I see a public service commercial about venereal disease. One of the symptoms in some vague way resembles my recent outbreak of acne on my body. Perhaps you can guess what happens next. Even though I have never done more than kiss a girl, I go to my father and express my concern that I have a disease. I don't recall his exact words, but basically he tells me we'll get it checked out, but for me not to worry about it just then.

It seemed like a cavalier attitude to take at the time, but looking back on it now, I assume he thought I had heard about the family curse of FAP and didn't want me to worry until it was time. It was ironic, because even though I didn't know he was talking about FAP, that was the only opportunity he had to discuss the illness with me.

Somewhere about this age, I also write my first short story. I am asked to read it aloud to the class, an excruciating but exhilarating experience.

### **Age: Fourteen - The First Touch of the Shadow**

My brother dies. He is seventeen and has recently undergone a semi-colectomy, the first surgical defense against FAP. He had been out partying one night, I believe, and was in great pain during the night before he was taken too late to the hospital. Years later my own surgeon theorized that the sutures holding the resected intestines weren't secure enough. But who knows? You know how it is: when you go to a new hair stylist, don't they usually tell you the last person to cut it did a hatchet job? I still don't know much about the disease at this time, don't even know I have it, so even though I am engulfed by the shadow of his death, I don't feel death's icy breath on my own neck.

### **Age: Sixteen - The Second Touch of the Shadow**

My father dies of cancer. Because I am a teenager, with hormones and acne raging, I don't ask a lot of questions about his death. Was it the polyps? Did he wait too long to have the ileostomy done? Or was it another form of cancer? I would never know. And so the second touch of the shadow puts grief in my heart, but not fear of my own mortality.

### **Age: Seventeen - Some Good News**

I meet the girl who would become my first serious girlfriend.

### **Age: Eighteen - More Good News**

I marry her.

Somewhere around this time, perhaps sooner, I have my first encounter with the sigmoidoscope. This was long before they developed the flexible sigmoidoscope. I guess such is the word I am looking for here.

### **Age: Twenty - A Lesson in Genetics**

My daughter is born. I don't have time to worry much whether the disease is in her system. She has too many other health problems: deafness, cleft palate and water on the brain, and a few other conditions to be named later. (And yes, the disease proves to be in her system as well.)

## Age: Twenty-three - The First Surgery

I have my semi-colectomy, the surgery that may have been responsible for my brother's death. Am I nervous? What do you think? Since I am writing this now, I won't try to keep you in suspense. Obviously I lived to tell the tale. With the looser stool and more frequent trips to the bathroom, I suppose the surgery was preparing me for the next operation.

Somewhere around this time, I see my first short story get published, in a California literary magazine called *Innisfree*.

## Age: Thirty - The Next Operation

The first operation proves to be a temporary solution, as FAP rallies and starts mass-producing polyps once again. A few years before I had the ileostomy done, I had gone in for the annual sigmoidoscopy (which I did every other year - you know what that's like) and after they got back the biopsies they called me and said they wanted to see me later that week. I got it into my head that there was cancer present and that I was going to die soon. It was the closest I've ever gotten to being depressed in my life. Finally I call the office and ask if it was serious. No, it isn't that serious. The surgeon ends up telling me the polyps are becoming active and I will need the second surgery within five years. (looking back, I'd say they were pre-cancerous, but he didn't use that word).

So I have the ileostomy done. We discuss internal pouches, but it seems experimental to me, and going out of state multiple times doesn't feel like an option. Perhaps if I had to make that decision today, I would choose differently, but I've never regretted it for a moment.

With today's abbreviated hospital stays and privacy laws, we in our ostomy support group find it almost impossible to visit post-surgical patients in the hospital anymore, so it seems strange to remember that I had my ostomy visitor even before my surgery. What a luxury that was. You'd think because I was never sick a day due to the illness, it would have been traumatic to have the surgery, but it never has been. I am rather laid back anyway, and compared to losing my father and siblings (a sister also died young at the hands of a drunk driver), I guess it just wasn't something to grieve over. Besides, I knew without the surgery my wife of twelve years would be grieving me relatively soon.

## Age: Thirty-five - Back to School

My wife graduates with a Social Work Degree, and puts me through college as an English major, where I decide to stop writing short stories and switch to novels instead.

## Age: Forty-five - FAP Stays Busy

My daughter has her first surgery, and we intend for it to be

her last. With her disabilities, she would be hard-pressed to take care of an ileostomy herself. Obviously we'd have it done if it were life and death, but nowadays they have discovered that Celebrex, which is used for arthritis sufferers, also acts to suppress and prevent polyps from forming. (My insurance won't pay for Celebrex, but a cheaper medicine seems to have the same quality, so they have graciously allowed me to take that.) So hopefully she will never need the ileostomy.

Also this year I have a scope put down my throat to check for polyps on the upper end for the first time. They find a few larger polyps, but nothing to panic over.

## Age: Forty-nine - Caught Holding the Bag

I publish my ostomy mystery novel. I had written it a few years before, but figured one of my other books would be the first one published. I mean, who would publish a novel with - yuck - ostomates as main characters? But an Internet-based publisher called *booklocker.com* accepted it. The down side is that they are small and don't do much marketing of their own. They build a page for your book on their bookstore website, make sure it is listed on *Amazon.com* and other places, and leave you to it. That means you need to publish a book where you can reach a selective audience for it. Like ostomates, I wondered? That's why I picked *Caught Holding the Bag*.

It has been a slow, tough process getting the word out, but on the

plus side, I have heard from a lot of great people who have devoted years to helping new ostomates, as I have done.

Publishing the book has had an interesting side effect. I have never been one to tell coworkers about my ileostomy. Let's face it, the subject doesn't come up very often in casual conversation ("Good morning, Peter, how is you colon today?")

But naturally some of them wanted to buy this book, so since I mention the surgery in my bio note, now they know. One woman told me her mother and aunt loved the book, and wondered how long it took me to do all the necessary research. (They didn't read the bio, apparently.) I told her I had the surgery done myself. She said, my, wasn't I a dedicated author? I realized a moment later she thought I was kidding. There's a testimonial for what we tell new ostomates - it isn't obvious to other people like you might initially think.

A coworker from another department came up to me in the main lobby and said, "I heard you wear a bag." That must have sounded odd to anyone walking by! Turns out her teenaged son had recently undergone an ileostomy. We talked for a while and I brought in some older *Ostomy Quarterly* magazines for them to look at together. So that was a nice result.

*cont. page 13*



*Another writer in the family?*



## COPING WITH LEAKS

It's every ostomate's worst fear: a leaking appliance. Who gets leaks and why do they happen? Even 'old hands' can have an accident but such things are more common with newbies. You can't learn it all overnight and accidents are part of everyone's learning curve. As you become more skillful in applying your bag, more knowledgeable about products and more in tune with your new body, the likelihood of leaks will decrease. Accidents are more likely to occur with an ileostomy or transverse colostomy than with a descending or sigmoid colostomy. The latter's waste tend to be more firm, hence less likely to leak. The more liquid the waste, the greater the likelihood of accidents. So who has the greatest chance of developing leaks? You guessed it -- urostomates.

### **Why do some people get leaks and others very few or none at all?**

**Your stoma may be too short.** Most surgeons will try to give you a stoma of reasonable length -- not too long, not too short. But despite their best efforts, the healing process is not always 100% predictable. Ideally, the stoma should protrude one half inch to an inch from your body. If it is shorter than this, it will be difficult for waste of any type to exit the body and fall cleanly into the bag. Stomas that are too short or flush with the skin should have a convex flange. This is a faceplate that is formed in such a manner that when applied, it gently pushes the peristomal skin down, giving your stoma more of a chance to expell waste into the bag rather than under the flange.

**Lumpy tummy.** Lots of us have lumps, bumps, cellulite,

stretch marks, old scars, pot bellies, dimples and hair plus we gain weight and we lose weight. All that can add up to quite a challenge for the best of products. A flange sticks best to an even, flat surface so if you have an irregular tummy you may need to even it out with paste, or if things still won't stick consider Eakin seals. Men need to carefully shave abdominal hair around the stoma.

**Some stomas are harder to manage than others.** Sometimes the placement of the stoma is in a difficult spot, ie too low for an overweight patient to properly see, or too high where clothing interferes. Sometimes they are placed too close to folds of skin, or to the navel, or other irregular areas of the abdomen. Ostomies should be sited by a qualified enterostomal (ET) nurse prior to surgery but sometimes this is not possible. Surgeries may be done on an emergency basis (ie rupture, serious injury to the bowels) or the patient may not have had access to ET personnel in their area. A poorly placed stoma will require more care and vigilance to avoid leaks. Consider using an ostomy belt.

**Are you emptying often enough?** Weight on the flange can increase the risk of a leak. Empty before your pouch is a third full, or sooner if you can.

**How active are you?** When you get home after surgery, you will want to rest and sleep. It stands to reason that a lot of lying down will increase the chances of waste staying near the top of the bag and getting under the flange. As you become physically active again, some positions that involve bending or twisting can cause a flange or bag to loosen or pop off. Consider using paste or Eakin seals under the flange, tape around the outer edges, or an ostomy belt.

**Is your changing technique correct?** You can forget what you learned in hospital, or misunderstand, or think you have it down pat and get careless. Or you may have been in a hospital with no ET staff and minimal post-op ostomy training. It's wise to see a qualified ET a few weeks after your surgery for review of appliance management and correction of any poor techniques you may have fallen into. ET clinics are listed in the back of this newsletter.

### **EDUCATE YOURSELF ABOUT PRODUCTS!!**

There are many different brands and models out there -- you don't have to stay with the same brand and model you were discharged with!! Some brands fit some patients better than others. Vancouver has excellent and knowledgeable suppliers of ostomy products -- see their ads in this publication. Phone them and discuss your needs and concerns. Don't put up with an appliance model that isn't right for you.

## PREVENTING LEAKS WITH EAKIN SEALS



### WHAT IS AN EAKIN SEAL?

Eakin Cohesive is a unique, highly mouldable, moisture absorbing skin barrier. It is used externally as an aid

in the prevention and treatment of skin irritations and as an aid to prevent leakage. It does not have a restrictive plastic backing and does not need to be cut to fit as with other skin barriers. Instead it can easily be stretched, compressed or moulded to fit the exact shape and size as required. Eakin Cohesive contains no active ingredients and no animal based substances. This means that the Eakin Cohesive will form a strong but inactive physical barrier allowing the skin underneath to rest and recover using its own natural granulation methods. It does not contain any solvents or vulcanised adhesives which frequently cause skin trauma. Eakin Cohesive also contains a unique carbohydrate content which is slowly released while the Seal or Skin Barrier is in position, diluting harmful enzymes.

T.G. Eakin Limited was formed in 1974 by Tom Eakin, an Irish pharmacist, with the aim of manufacturing ostomy products. The seals are functionally comparable to ostomy pastes since they can be moulded and squashed by hand to fill up scar areas and help to produce a flat skin surface to which a pouch may be fitted. Eakin seal material is also used in hospitals to dress serious wounds that resist healing with conventional dressings. This product is still made only in Ireland, by the Eakin family.

### HOW TO USE EAKIN SEALS

Warm the seal in your hands prior to shaping it to fit your stoma. Your skin should be clean and dry and free of any soap residue or any skin prep solutions. You can then gently stretch and

knead the seal until the inner hole is the same size as your stoma. Once applied, the seal should fit snugly, touching the base of the stoma around all sides, in a “turtleneck”. You can then apply your regular appliance over the Eakin seal.



*Before shaping and moulding*



*Stretching the seal*



*Seals can be cut, rolled and flattened*

An Eakin seal can also be used to protect and heal irritated skin. Cut a portion of the seal, warm and flatten it until it is the right size and shape to cover the irritated area. It will stick to your skin without need for any adhesive and you can then apply your regular flange over top. The seal will soothe your sore skin and the pouch will stay in place. Got a chronic itchy spot? Put a bit of the Eakin material over the affected area and notice the difference.

It takes a bit of practice to mould the seals and those with arthritic hands can find shaping and moulding time-consuming. Putting your seal in the microwave for 30 seconds can speed up the process.



*Pieces can be customized to deal with a variety of problems*

Eakin seals should not be used over broken skin or open sores, however. If your skin has deteriorated to this degree you need to see an ET nurse.

Eakin seals are marketed exclusively by Convatec.



*A close fit is essential in leak prevention*

*Thanks to Michael Grubsztajn, Associate Product Manager, Convatec Canada for Eakin informational package*

# POUCHITIS

As improved surgical techniques make it possible to reverse more ileostomies with internal pouches, incidences of pouchitis will be more prevalent.

**What is pouchitis?** Pouchitis is an inflammation of the mucous lining of the pouch. Its symptoms for most patients are an abnormally large number of stools: an increase from 4 to 6 on average, or very frequent stools (8 or more per day). Patients also may experience rectal bleeding, abdominal cramping, a sense of “urgency” before having a bowel movement, and or fever.

**How is pouchitis diagnosed?** Patients who have any of the symptoms listed above could have pouchitis. However, several other conditions also could cause similar symptoms. These include irritable bowel syndrome, small bowel obstruction from scar tissue, narrowing of the join (anastomosis) between the anus and the pouch, antestinal infection with bacteria or parasites, and Crohn’s disease. For this reason, patients whose symptoms suggest pouchitis should be seen by either their colorectal surgeon or gastroenterologist or have a flexible sigmoidoscopy examination of the pouch with a flexible lighted instrument. At the time, biopsies (tissue samples) of the pouch should also be obtained. In patients with pouchitis, flexible sigmoidoscopy will reveal inflammation, similar to that found in ulcerative colitis, in the mucous of the pouch. When examined under the microscope, the biopsies also will show inflammation. If inflammation is not present, then other causes for the symptoms should be considered.

**How often does pouchitis occur?** At Mount Sinai Hospital, approximately 40% of our patients with the Pelvic Pouch will develop pouchitis at some point in their life. The longer the time since the pouch was created, the more likely it is that pouchitis will occur.

**Can pouchitis be prevented?** Drink plenty of fluids, eat yogurt that includes bacteria acidophilus, living strains of *L. Bulgaricus* and *S. thermophilus*, don’t delay going to the bathroom. Go to the bathroom before sleep. Pouchitis does not affect everyone and people report that it is better than ulcerative colitis.

**What causes pouchitis?** The cause of pouchitis is not known. Researchers suggest several theories -- an excess of bacteria in the pouch, a recurrence of inflammatory bowel disease in the pouch and misdiagnosis of ulcerative colitis.



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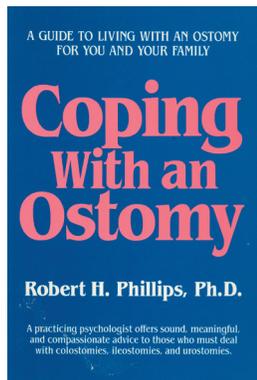
In a minority of patients, it may be difficult to differentiate between Crohn’s disease and colitis. Problems that may occur postoperatively could be related to the fact that the patient has Crohn’s disease.

People who suffer from pouchitis often improve with antibiotics, which suggests that bacteria are an important factor in the development of this condition. Pouchitis occurs more commonly in people with extra intestinal problems associated with ulcerative colitis (e.g. arthritis or abnormalities of the liver, skin or eyes). These findings suggest that pouchitis may be a new type of IBD which recurs in the pouch. Most patients with pouchitis do not have Crohn’s disease. Research is being done to identify the causes of pouchitis. Some investigations are looking for “triggering” bacteria or disease markers, such as antibodies. One early finding is that pouchitis is more common in ulcerative colitis patients who have antineutrophil cytoplasmic antibodies (ANCA) in their blood. Not everyone who is ANCA positive will get pouchitis. The most likely cause is twofold: a genetic susceptibility to both ulcerative colitis and pouchitis, combined with a “trigger” such as bacteria, within the stool in the pouch.

## BOOK REVIEWS

### COPING WITH AN OSTOMY

A Guide to Living with an Ostomy for You and Your Family



Dr. Robert H. Phillips, Ph.D.

#### REVIEW:

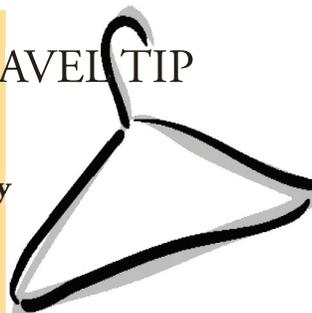
Written by a psychologist, this older (1986) but still very useful book deals with the psychological aspects of ostomy surgery as well as social and practical issues. Anger management, dealing with stress, financial considerations, coping with others and lots of

'how-to' information make this book a worthwhile read for the new ostomate, or one who is struggling with the emotional aspect of a new surgery, as well as the family member who wants to understand and help. I was also pleased to see a section on irrigation for colostomates which is too often overlooked or under-represented

in some publications. Also included are children and adolescents with ostomies. At 275 pages, this book is more comprehensive than what we usually find. Easy read, recommended.

## UROSTOMY TRAVEL TIP

I have learned a few tricks on managing my urostomy that have been helpful. One I've learned is a useful method on how



to hang a night drainage bag in a hotel. It came to me one evening to take a clothes hanger from the closet and insert it in between the mattress and the box spring with one corner protruding. I then hang the bag on it and it works just fine.

- BOA Member Richard Kimball

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**ODD SPOT**

**I DON'T  
THINK SHE  
HAS AN  
ILEOSTOMY:**

The world's first ever Bratwurst Eating Championship was won by 99-pound Sonya Thomas in August 2005. Also known as “The Black Widow” on the competitive eating circuit (yes there is such a thing -- check out the International Federation of Competitive Eating at [www.ifoce.com](http://www.ifoce.com) and fulfill your life-long dreams), Thomas downed 35 brats in 10 minutes to take the title and break the previous record of 19 1/2 brats. One day earlier, Thomas ate 22 grilled cheese sandwiches for practice.



*(Associated Press)*

*FAP and Me cont.*

**Age: Fifty and Beyond?**

So what's next? Danged if I know.

Hopefully my daughter and I will continue to coexist with the wicked FAP gene.

Hopefully my wife and I will continue to coexist also (it seems likely - 31 years now and still at it).

Hopefully “Caught Holding the Bag” will eventually sell enough copies to make publishing a second book feasible, but it has been an interesting ride in itself. Besides, I would keep writing novels even if I was barred from publishing them, and sometimes the way the publishing industry works, it feels that way. It is that old paradox, to get a publisher to look at your book, you need an agent; to get an agent, it helps to have been published (though I had an agent for a few years, and he didn't seem to be working all that hard for me).

All in all, I can't wait to see what happens next. What's the alternative?



**WHAT I'VE LEARNED DEPARTMENT:**

**One good turn gets most of the sheets.**

## VISITOR REPORT

Requests for patient visits this reporting period came from Vancouver General, Lion's Gate hospitals and from the BC Cancer Agency.

Colostomy	1
Ileostomy	2
Pre-op	4
TOTAL	7

Many thanks to my excellent crew this round:  
Arlene McInnes, Maxine Barclay, Sandra Dunbar, Jenny Robulack and Earl Lesk.

## HINTS & TIPS

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## Internet Addresses of Interest to Ostomates

These websites have a good deal of ostomy and related information.  
Several have links to other websites.

**Vancouver Chapter:** <http://www.vcn.bc.ca/ostomyvr/>

UOA of Canada Inc.: [www.ostomycanada.ca](http://www.ostomycanada.ca)

**NEW** <http://p207.ezboard.com/bostomyforum66946>  
(US - based ostomy forum. Extensive resource, good section on irrigation)

<http://www.matchlowestprice.com>  
Ostomy products at wholesale prices. Popular and more obscure brands, lots of pictures.

**NEW** <http://www.dukemedicalsupply.com/dukemedicalsupply/documents.asp?a=b>  
(Hollister -- downloadable booklets on managing your ostomy. Nice design! Also in Spanish)

**NEW** <http://www.healthservices.gov.bc.ca/waitlist/>  
(How busy is your surgeon? Interesting statistics on surgical wait times in BC)

**NEW** <http://www.us.coloplast.com/ECompany/USMed/Homepage.nsf/1989cec9be30ee68c12569ff0036969d/75e3f83b4ae56cdd85256ec400747f86?OpenDocument>  
(If this is too long to type, try Coloplast Patient Education Videos! Interviews, product info, how to change and empty appliances)



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