



Vancouver Ostomy
HIGH *Life* 

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UOA ANNUAL CHRISTMAS PARTY!

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

Sunday, December 7, 2003
 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	\$15.00
One Guest per Member	15.00
Additional guests	16.00
Children (4 to 11 years)	10.00
Children (under 4 years)	free

Please make your reservations no later than Sunday, November 30 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 11th 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.



President's Message

Hi Everyone,

Here we are at the end of the summer, and what a glorious one it has been. I hope that you all enjoyed yourselves?

The meeting on the 21st September was a great success. I think that all those that attended enjoyed themselves.

We are still looking for a volunteer for vice president, so I hope that one of you reading this article will come forward to fill this position. I am sure that whoever does volunteer, he or she will find it rewarding.

Also I have had a request from the (SOSA) Spouse and Significant Others committee, for a volunteer from each chapter to be a contact person. If you are the one to fill this position, please contact me and I will give you more information.

I hope to see you all at the CHRISTMAS PARTY. Last year with my wife and grandchildren we attended and had a wonderful time.

Best wishes to you all,

RON.

Mailbox

Dear Friends and Fellow Ostomates,

I wish to thank you for all your kind words and help you gave me during my lengthy stay at Lion's Gate Hospital. I thank Fred and May for keeping my garden green and weed-free, Ivor and Joan for their many visits and flowers, and Debra, Lore, and Mien who kept my reading material up to date. Thanks to all for the cards and phone calls I received. I am home now and hope to stay.

I take this opportunity to

congratulate long time member Tom Woodcock on his 90th birthday!

Remember our Christmas party on the 7th of December! We will have clowns, Santa Claus, live music and of course our traditional turkey dinner with wine and lots of fun. Hope to see you there.

Thank you all again for your moral support.

*Love,
Lottie*

From the Editor

We all have a story to tell. 'Vignettes' will be a regular column featuring local (or not so local!) people with ostomies -- a small window into the lives of people who may be very different from each other but who share one thing in common: they have an ostomy. Yvonne Shaw is our first 'interview' and a most interesting lady she is.



I gave Terry Gallagher a more difficult assignment this time around -- write about sex and intimacy from a man's point of view. It's a topic not often addressed in depth and my British stringer has done an excellent, well-researched article.

If you notice some of the UOA and related websites on the internet addresses page have been replaced, fear not -- they're not being deleted, just rotated so new sites can have some exposure in the limited space. People tend to stop reading a column if the information never changes and I do **love** to keep readers on their toes. If you internet surfers out there find a site of interest, pass it along to me.

Cheers & Best of the Season to Everyone,
Debra



The Vancouver Chapter would like to extend a warm welcome to new members John Finley, Mary Ann MacKinnon, Arlene McInnis and Brenda Weishaupt.

PAST PRESIDENT FRED GREEN

Submitted by Ivor Williams

Fred Green is an ostomate of long standing, having received a conventional ileostomy performed by Dr. Ken Atkinson at St. Paul's Hospital in 1973 as a result of his ulcerative colitis. His E.T. at the time was Helen Manson, and he received a visit from Vancouver Chapter's May Fawcett. Encouraged by all three of the above, he joined the Vancouver Chapter and immediately became active. Incidentally, Dr. Atkinson, Helen Manson and May Fawcett all later became Honourary Life Members of the chapter (not entirely because they persuaded Fred to join, although that was a great favour to the chapter).

Fred immediately became Editor of this Highlife newsletter and served in that capacity for the years 1973 and 1974. He had heard of the internal pouch procedure developed by Dr. Nils Kock, and traveled to Zurich, Switzerland in 1974 to have his ileostomy modified in that way by Dr. Kock himself.

Fred took over as Chapter President for the years 1975 and 1976. He was a very innovative and active President during that time, involving the chapter in a number of activities not previously done. Among other things, he obtained a "New Horizons" grant from the provincial government in order to establish a drop-in centre for ostomates. Fred's career prevented him from remaining active in the chapter after 1976, but he retained his membership and his friendship with other members through the years.

More than twenty years later, this writer was delighted to receive an e-mail from Fred, saying that he had retired and wished to again become active in the chapter. For some time, Lottie Calli had been wanting to give up the editorship of the Highlife, a job which she had performed admirably for many years, and Fred volunteered to again take over as editor.

The arrival of Fred, along with newcomers Earl Lesk and Bill Clarke, breathed new life into a chapter that had been going downhill for some time. We had wondered at times whether the chapter could survive much longer, but decided that we could not stop the visiting program or the newsletter. Fred did a wonderful job with the newsletter for the years 1999 and 2000. Who could forget his column "A Streetcar Named Longevity", wherein he used his interest in alternative medicine to illustrate ways of living a longer and healthier life?

At that time, this writer was Chapter President, and in the year 2000, Fred and I agreed to change jobs, and he became President again, while I edited the newsletter. He was again a very proactive President. At the meetings, he often demonstrated alternative medicines and various exercises with equipment he had brought from home, and conducted interesting meetings, resulting in greatly increased meeting attendance.

Fred also took a great interest in the Youth Camp,



contacting the children's parents each year, even meeting one young ostomate at the ferry and seeing that all the children we sponsored got away safely on their flight. He also did a great deal of work in preparing applications for grants from the Vancouver Sun Children's Fund to assist us in sponsoring these children.

In order to allow him and his wife, Maye to be free to do all the travelling they wish to do, Fred stepped down as President in 2002. When nobody came forth to fill the position, he carried on with all the necessary duties, until Ron Dowson came along and volunteered for the job in 2003. Ron will tell you that Fred has been a great deal of help to him in showing him the ropes and indoctrinating him into the position. Fred continues to help out wherever he can, both to the chapter and to individual members.

The Vancouver Chapter is indeed fortunate to have such a willing and exceptionally able volunteer as Fred Green.

TIPS & tricks

If you're going to a hospital or clinic for any kinds of tests -- Xray, CT scan, ultrasound etc. -- take along a spare pouch. Sometimes a test procedure may require temporary removal of your pouch and nurses or technicians on hand may not necessarily be conversant with ostomy supplies. Don't assume that because you are in a hospital environment that the attendant personnel will understand your particular system or that your brand/size will be on hand!

Great Comebacks Award Program

The Great Comebacks Award Program, established in 1984, was designed to support and enhance the quality of life for people with an ostomy and/or inflammatory bowel disease (a collective term for Crohn's disease and ulcerative colitis) by giving special recognition to those whose life stories inspire others facing similar challenges. The program is sponsored by ConvaTec and the Crohn's & Colitis Foundation of America, Inc. (CCFA).

2002 Great Comebacks® Award Winner: Charlie Grotevant

On the country roads of Buckingham, Illinois, a running farmer is not a typical sight. In fact, other farmers still stare at 60-year-old Charlie Grotevant when they see him whip by, even though, by Charlie's own calculations, he's logged some 32,000 miles over the last two decades — much of it on the same roads.



Charlie has completed no fewer than 650 races, including 11 marathons. That's an impressive performance for anyone, farmer or not...and even more impressive given Charlie's medical history. "Some people say to me, 'I wish I had the guts to run,'" he says. "I say, 'Well, I'm running without any guts!'"

Diagnosed in 1977

Since he was a child, Charlie suffered with bouts of stomach aches and diarrhea. But that didn't stop him and his wife, Joyce, from taking up farming in 1966. "She's been my farming partner for 35 years, and my marriage partner for 40 years," he explains. "She is my best friend." Farming is hard enough, but it really started becoming a challenge when Charlie began experiencing more severe episodes of bowel problems, or "nervous bowel" as his family doctor called it, in the early seventies. By 1977, he had lost the strength to perform his farming chores and entered the hospital. There he was diagnosed with chronic ulcerative colitis.

For the next six years, Charlie suffered many flare-ups of his condition, each followed by periods of remission. But they were taking their toll. "Each flare-up increased in severity, and greatly limited my ability to conduct the physical activities of my farming," he recalls.

The road to recovery

In the spring of 1983, Charlie took up running in hopes that a better physical fitness level would alleviate or lessen the severity of his debilitating flare-ups. After a few months, his blood pressure and pulse rate were remarkably lower. He even competed in a local road race. But weeks later, Charlie again became disabled by the colitis.

"I needed to rid my body of this diseased tissue if I wanted to continue

the physical work of farming," he says. Ileostomy surgery soon followed. Charlie credits his ET nurse, Marie Bozinovich, for starting him on his successful road to recovery. One thing he remembers her saying was that food would taste so good after his years of illness, that he might have to exercise more to keep the weight off!

Within months, Charlie asked his doctors if he could resume running, an activity he had really begun to enjoy. They agreed, so long as he was careful to avoid dehydration. He started slowly, while "what was left of my insides resettled," he says. As he found his body adapting to the change, the fitness running evolved into racing. "Some people call it an addiction; I think

'self-renewing compulsion' is a better term," he says with a smile.

A life back on track

Charlie started with 10K races, worked up to 10-mile races, and in 1988, ran his first marathon in Chicago. At his third marathon in Fort Worth, Texas, he qualified for the elite Boston Marathon. He competed in Boston in 1990, 1991, 1994, and 1997.

The 1991 race was his best: he finished the 26.2 miles in three hours, 12 minutes, and 20 seconds — "a pretty respectable time," he says modestly. Not content with just running, Charlie has also taken up bicycling, logging 2200 miles in the year 2000 alone!

Then, there's still the farming — not exactly a desk job. "My physical life changed because I am now able to do all of the lifting, climbing, shoveling, and machine-operating duties of farming," he explains. Charlie and Joyce still do all the work on their 1300-acre farm, which includes planting and harvesting 585 acres of corn, 590 acres of soybeans, and 80 acres of wheat each year. "Every now and then we get a grandchild to help with some errands," Charlie says.

Helping others achieve their own great comebacks

As if all of this wasn't enough, Charlie still finds time to help others who face similar challenges. Both Charlie and Joyce are active in the Kankakee (Illinois) Ostomy Association, where they serve as trained ostomy visitors. He credits the United Ostomy Association Visitor Training Programs for helping him develop his skills in providing positive-focused visits to ailing or recovering people living with ostomies. "My dream is to continue to live a useful and positive life, to encourage others to push themselves physically and mentally as they become involved in their communities, and to share my enthusiasm for life with others in such a manner that they become enthused about their lives," he says.

In recognition of his own durability, determination, and dedication, Charlie Grotevant was presented with the 2002 Great Comebacks® Award. Lately, Charlie has been laying off marathons — not because of his ileostomy — but because of wear and tear on his back and one of his knees.

He now sticks to half-marathons since, as he says, "I want to be running five years from now." Chances are, the neighbors will still be gaping then...if Charlie's track record is anything, *cont. page 12*



SEX AND INTIMACY FOR THE MALE OSTOMIST

By Terry Gallagher

In advance, I would like to say that I hold no claims to being an expert or to have all the answers, but I make this offering in the hope of provoking discussion,

thought, or maybe even action!

Let's look at the facts for a moment. It is worth remembering that one in ten men in the UK will suffer from erectile dysfunction (hereafter referred to as ED) during their lifetime. That amounts to 2.3 million men out of a population, in total of about 55 million! Many men are shy about discussing this with their doctor or their nurse, but it is a common problem, especially following stoma surgery and good treatment is available. I was talking to a nurse who specializes in ED who said that many health care professionals working in the field of stoma care are reluctant to talk about this subject. Fortunately, my stoma nurse, a marvellous lady called Steph, is not too embarrassed so my wife and I, at her pre-operative meeting to discuss the pros and cons of urostomy surgery and what to expect, discussed ED with us both and also pointed out how to get treatment if needed.

Male ostomists belong to a group of people who have a tendency to suffer from erectile dysfunction, also called impotence. Radical pelvic surgery, or the removal of the prostate can cause ED. Prostate removal is frequently done during urostomy surgery at the same time as the bladder is removed. Because of the formation of a urostomy, the first sign of prostate cancer - urinary obstruction - is, of course, absent. So if a person with a urostomy develops prostate cancer, the first signs of the disease may be when it has spread beyond the prostate to the point of being incurable. For this reason most surgeons will remove the prostate at the same time as the bladder 'just in case'. My surgeon did this when I had my urostomy. Even with nerve-sparing surgery, the ED rate for those who have had their prostate removed is 70%. Removal of the rectum is considered radical pelvic surgery as the surgeon is cutting around those delicate nerves which control erection. This particularly applies to those with ileostomies or colostomies.

It may seem a strange way to start talking about sex and intimacy by discussing ED, but, after all, there's no point in discussing intimacy if there's no chance of 'fireworks'!

If a person does have ED, then there are several ways of approaching the problem to get help. In the UK these are via the person's general practitioner (family doctor), through the urology department at the hospital, perhaps during a routine post-operative check-up, or some hospitals have a dedicated clinic where referral can be made, for example, by the stoma nurse (ET).

Let's look at the treatment options. Usually, in discussion with the ostomist, one line of treatment is tried. If that is ineffective or only partially so, another option will be tried in the hope of finding a workable solution. These solutions are, at the present time:

1. Oral drug therapy. I suspect that most people will

immediately think both of this option and of Viagra™ (sildenafil), the first drug available to treat ED orally. There is also a new drug called Cialis™ which is supposed to be effective for up to 24 hours. However, a word of caution at this point. The Department of Health of the British Government in guidelines on the administration of sildenafil quotes a success rate of 43% for radical prostatectomy, so perhaps urostomists need to look elsewhere for their first treatment attempt.

2. Sublingual drug therapy. Here a tablet, called Uprima™ is placed under the tongue where it is absorbed more rapidly than if it were swallowed. Like the oral drug therapy, this is **not** an option for people with heart problems who are taking nitrates.
3. Transurethral pellet. The trade name is Muse™ and the drug is contained in a very small pellet which is inserted by means of a special sterile applicator into the urethra from the tip of the penis. As passing urine is an important first step to both lubricate the passage of the applicator and to help the pellet dissolve, this is not a first choice option for those who have a urostomy.
4. Intracavernosal injection. This involves injecting a drug straight into the shaft of the penis after suitable instruction by a nurse or a doctor. Caverject™ is one such product.
5. Vacuum therapy. In this method of treatment, a vacuum pump is placed over the penis, air is withdrawn and the vacuum causes blood to be drawn into the penis causing it to become erect. A constricting ring is slid down over the base of the penis to maintain the erection for up to 30 minutes after which the ring must be removed.
6. Surgical implants. These are 'last resort' if all else fails. One operation inserts flexible rods in the penis to produce effectively a permanent erection, another type has a pump in the scrotum so that two tubes inserted into the penis may be inflated producing a 'natural' looking erection. However, surgeons will have wanted all of the above non-surgical methods tried first before considering this.

So these are the possible treatments, other than psychological therapies which are unlikely to be the cause of ED in an ostomist who has had major abdominal surgery. It is worth noting that time is a great healer, however. Major abdominal surgery often causes internal bruising to the nerves controlling erection and, together with the post-operative effects of weakness and debility, ED may occur on a temporary basis following major abdominal surgery if nerves are bruised rather than cut. However, there are usually indications that this is reversing within about three months of surgery if it has been a problem and then patience is called for until six months post-operatively when medical help should be sought if the problem hasn't resolved.

Let's look at each treatment in more detail, starting with the oral therapies. Viagra™ has to be taken about 30 minutes to an hour before planned sexual activity and will be effective, if it works for that person, for up to four hours. It may be taken no more than every 24 hours and, if taken with food, the effects may be delayed. It has a 'natural' effect in the sense that sexual stimulation, as in normal foreplay, is needed to bring about an erection. Like all drugs, there are side effects which may or may

cont. page 10

GUT FEELINGS?

Here are 7 home cures for your indigestion

YOU COULD NOT RESIST. The turkey, the ham, the sauces and side dishes, the desserts and, and . . . and now you're paying the price. Search the cupboard: here are some old folk remedies for battling indigestion that may work for you, even if doctors don't know why.

- **Apple cider vinegar.** Mix one teaspoon in a glass of water and drink. It may seem counterproductive, but "some people really do benefit from the extra acidification," says Ronald Hoffman, M.D., author of *Seven Weeks to a Settled Stomach*.
- **Papaya.** There's no good scientific proof that papaya extract actually helps aid digestion, so the U.S.D. food and Drug Administration no longer allows papaya products to make that claim on labels. You can still find papaya-enzyme tablets in health food stores, however, and many people swear by them. An enzyme in papaya, called papain, breaks down proteins and may mimic two digestive enzymes in the stomach: pepsin and trypsin.
- **Activated charcoal.** These tablets, available in drugstores, are an all-purpose antidote used in hospital emergency rooms for most types of poisoning. Folks have used them for years to alleviate all sorts of gastric ills. They work by rounding up gasses in the stomach.
- **Cardamom seed.** Many fragrant spices, such as fennel, coriander, cardamom and ginger, have a long history as digestive aids. They contain ingredients that may stop nausea, soothe intestinal spasms and relieve gas buildup.
- **Baking soda.** Mix a teaspoon of sodium bicarbonate in a glass of water and drink. It'll make you burp and ease your bloating. Sodium bicarbonate relieves stomach gas and neutralizes acid, which is why it's found in a number of antacids. Since it's high in sodium, however,



doctors suggest you use it only occasionally.

- **Honey.** The use of honey to remedy stomach problems dates back to Ancient Egypt. Honey has some interesting antibacterial properties. In fact, researchers in New Zealand found that a certain type of honey kills the bacteria that causes ulcers and gastritis.
- **Kelp tablets.** Take a few with water. Kelp and other seaweeds contain substances that help bind up stomach and ease indigestion, explains Arthur Jackowitz, Pharm. D., chairman of the department of clinical pharmacy at West Virginia University School of Pharmacy in Morgantown. Seaweed is high in sodium, Jackowitz cautions, so it shouldn't be taken by those on salt-restricted diets.

- Source, Jeff Stevenson, *Men's Health*, Sept. '95, contributed by Mr. Sean Mair



"Dr. Smith will be your anesthetist, Dr. Lewis will be your cameraman, Dr. Murphy is on lighting and Dr. Fleshman is on Moog synthesiser."

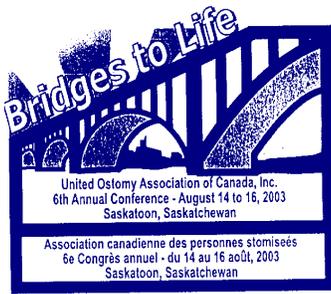
VISITOR REPORT

Sept./Oct. 2003

Requests for in-hospital, home and phone visits for this reporting period came from VGH, Port Coquitlam, Richmond Home Care and from within the chapter itself:

Pre-op:	1	
Colostomy:	2	
Ileostomy:	3	
Urostomy:	3	Total: 9

Many thanks to my excellent crew this round: Earl Lesk, Linda Jensen, Maxine Barclay, Alan McMillan, Al Ashcroft and Joan Williams.



Bridges to Life Conference

- by Lorne Aronson, National President, UOAC

The first thing I have to say about our latest conference held this past August is WOW! From the time we arrived to when the last toast was given, this annual meeting was a joy to attend. I want to thank the Saskatoon Chapter for making all of us feel "at home". I want to thank the entire organising committee for their hard work in seeing this project to a successful conclusion.

Your Board worked hard on the Wednesday at our Board meeting where we discussed everything from soup to nuts! This business meeting takes the whole day from 8:15 a.m. to 4:45 p.m.

with a break for a short lunch.

Some highlights of the conference were the fashion show of WeirComfee clothing (that I participated in) on the Wednesday evening "Taste of Saskatoon" opening event. I want to thank Trish McCormick for being my runway partner! Pictures will be published in the next issue of Ostomy Canada. Thursday's Grand Opening was punctuated by a keynote address by Arlene Jorgenson. All of the spouses I spoke to remarked on the enjoyable walking tour they had of the historic Broadway district of Saskatoon. We had the grand opening of exhibits. The exhibit hall itself was a roaring success. Treasurer Gene Zapf along with Vice President Pat Cimmeck held a raffle of items from every region of Canada.

Thursday evening (although quite warm) we enjoyed the Prairie Town Dinner sponsored by Coloplast. The prairie town shown to us was a replica of a typical town on the prairies circa the early 1900s. The unique thing I found was the entire main street presented was entirely indoors complete with authentic cars, apothecary, dry goods shop, etc.

Friday's agenda proved to be most interesting with lectures given throughout the day. The evening was another banquet, the "Grand Prix Renaissance Award" sponsored by Convatec. This year's Renaissance Award recipient was Dr. Kevin McHugh, the President of the Hamilton Chapter.

Saturday was started early with the national Council Meeting (this is the business end of the weekend) where issues of the day were discussed and debated. The Hollister Bertha S. Okun Lectureship proved to be the highlight of the day. The presenter, Cathy Ripplinger Fenwick, M.A. presented "Humor Matters -- Celebrating Life." The evening was topped off with the Farewell Banquet. At this point I want to say we shouldn't call this the farewell banquet but rather the last banquet before our next get together! The music, wine and centrepieces were sponsored by Hollister Limited.

The Unsung Heroes awards and the Exhibitors certificates were presented. As well UOAC's major awards were given out. David Metcalfe was the recipient of the Maple Leaf Award. The President's Award was presented to Di Bracken, past President. The E.T. Award went to Susan Hunter from Regina, Saskatchewan. The Friends of Ostomates Worldwide - Allan Porter Memorial Award was presented to the Vancouver Chapter for their consistent contribution of supplies. The new Board was presented to attendees. They are: President Lorne Aronson, Vice-President Pat Cimmeck, treasurer Gene Zapf, Secretary Doug Graham, Past President Di Bracken and directors Ken Sanderson, Jenny Robulack, Bev Fry, Al Markel, Murray Norman, Jean Pierre Lapointe, Roger Ivoll, and Joel Jacobson. On Sunday the Board of Directors met from 8:00 a.m. to 10:45 a.m.

My message to you is the best way to experience a conference is to attend one if at all possible.

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ALAN PORTER MEMORIAL AWARD

It is with great pride the Vancouver chapter receives this award, in honour of Allan Porter, one of the first directors of FOW Canada. The Allan Porter Award recognises the efforts of chapters which have made exceptional contributions to the lives of ostomates throughout the world. Our chapter wishes to thank those individuals and companies who have made a difference.

In late 1982, or early 1983, the United Ostomy Association Inc. in the United States initiated a program to help needy ostomates in other, less fortunate, countries. Ostomates in underdeveloped countries were stigmatized and sometimes forced from their homes and ended up living on the streets because of their offensive odour. The primary reason was that up-to-date, odour proof pouches, were either not available or too expensive for the majority of the poorer people. These unfortunate people were forced to improvise, using homemade appliances such as plastic bags, rubber gloves, pieces of old tire inner tubes and in some cases even half coconut shells. These makeshift appliances were usually fastened to their body by some type of rubber belt or cords. There was virtually no seal between the stoma and the appliance and the odour was a fact of life for these people.

In 1983, Archie Vinitsky, the co-founder and first President of I.O.A. addressed a group of people at a special I.O.A. session

during the U.O.A. Conference in Boston, MA. Maria Siegl from Canada was present at that meeting.

After her retirement from Hollister Limited, Maria had travelled to many countries and had seen first hand the miserable conditions under which some ostomates lived. She was very enthusiastic about this project and asked Archie if she could start up this project in Canada and this was agreed to. Thus the seed was sown that eventually grew into the present FOW (Canada)



Since 1986 F.O.W. (Canada) and its predecessor F.I.O.A. (Canada) has shipped over 45,000 kilograms (99,000 lb.) of ostomy supplies to 28 different countries. From a small acorn, a fairly large oak has grown.

The packing procedure has become somewhat more arduous and complicated over the years. In the earliest days most of the appliances were of the one-piece variety but today the majority of the appliances

received are two-piece and this means that flanges and pouches packed in the same carton must be matched size for size. The cartons are packed as to type of ostomy (Colostomy, Urostomy, etc.) Each carton contains on the average, 22 boxes of appliances and weighs an average of 7 kilograms. After packing and weighing, an identifying, numbered, label is attached to the outside of the carton showing the type of ostomy supplies inside and the weight. A summary is then made of all the cartons and for customs purposes this summary must show the number of individual boxes inside each carton and the names of the manufacturers.

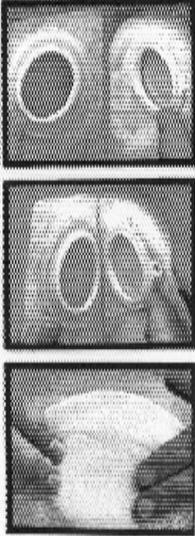
A typical packing may consist of 160 cartons weighing 1,120 kilograms; that's over a ton of appliances including boxes. Proper paperwork must then be obtained from the consular office of the country to which the shipment is being sent and arrangements made with a broker for the actual shipment. All of this work is carried on by a relatively small group of volunteers. The principal problem is money. It is very expensive to ship these items. Over the past six years shipping costs have been approximately \$35,000.00. The F.O.W. program needs your continued support -- please be generous.

Source: FOW Canada

For more information on how to make donations of money (tax-deductible) or unused ostomy supplies, please contact Earl Lesk, 604-327-7661.

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Vignettes

I thought I'd start at the 'top', so to speak, for this first in a series of interviews -- at age 93, Mrs. Yvonne Shaw is our oldest chapter member. I had the pleasure of meeting this gracious lady in her home this October. My one regret is that I have but a single page to repeat only a portion of what was a delightful account of a fascinating and full life. My thanks to Yvonne for giving her time and for a most enjoyable afternoon.

Debra Rooney: First, tell us a bit about yourself, how long have you lived in Vancouver?

Yvonne Shaw: I was born in France, actually. I came to Vancouver with my family from the Phillipines on the Empress of Russia. My sister needed treatment you see, and the Phillipines didn't have adequate facilities so we came here. There was a wonderful sanitarium in New Westminster. My mother went to San Fransisco and then to Los Angeles, thinking it might be better, came back and said there was nothing to compare, so we stayed here. That's how I came here.

DR: How old were you?

YS: I was 16. I looked older than I was and got into a number of clubs, underage!

DR: And how old are you now?

YS: I just turned 93.

DR: What sort of ostomy do you have?

YS: I have a colostomy.

DR: When did you have this, what was your diagnosis?

YS: I was in California at the time -- I used to go there or Hawaii at holiday time every winter -- and I started showing blood in the stool. I quickly phoned a friend of mine who was knowledgeable about medicine; she made an appointment with a specialist. In fact, I had two specialists. This was in Los Angeles and they said 'Without doubt, -- it's cancer.' I didn't think anyone in Vancouver could do the operation but they phoned and talked to my doctor here and were pleased with the conversation and said yes, I should go back and they'll do it in Vancouver. So I went back to Vancouver and had the operation.

DR: You had it here, then. What year was this?

YS: Yes, here in Vancouver. Dr. Mackenzie and Dr. Bell, two doctors. That was in 1975; I was 65.

DR: What kind of support was available to you at that time, was it something people kept hidden?

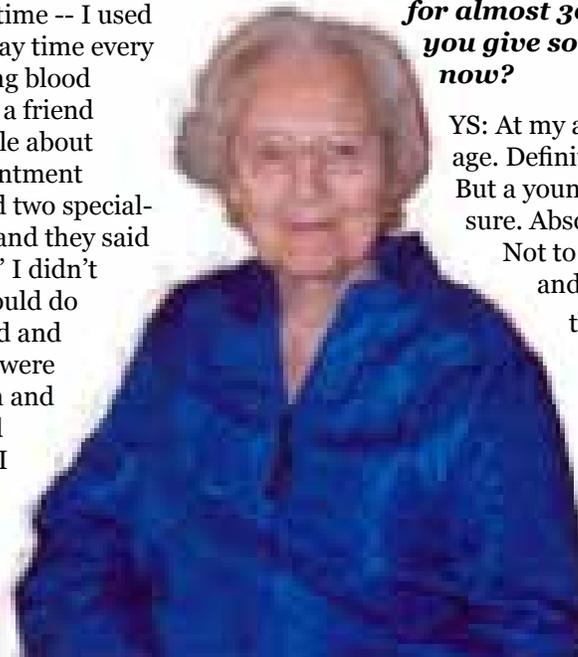
YS: People didn't talk too much about it, it was, you know, something I didn't know anything about. I had never heard about it. I was shocked. Completely shocked. I got information from the hospital, they gave me pamphlets and information about your diet and everything that could be useful and then there was always somebody at the hospital I could phone and ask advice from, nurses. I was taught how to irrigate soon after the operation.

DR: How did getting cancer and having an ostomy change your life?

YS: Oh, I was horrified. As a matter of fact, the night I was going to be operated on I decided I wouldn't have the operation. I was petrified. But I had it and after a while, I was, well, not quite satisfied but it didn't interfere with my life, my way of living. I was very fortunate. I was very fond of swimming, I was able to keep on swimming. I was a golfer and I kept playing golf so it really didn't interfere. The only time I had a little difficulty was travel. I loved travelling and was always nervous I was going to run out of supplies, what if I didn't bring enough with me and that sort of thing. That was the only thing I was nervous about. Adjusting was difficult at first, adjusting to irrigating every other day but it never interfered with my pleasures, as I say with all the travelling I've done.

DR: You've lived successfully with an ostomy for almost 30 years -- what advice would you give someone who is facing surgery now?

YS: At my age -- I wouldn't have it, not at my age. Definitely. It's too much to go through. But a younger person, a young person? For sure. Absolutely. I'd tell them not to hesitate. Not to hesitate. My life has been so full and I've been able to do almost everything I wanted to.



Sex and intimacy cont. from page 5

not be troublesome. Cialis™, the newer drug, again requires sexual stimulation to be effective, but is not affected by food and can be taken between 30 minutes and 12 hours before intercourse and may be effective for up to 24 hours. It too cannot be taken more than once a day and shouldn't be taken every day. The common side effects, shared with Viagra™, are headache and indigestion. As noted above, Viagra™ and Cialis™ cannot be taken if the person is taking nitrates such as GTN. These drugs, even though Cialis™ is more effective, may work for less than half of all men who have had a prostatectomy.

Uprima™ is taken under the tongue and should be put there about 20 minutes prior to sexual activity. A second dose can be taken no sooner than eight hours after the first one. There are restrictions on driving within 2 hours of taking Uprima™. Again sexual stimulation is necessary to achieve an erection but it can be taken, under medical guidance, by people who are taking nitrates.

Muse™, the transurethral pellet, comes in a sterile dispenser and is temperature sensitive. It has to be kept in the fridge (which could be a disadvantage with children, especially curious ones, in the house!) It should be taken out to warm up to room temperature before use. The applicator, sealed in a foil packet, contains a tiny pellet of the drug, called alprostadil which is about the size of a grain of rice. After passing urine, the stem of the applicator is inserted into the urethra at the tip of the penis with the penis being pulled out to its full length. The button on the top of the applicator is pressed to eject the pellet into the urethra. The pellet must then be massaged down the shaft of the penis towards the base to be fully effective. The man needs to stand or walk around for the ten minutes or so until the erection occurs - sexual stimulation is not necessary here - and then the erection lasts for between 30 to 60 minutes afterwards. This system relies on the urine to dissolve the pellet and a person with a urostomy will almost certainly be unable to use this system, but it is effective for those with colostomies and ileostomies.

Viridal™ Duo and Caverject™ are injections based on the same drug as used in the transurethral pellet, namely alprostadil. The syringes contain both the water for the injection and the drug in the form of a powder. In the Caverject™, for example, the barrel of the syringe is screwed in to mix the powder and the water. The syringe is then shaken, held with the needle upright and the air squirted out in the way so beloved of old hospital dramas! There is a twist dosing system to set the dose to the amount recommended to produce a satisfactory erection as recommended by the doctor or the nurse. The needle is inserted into one side or the other of the penis, avoiding veins, and the plunger depressed. Results are very rapid and the drug can be used up to three times a week. The obvious drawbacks to this are the bruising which can occur following the injection and actually self-injecting. However this is usually quickly overcome. The major drawback is priapism - a painful erection which lasts for more than four hours. After that time it becomes a medical emergency and medical intervention has to be sought. It should be noted that this is very rare, especially if the recommended dose only is used.

There are many makes of vacuum device. All work in a very similar way. Lubricant gel is applied around the base of the penis, followed by a transparent plastic cylinder with a restrictor ring slid over the bottom of the cylinder. Air is pumped out of the cylinder, either manually or by an electric pump. The vacuum formed draws blood into the penis until it becomes erect and the restrictor ring holds the blood within the penis to maintain the erection for up to 30 minutes. After that the ring must be removed, to allow normal blood flow to resume, although the pump may be used several times a day without harmful effects. The drawbacks are that the penis can look a little blue and feel cold, although having a warm shower first will help with this, and the 'hinge' effect. The erection does not extend to the part of the penis between the legs, so the erection may bend where the ring meets the body. However, this is a popular drug-free method of obtaining an erection, especially for those who have side effects from the drug therapies. It has a success rate over 90%.

Now that 'intimacy' is possible, by whatever means, let's look at some common 'problems'.

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1. *My stoma may get damaged during intercourse.* We all know that our stomas bleed if we clean them a little too vigorously during a pouch change. However the stoma itself is quite robust and is well able to withstand the intimacy of sexual intercourse within normal limits. It should be noted, however, that those who like to 'experiment' should never try to use their stoma for sexual purposes as that **will** damage the stoma. (This is more common than you'd think, according to discussions I had with a surgeon involved in stoma care whilst researching this article)
2. *My pouch will get in the way.* This is possibly true so there are two strategies for dealing with this. Some men wear boxer shorts in bed with a fly opening. This keeps the pouch out of the way and is a popular solution. Apart from open crotch underwear, some women wear a 'boob tube' (a knitted stretch fabric tube) over their abdomen which holds the pouch in place. There are now manufacturers who have become 'stoma aware'. I have been involved on a voluntary basis with a major underwear firm called Vayani Enterprises who

cont.next page

make for most of the big high street stores in the UK. We have been developing stoma underwear for men and their design team have been doing the same for women. The garments have pockets to hold the pouch appropriately. The design team have also been producing 'night-time' garments for intimacy, suitably lace trimmed (for the ladies of course!) under the brand name *Cuiwear*. There are other firms which produce such products and are well worth considering.

3. *My 'significant other' won't find me attractive anymore because I've got a stoma.* It is worth remembering part of the wedding service where each promises to the other "For better, for worse". My wife doesn't care whether I have stomas: I'm still myself and still her husband, come what may. It is extremely rare that couples break up when one of the pair has to have a stoma, and usually in those cases, the stresses and strains of the marriage were showing long before the surgery. Let's face it, in a loving relationship, love conquers all.
4. *Will it hurt?* The short answer is 'maybe' but please read on! Stoma surgery is major surgery. Bear in mind that my local hospital does both kidney transplants and urostomy surgery. A kidney patient is routinely in for five days post-operatively whereas the urostomy patient is in for fourteen days. Muscles which have been cut and rejoined during surgery need time to heal, so waiting until the person can move comfortably following the surgery is probably just plain common sense. Perhaps starting off with a different position may be helpful. I really don't want this to turn into a 'sex manual' but there are issues which need discussing! Perhaps a side- by side approach in the earlier days post operative may be worth considering as placing less strain on those abdominal muscles and not putting pressure on the abdomen. If the male has recently had stoma surgery, the 'missionary' position (male on top) may not be the ideal. Perhaps he could lie on his back with the female kneeling across his hips: this could well be the answer to avoiding pressure on the abdomen. However once full healing has taken place, virtually any sensible position will not cause either pain or problems. (please note, we're taking common sense here - we're not considering the sort of violent sexual athletics described in books such as the *Kama Sutra* and no, I haven't read it, but its reputation precedes it!)
5. In the early stages post-operatively, gentleness is the key to successful intimacy. Sometimes 'pressure to perform' may cause problems such as premature ejaculation. The use of a condom to reduce sensitivity is a common solution to this. A lubricated condom may also be useful if the female has had the surgery and is experiencing some vaginal dryness which can make intercourse uncomfortable.
6. *What if my pouch bursts?* There are several strategies to avoid this. Emptying pouches before intimacy is a 'must' and really a matter of common sense. Taping round the edges of the wafer will secure the wafer and provide self-confidence that the wafer won't come off at an inopportune moment. I wear a belt with my two piece pouches and wafers. The belt is 1" wide elastic

with loops which clip onto the pouch and hold it firmly against the abdomen. (By the way, in case you're wondering, both my ileostomy and urostomy are at the same level and I join the two in the middle with a white boot lace - a thought for those with two stomas). I prefer a clip on my ileostomy pouch and can tuck the clip up into the belt to avoid it getting in the way. Others successfully use the Velcro closure pouches to avoid the use of clips altogether. Urostomy taps can be tucked into the side of the belt in the same way to get them away from the front of the abdomen.

Perhaps the most important point is not to make a big issue out of sex and intimacy. Worrying too much is a sure recipe for things to go wrong. The manufacturers of the vacuum devices and the injection kits suggest that the other partner be involved with their use. Some men who inject have had their partners taught to carry out the injection and they incorporate that into their love making. In the same way, the female may apply the vacuum device to obtain her partner's erection. It is reported that, far from making intimacy cold and clinical, some couples report that this has improved their relationships. It is **vital** that couples talk to each other openly and honestly in the discussion of any problems. Frequently ED clinics involve both partners in a relationship so that mutual understanding may be engendered.

Having a stoma should not, and for the vast majority will not, spoil their sexual relationships with their partner. They will have discussed the issues and worked out ways around the problems which arise due to the post surgery healing issues. The other partner will know that he or she will not hurt their loved one's stoma during sexual activity. Perhaps if you're reading this and some of this applies to you, why not sit down with your partner and go through this article together? It may encourage you both to sort out any issues and to set to rest any wrong ideas. Above all, help is out there. It is a very common problem even amongst the 'normal' male population, so there is no need to be embarrassed. If you do have a problem with ED, talk to your doctor or your stoma nurse and, if they don't deal with this themselves, ask to be referred to someone who can help. Help is out there and, even if several different methods have to be tried before one succeeds, something will work!

Bibliography:

- Caverject™, Muse™, Viridal™, Uprima™, Viagra™ and Cialis™ patient information leaflets.
- The Electronic British National Formulary
- "The use of viagra (sildenafil) in the treatment of impotence (erectile dysfunction)" - Department of Health document
- "Impotence Explained" - The Impotence Association
- "A Better Solution for Caring Couples" - Osbon Medical UK Ltd
- "Understanding Male Impotence" - Rapport Ltd.

to go on!



Source: Rolf Benirschke Great Comebacks™

True Trivia

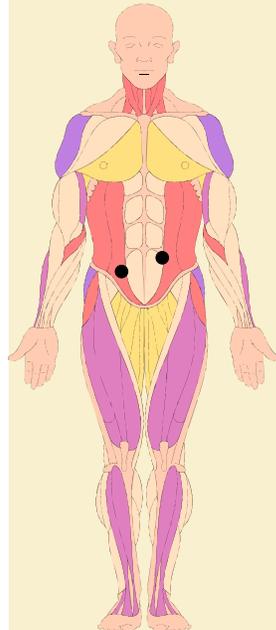
Department:

(Can You Live Without Knowing These Things?)

1. Coca-Cola was originally green.
2. The first couple to be shown in bed together on prime time TV were Fred and Wilma Flintstone.
3. It is impossible to lick your elbow.
4. The first novel ever written on a typewriter: Tom Sawyer.
5. What do bulletproof vests, fire escapes, windshield wipers and laser printers all have in common? All were invented by women.
6. At least 75% of people who read

Parastomal Hernias

When a stoma is brought out to the surface of the abdomen it must pass through the muscles of the abdominal wall, thus a potential site of weakness is immediately created. In the ideal situation the abdominal wall muscles form a snug fit around the stoma opening. However, sometimes the muscles come away from the edges of the stoma thus creating a hernia - in this case, an area of the abdominal wall adjacent to the stoma where there is no muscle. Factors that can contribute to causing a stoma hernia to occur include coughing, being overweight or having developed an infection in the wound at the time the stoma was made. The development of a stoma hernia is often a gradual phenomenon, with the area next to the stoma stretching and becoming weaker with the passage of time. This weakness, or gap, means that



every time one strains, coughs, sneezes or stands up, the area of the abdomen next to the stoma bulges, or the whole stoma itself protrudes as it is pushed forwards by the rest of the abdominal contents behind it. As with all hernias the size will increase as time goes by. Stoma hernias are rarely painful, but are usually uncomfortable and can become extremely inconvenient. They may make it difficult to attach a bag properly and sometimes their sheer size is an embarrassment as they can be seen beneath clothes. Although a rare complication, the intestine can sometimes become trapped or kinked within the hernia and become obstructed. Even more seriously the intestine may then lose its blood supply, known as strangulation. This is very painful and requires emergency surgery to untwist the intestine and prevent the strangulated part of the bowel from being irreversibly

damaged. Regardless of inconvenience or pain, hernias are defects in the abdominal wall and should not be ignored simply because they might not hurt. There are surgeons who advocate that small stoma hernias that are not causing any symptoms do not need any treatment. Furthermore, if they do need treatment it should not be by operation in the first instance but by wearing a wide, firm colostomy/ileostomy belt. This is probably true with small hernias, in people who are very elderly and infirm or people for whom an anaesthetic would be dangerous (serious heart or breathing problems, for example). Operative repair of the stoma hernia may be given serious consideration to improve the quality of life, prevent progressive enlargement of the hernia with time and make it easier to manage the stoma.

Source: The British Hernia Centre

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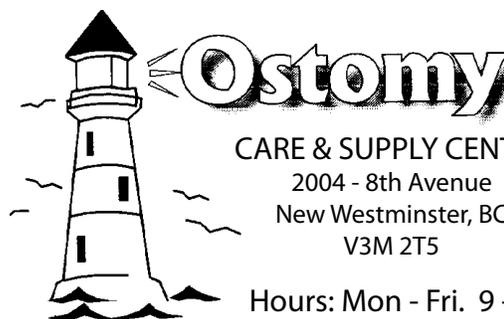
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Sex and intimacy cont. from page 11

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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.

Internet Addresses of Interest to Ostomates

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

UOA of Canada Inc.: www.ostomycanada.ca

NEW

Stoma Cups: <http://www.rcscompany.com/index.html>
(That's cups, not caps --intriguing product for use when bathing/showering/changing)

International Ostomy Association: www.ostomyinternational.org

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

Coquitlam Chapter: www.geocities.com/coqcon

<http://www.spinalcord.uab.edu/show.asp?durki=21574>
(of interest to those with spinal cord injuries and/or their caregivers)

NEW

Gut Feelings: <http://www.gutfeelings.com/DIVERTICULITIS.HTML>

Friends of Ostomates Worldwide: www.fowcanada.org/

Crohn's & Colitis Foundation of Canada: www.cffc.ca

Young Ostomates United Inc.: <http://home.vicnet.net.au/~youinc/>

Stuart Online: www.stuartonline.com

Continent Diversion Network (Internal Pouches) www.ostomyalternative.org

Evansville Ostomy Association: <http://www.ostomy.evansville.net/>
(extensive resource site, lots of good links. Has message board as well.)



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