

MORRIS COUNTY OSTOMY ASSOCIATION OF NEW JERSEY

AN AFFILIATE OF UNITED OSTOMY ASSOCIATIONS OF AMERICA, INC.

THE DOCTOR/PATIENT PARTNERSHIP

Carol Larson

When support groups of people who have survived a serious illness gather, it's a good bet that eventually their doctors become the topic of conversation. Because of the life and death issues involved, strong feelings emerge. Good experiences tend to breed hero worship, while unpleasant encounters can leave everyone bitter. The impressions that make these relationships work the best are based mostly on the gifts of a good diagnostician and the ability of doctors to connect with their patients while dispensing care. Stories about insensitive physicians top the list.

We have our good stories too, praising the doctors who have what is known as "a good bedside manner." The realities of modern medicine make it hard to establish much of a personal exchange. Time allocated for most appointments is short, and patients are usually scheduled in tightly. Instant judgments abound. Some hasty comment, look of boredom, or impatience on the part of the doctor can influence the effectiveness of care more than it should. But rudeness works both ways. Patients need to do their part to pay attention and make the best use of this time.

How to get the best care possible:

Be Selective

- If you have insurance, call the number on your card and find out which doctor is in your network.
- Call another doctor you admire and ask for a referral.
- Find a doctor who is convenient for you to see and who works in a hospital you would prefer.

Be Efficient

- Be on time for your appointments.
- Bring in a list of your medications and insurance information.
- Deliver your information concisely. If you are experiencing pain, grade the pain from 1-10. Be specific about your concerns.
- Don't expect a doctor to want to listen to unrelated facts.
- Don't try to upstage the doctor with a diagnosis you pulled off of the Internet or from well-meaning friends.

Listen Carefully

- Take notes. Bring a list of questions you had beforehand.
- Write down treatments or words you don't understand.
- Be reasonable and respectful. Understand that both of you will not always be at your best, especially when an illness is hard to treat.
- It is primary to your care to be able to accept honesty and not try to persuade **your** doctor to give you glib promises.
- Repeat the doctor's message out loud so that you truly understand what is being said.

Source: UOAA

WINTER 2015-2016 NEWSLETTER

www.ostomymorris.org

MCOA OFFICERS

President: Johann Norris
973-377-2597

Vice President: Kris
Kirkpatrick
973-822-3440

Secretary-Treasurer: George
Salamy 908-879-1229

Newsletter: Walter Cummins
973-822-1146

Fund Raising: Tony Padula
201-433-8054

WOUND, OSTOMY, CONTINENCE CLINICIANS

Toni McTigue,
MSN, APN, CWOCN
973-971-5522

Janet Doyle-Munoz,
MSN, RN, CWON
973-971-4191

Laura Doyle,
BSN, RN, CWON
973-971-5940

PHYSICIAN ADVISORS

Dr. John Dalena
(Gastroenterologist)
973-401-0500

Dr. Rolando Rolandelli
(Colorectal Surgeon)
973-971-7200

Dr. Ian Atlas
(Urologist)
973-539-0333

PSYCHOLOGICAL REACTIONS TO OSTOMY SURGERY

Lisa Caraffa, PhD

Note: Lisa Caraffa, who has a doctorate in psychology and an ileostomy, spoke at a United Ostomy Association conference about psychological reactions from the perspectives of both a specialist in mental health and person who has experienced ostomy surgery. This report will excerpt her findings

I've been asked to talk about the psychological response to ostomy surgery. I am going to be focusing on the traumatic aspects of our experiences so that those of us with ostomies and those who help ostomates will be less prone to minimize the significance of this surgery, to be less avoidant of the normal range of feelings that follow major surgery and to help alleviate the sense of feeling lonely and different that ostomy surgery can cause.

Having a chronic, sometimes life threatening disease is traumatic. Having ostomy surgery is also traumatic. How we respond to this trauma and how we cope with the changes in our body image, our changes in toileting habits can affect our personal well being and our relationships with others.

The more we understand about the normal phases that people go through after traumatic events, and the more we understand the range of feelings and coping styles people have, the better we will be in understanding what our own needs are and then we will be able to help the people around us – friends and family – understand our needs and know better how to help us.

It is generally believed that there are approximately 5 phases of trauma but I must point out that everyone responds differently. Some people may skip certain phases entirely, or go through them either very quickly or very slowly. You should also remember, that some of the factors affecting trauma-preventability, expectedness and amount of suffering, all have an impact on how quickly or slowly people move through the 5 phases of trauma recovery. You may recognize yourselves in some of these phases.

Phase One is the time immediately after the crisis. It typically lasts a few days to a few weeks. Perhaps you have just learned that you have cancer or have been told that ostomy surgery is needed. Many folks, during this phase, may experience feeling numb – as if they are just going through the motions, they may be tearful, sometimes there are mood swings, anxiety (talking a lot, agitation, tense silences or withdrawal), poor concentration, forgetfulness. This is all natural. The mind is overloaded and just can't take in more information, the person can't concentrate, he forgets things.

Phase Two begins with an increase in activity. We start taking control again, we make decisions, start getting our life back in order. We get second opinions, we call our insurance companies, we read books about our problems. Phase Two is deceptive because the trauma survivor and the people around him/her thinks that the worst is over, the crisis is resolved. Actually, this is nature's way of allowing us to meet major responsibilities in our lives. This stage may last weeks or months and delays the actual grief process.

In Phase Three, in which anger, grief and depression are often experienced. Sometimes, people in the early stages of Phase Three have directed their anger in very constructive ways. 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. That of LONELINESS. The survivor comes to grips with the fact that the people around them can't entirely understand the experience that they have had.

I think this is a very important factor, and particularly so for ostomates. We have had a traumatic life event, but because it involves bathroom functions, we are inhibited from talking about it freely in this society. This culture has a lot of shame and anxiety around bathroom habits which makes it difficult for us to reveal our surgeries to others and this gives us a greater sense of loneliness or feeling separate or different.

I still rarely hear the "O" word – ostomy – under any circumstance. We'll know we've finally made it when we have a postage stamp honoring ostomates!

Unfortunately, all of this keeps us feeling separate, different and alone, UNTIL we find each other and the UOA.

It was also great to be with folks who used humour and laughter to deal with their surgeries and I cherished the opportunity to talk openly with people who have "been there-done that".

Phase Four often starts when some small or positive event gives the survivor hope. This could be a variety of things—for me it was the recognition that I wasn't the only person in the world with an ostomy. For others the moment of change could start with a phone call from a concerned friend, or turning on the TV and seeing something particularly uplifting. It could even be particularly well written Hallmark card.

This stage begins with hope, we begin to find meaning in our lives and the healing begins.

Take a moment and reflect on what turning point you may have experienced, or what gave you the courage to move on.

The 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 for us as we go on with our lives. The ostomy is in the background of our lives. It's there, but we don't focus on it anymore.

We all have the need to feel in touch with ourselves and connected to other people. A good connection is based on how well we know ourselves and how well we accept the different parts of ourselves.

STOMA HERNIA

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.

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. 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 (for example, serious heart or breathing problems).

If symptoms are severe enough, the hernia is repaired. The repair of a stoma hernia requires that the abdominal wall tissue is made to fit back snugly around the stoma, leaving no weakness. Over the years many different surgical approaches to this problem have been tried.

There are two options. One can move the stoma to a new site on the abdomen, i.e. create a new opening elsewhere and repair the hernia at the old site as one would any other hernia, or one can try to repair the hernia around the stoma, leaving the stoma where it is. Repair of the hernia without moving the stoma involves opening the abdominal wall over the hernia adjacent to the stoma and re-suturing muscle and supporting tissues in the area.

Because moving the stoma is a major operation, a recent alternative is repair with mesh over and beyond the weakened area to reinforce the whole weakened muscle structure. Once inserted, the mesh rapidly becomes incorporated within the muscle and surrounding tissue and forms the core of a much stronger area within the abdominal wall. This use of mesh, rather than stitches, serves to avoid future recurrences, which happen when the stitches used with other methods are pulled away from the tissue.

While there can be no guarantee of the permanence of any stoma hernia repair, it is felt that this technique offers the least risk of recurrence.

Source: The British Hernia Centre

DUES

If you haven't already sent a check or cash, 2016 dues are due.

Dues are still \$20.00, and you can send to:

George Salamy, Treasurer
30 Wyckoff Way, Chester, NJ 07930

DONATING SUPPLIES

Group members may send unused ostomy supplies to Friends of Ostomates Worldwide, an organization that provides ostomy materials to needy ostomates throughout the world. For more information about Friends of Ostomates, click "Donating Ostomy Supplies" on the list of links on www.ostomymorris.org. Their address is 4018 Bishop Lane, Louisville, KY 40218.

MEETING SCHEDULE

Meetings start at 7:30 p.m. and end at 9 p.m.

FEBRUARY 17, 2016

Open meeting

MARCH 16, 2016

Coloplast Ostomy Territory Manager

Ed Carmody

APRIL 20, 2016

Celebration Ostomy belt representative

Jack Millman

MAY 18, 2016

Jean-Marie Rosone, LCSW Carol Simon
Cancer Center (First Recipient of the Joseph
A. Trunfio Healing Culture Champion
Award January 2015)

JUNE 15

Byram Healthcare representative

Jeff Hamill

MORRIS COUNTY OSTOMY ASSOCIATION

The Morris County Ostomy Association is a community-based, local organization made up of volunteers whose purpose it is to reach out to ostomates and their families, providing them with a network from which they can share experiences, obtain information, and gain emotional support.

The association's voluntary visitation program offers support on a one-to-one basis to patients and their families. The ostomy volunteer visitor is carefully chosen and trained. The visitor is well adjusted to his/her ostomy and is able to offer additional support and information on ostomy care and management at home.

The Morris County Ostomy Association holds regular monthly meetings. The meetings normally consist of an informal gathering of ostomates and individuals who may be contemplating ostomy related procedures. Families and friends as well as significant others are always welcome.

The evening usually involves an informal talk by a physician, a nurse specialist, a distributor of ostomy supplies, or social worker. Presentations are always on a topic of interest to the entire group. Most importantly, the meeting offers the opportunity for individuals to share information and discuss mutual interest and concerns.

MCOA

Morristown Medical Center
Atlantic Health Group
100 Madison Avenue
Morristown, NJ 07962

