



Spokane Ostomy Support Group Newsletter

Affiliated with United Ostomy Association of America, Inc.

Published Quarterly by Local # 349 (SOSG) - Editor: Phillip R. Moyle (SOSG.Input@gmail.com)

16 - 1 & 2 (First Issue) Advocates for Ostomates & Caregivers Winter-Spring 2016

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MEETINGS & ANNOUNCEMENTS

Spokane Ostomy Support Group (SOSG)

Meetings for ostomates & caregivers are held on the first Tuesday each month (February-November) 6:30-8 p.m.

Providence Sacred Heart Medical Center
101 W 8th Ave, Spokane, WA 99204
Mother Joseph Room,
next to the cafeteria on L-3

* Please contact Susie Leonard Weller for questions and/or comments:
call 509-255-6676 or
email SOSG.Input@gmail.com

All are welcome to join us!

Upcoming Meetings & Topics

- April 5 - Meet Kerry McGinn, author of 'The Ostomy Book'
- May 3 - Five Phases of Moving Forward
- June 7 - Urostomy Support Resources
- July 5 - Dinner & social meet @ Perkins
- August 2 - How Many Ostomates Are There? Statistics & Other Fun Facts

Regional / National Events

6th National Conference, Irvine, CA
8 / 22-26 / 2017

SUSIE & CAROL'S CORNER - WAZZUP

Spokane Ostomates Start Newsletter

Carol Nelson

Welcome to the first edition of the Spokane Ostomy Support Group (SOSG) newsletter! Our goal is to reach out to ostomates & caregivers who regularly attend our support group meetings as well as to those who are unable to do so.

Each quarterly issue of the newsletter will include contact information for both local and national ostomy resources, a "Nurse's Corner - Q & A" written by an ostomy nurse in response to your questions, information about topics to be presented or discussed at upcoming meetings, and one or more articles about various aspects of living with an ostomy.

As timing and interest allow, we will also try to coordinate the content of newsletter articles with topics discussed at our monthly meetings. We welcome ideas about potential article topics, inquires to our "Nurse's Corner," and other suggestions that will help us provide the type of information you need and want. We will make every effort to respond to and accommodate your input. Please send suggestions, ostomy nurse questions, & humor ideas to SOSG.Input@gmail.com by June 20th.

Susie and I would like to extend a special thanks to Phil Moyle who designed the template and has helped get this project moving. We also appreciate Rich Judd from Byram Healthcare who provided many of the contacts and offered to mail the newsletter out to those who don't have access to email.

DIVERSION INSPIRATION & HUMOR

(submissions & ideas welcome)





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NEWSLETTER

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NURSE'S CORNER - Q & A

Introduction

Greetings & welcome to the "Nurse's Corner - Q & A!" As mentioned earlier in our newsletter, input from those attending recent support group meetings expressed interest in including a column in which an ostomy nurse could respond to direct questions submitted by you, ostomates and caregivers in our support area. The column could also address other subjects, such as a new technology or appliance, that an ostomy nurse considers important to convey to our readers. So we encourage our readers to submit "Nurses Corner" questions to *SOSG.Input@gmail.com*. We can't promise that every question will be answered here, but the nurses will make every effort to respond. If your question is not addressed here, please feel free to contact an ostomy nurse. Note that an MD referral is required for an appointment with an ostomy nurse at one of our local medical facilities.

Information on two local ostomy care clinics are listed in the "Important SOSG Support Contacts" box on the last page of the newsletter: the Providence Sacred Heart Medical Center - Outpatient Ostomy Clinic, and the Deaconess Medical Center - Wound Center. There are also other medical facilities in the area that have ostomy care support.

Ostomate Bill of Rights

Teresa Patterson, RN CWON - Providence SHMC, wants to start off this column with a review of the *Ostomates Bill of Rights*. The United Ostomy Association (UOA), the predecessor organization to UOAA, produced a document in 1977 titled *Ostomate Bill of Rights*. In addition, the [International Ostomy Association](#) (IOA) prepared a somewhat similar document in 2004 titled *Charter of Ostomates Rights*. The Ostomate Bill of Rights was presented to UOA by the International Association of Enterostomal Therapists (now known as Wound Ostomy Continence Nurses) at the UOA House of Delegates Meeting during the Annual Conference in 1977.

It is our goal to inform ostomates that all elements of quality care should be available to them.

The ostomate shall:

1. Be given pre-op counseling
2. Have an appropriately positioned stoma site
3. Have a well-constructed stoma
4. Have skilled postoperative nursing care
5. Have emotional support
6. Have individual instruction
7. Be informed on the availability of supplies
8. Be provided with information on community resources
9. Have post-hospital follow-up and life-long supervision
10. Benefit from team efforts of health care professionals
11. Be provided with information and counsel from the ostomy association and its members.



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Adopted by the United Ostomy Association House of Delegates at the UOA Annual Conference 1977.

***** "SEASONAL ARTICLE(S)" *****

Five Psychological Phases of Moving Forward-- by Lisa Caraffa, Ph.D.

(Lisa, a psychologist and an ileostomate, shared these reflections from a speech she gave at the UOAA Convention. Her article has been edited and summarized by Susie Leonard Weller)

Having surgery for an ostomy can be traumatic. It is important that ostomates, as well as their loved ones, fully understand the long-term impact of the surgery. The purpose of this article is to normalize the common coping styles and phases of emotions that many ostomates go through as they learn to adjust to their new body image and toileting habits.

Traumatic events are different from life's daily misfortunes. Ostomy surgery, whether due to cancer, Crohn's, ulcerative colitis or other conditions, can be traumatic. Or it often involves a major life change to the body, and often results from a life threatening or a serious circumstance.

The amount of trauma someone experiences is influenced by three major factors:

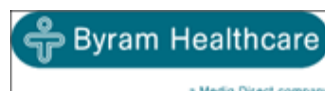
1. Natural loss that is accidental, with no control over it vs. a human made loss caused by negligence
2. The degree to which the event is expected or whether or not the event could have been prevented
3. The amount of pain and suffering experienced from the surgery or unexpected consequences and side effects

Compare the response of those needing an ostomy due to Crohn's disease, with a person whose survival unexpectedly requires an ostomy due to being hit by a drunken driver in a car accident. Someone who has dealt with ulcerative colitis for 20 years and anticipated that an ostomy surgery might become a future option, will generally experience less trauma than the person who is diagnosed with colon cancer on Tuesday, and needs to have an ostomy by Thursday.

It is natural for people to think that they can prevent bad things from happening to them if only they can control their circumstances. However, the problem with believing we have complete control over our lives and illnesses is that we keep trying to figure out what we failed to do. We think to ourselves: "If I had all that control, then I must have done something wrong." It is easy to stay miserable by staying stuck in the "if only I had" type of thinking. In order to get past this, we need to face the fact that bad things can randomly happen—even to good people. Moving on includes surrendering what we don't have control over and focusing on what we *can* do.

There are typically **5 phases of coping with trauma**. However, everyone responds differently. Some may skip certain phases entirely, or go through them either very quickly or very slowly.

Phase One is the time immediately after the crisis. It usually lasts for a few days or up to a few weeks. When people first learn they have cancer, or hear they will need surgery for an ostomy, many feel numb. They may act as if they are just going through the motions. Some





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might be tearful, experience wide mood swings, feel anxious, be overly talkative, act agitated, withdraw in silence, have poor concentration, or be forgetful. This is all natural. The person is on overload and the mind just can't take in more information.

Phase Two begins with an increase in activity. Ostomates often start taking control again, making decisions, and getting their life back in order. They get a second opinion, call the insurance company, read books about their medical concerns, or join a support group. Phase Two is deceptive because the trauma survivor and the people around him/her think that the worst is over; the crisis is resolved. Actually, this is nature's way of coping to manage life's responsibilities. *This stage may last weeks or months and can delay the grief process.*

In Phase Three, anger, grief and depression often emerge. A friend of mine developed colon cancer at a fairly young age. After a short period of recovery, he went back to work and moved on with his life. However, four years later, as he approached his five year mark, he became very depressed for no apparent reason. He realized that he was thinking a lot about his surgery and the reality of having had cancer. He had finally moved into the next phase.

Sometimes, people in the early stages of Phase Three direct their anger in very constructive ways, such as forming MADD (Mothers Against Drunk Drivers). Being active in this positive way helps give some relief from the sense of anger, sorrow, and loss of control-- but then comes the worst feeling. . . **LONELINESS!** The survivor comes to grips with the fact that the people around them can never entirely understand their experience.

Phase Four often starts when some small or positive event gives the survivor hope. I realized that I wasn't the only person in the world with an ostomy. I saw 40 people of all ages and genders at an ostomy support meeting who all looked NORMAL! I realized that I had been thinking of myself as abnormal and this was my turning point. I stopped feeling alone and different. I cherished talking openly with others who have "been there and done that."

The Fifth and last phase is the conscious acceptance of what has happened to us. It does not mean that we forget what happened, or that we pretend that it was not a significant crisis; we just find a place for it. It becomes a simple fundamental fact of life as we go on with our lives. The ostomy is in the background of our lives. It is there, but we don't focus on it anymore.

Here are four tips as you move through all five phases towards acceptance and integration:

1. Recognize, understand, and acknowledge the type of trauma and the depth of loss that you have experienced.
2. Understand that breakdown often precedes breakthrough and acceptance. It is important to go through Phase Three and to find appropriate ways to release your feelings about your loss. Feel the pain, accept it and express it. To move on, let go of the old ways of living. Find new ways to adapt to and integrate your life changes.
3. Regain your sense of safety and trust by exploring what you *do* have control over in your life. Talk with other ostomates and gather new resources to address your concerns.
4. Look for the positive aspects and find the humor within your challenging experiences.



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Your ability to understand the normal phases of adjustment and to accept where you are in the process, allows you to better educate yourself and those around you. Be clear about what kind of support you would like from them.

Support Resources for Urostomates Who Are Also Bladder Cancer Survivors

by Susie Leonard Weller

Alan Roecks, coordinator of the Inland Northwest Bladder Cancer Support Group, estimates that about 70% of their members in Spokane have a urostomy. According to the Bladder Cancer Advocacy Network (visit www.bcan.org for more details), approximately 15% or 1 out every 7 people with bladder cancer, will have their bladder removed due to disease or malfunction.

A urostomy, is a surgery to divert and eliminate urine. The surgeon creates an opening in the abdominal wall, called a stoma, through which urine passes. Patients are taught how to attach an external, disposable bag which collects their liquid waste until it can be emptied.

A common concern for urostomates (and other ostomates) is knowing what to do when unexpected things happen. Alan describes what he did when he was going through 8 pouches within 10 hours on the morning of Christmas Eve, in 2015:

“As a new urostomate for less than four months, I was frustrated and not sure where to turn. Recalling a discussion of what do to in an emergency from the Spokane Ostomy Support Group meeting, I contacted the Wound and Ostomy Center at Sacred Heart, praying someone would be working, given the looming three-day holiday weekend. I was able to reach Beth Wrigley, a RN, who quickly surmised that my problem was due to defective pouches. She put me in contact with Rich Judd, the local Byram Health Care Regional Manager. He organized an emergency pouch supply kit for me just before the close of business on Christmas Eve.

In addition, Beth recommended that I move to a new, highly regarded ostomy pouch product, called the Coloplast SenSura MIO which sticks better to the skin. I tested various MIO products, including their one-piece and two-piece pouches. I also explored pouches with varying levels of convexity, as well as those with opaque or transparent covers. I’m grateful to have found new urostomy products that are a better match for me. My pouch now lasts up to five days. I also wear an ostomy belt for extra support that allows me to play tennis, swim and regularly go to the gym.

The United Ostomy Association of America (UOAA) website at www.uoaa.org suggests these tips for urostomates:

- Attend support meetings in your region, and subscribe to the *Phoenix Magazine* to learn new resources on how to live well with your urostomy.
- Unless otherwise indicated, maintain a slightly *acidic pH level* for your urine, rather than an alkaline state. A slightly acidic urine can discourage bacterial growth. If the stoma





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appears whitish in color, increase your intake of acidic foods, such as: most meats, fish and poultry, breads, cereals, grains and pasta, eggs and cheese, prunes and plums.

- Drink sufficient fluids to keep your urine diluted.
 - Change your barrier and pouch regularly (typically every 3-4 days) to avoid leakage and skin irritation. If itching and/or burning occur, change them more frequently.
 - When removing the skin barrier gently *push* your skin from the pouch rather than pulling the pouch from the skin.
-
- Keep your skin clean with water. If necessary, use a mild soap and rinse very well. This can be done in the shower or tub. Pat your skin dry, or use a hair dryer on a low setting, before applying the skin barrier and pouch.
 - Notice any sensitivities and allergies to your adhesive, skin barrier, tape or pouch material. Since your body can become gradually sensitized, these reactions can develop weeks, months or years after using a product. Ostomy supply companies use different **chemical formulations for their materials. Try another manufacturer, if necessary.**

Urostomates can receive additional support through the Inland Northwest Bladder Cancer Support Group. They also meet on the first Tuesday of the month. Members gather at 5 p.m. at the Perkins Restaurant, on 12 E. Olive, in downtown Spokane. For more information, contact Alan Roecks at (509) 269-8026, or email him at: BladderCancerGroup@gmail.com. Alan has coordinated the meeting time and date, so that urostomates can also join the general Spokane Ostomate Support group meeting from 6:30 to 8:00 p.m. at the Providence Sacred Heart Medical Center.



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IMPORTANT SOSG SUPPORT CONTACTS

Providence Sacred Heart Outpatient Ostomy Clinic - M-F 8-2:30 (509-474-4950), leave a message if you don't reach someone live); appointments & MD referral required; No walk ins; Can be seen for follow up, checkup, questions, problems.

Deaconess Medical Center - Wound Center - M-F 9:00-3:00 (509- 473-3074); appointments & MD referral required.

Ostomy Visitor Program - Those who have had or are facing potential ostomy surgery should contact Carol Nelson (509-433-1242; carol@nelsonwheat.com) to arrange contact with or a visit from an experienced and trained ostomate Visitor.

Inland Northwest Bladder Cancer Support Group - A support group for urostomates and bladder cancer patients. Members meet the first Tuesday of the month at 5 p.m., Perkins Restaurant, on 12 E. Olive, in downtown Spokane. Contact Alan Roecks (509) 269-8026, or email him at BladderCancerGroup@gmail.com.

United Ostomy Association of America (UOAA) - (800-826-0826); P.O. Box 525, Kennebunk, ME 04043-0525; Link: <http://www.ostomy.org/Home.html>.

Phoenix Magazine - (800-750-9311); The Phoenix Magazine, P.O. Box 3605, Mission Viejo, CA 92690; Link: <http://www.phoenixuoaa.org/> (get a free sample copy).

Primary Producers of Ostomy Products:

Hollister 1-888-808-74556
<http://www.hollister.com/>

Coloplast 1-888-726-7872
<http://www.coloplast.us/Ostomy>

Convatec 1-800-422-8811
<http://www.convatec.com/ostomy/>

