

# The Mailbag

The Ostomy Support Newsletter Of Jacksonville, Florida

Support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street

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**Mark your calendar and plan to join us  
for our next chapter meeting.**

**August 16th**

**3PM**

**4836 Victor Street**



**For more information please visit the  
International Ostomy Association Website:**

**<http://www.ostomyinternational.org>**

### ***World Ostomy Day***

I am pleased to announce that arrangements for celebrating WOD2009 are well underway in many countries throughout the world. The day is being recognized throughout the World on the 3<sup>rd</sup> October but the UOAA (United Ostomy Association of America) are celebrating WOD2009 on the 17<sup>th</sup> of October. Whilst it would be better if all countries celebrated it on the same day, if that is not possible it is important that World Ostomy Day is celebrated which ever date is selected, it is an excellent opportunity to get our message out to the general community on the needs and aspirations of Ostomates wherever they may be.

Peter McQueen, WOD 2009 Coordinator (For more information please visit: <http://www.ostomyinternational.org>)

## Life with an Ostomy

A compilation of good advice from professional sources

Remember when you were in the hospital . . . you were told you would have to live with an ostomy? When you looked at your stoma for the first time, what was your reaction? Most likely, you were shocked, depressed and scared. You could not imagine how you were going to live with "this thing". How far have you come since then? Do you still call your stoma "the thing", or have you given it a special name? Do you sometimes even forget that your stoma exists? Everyone's adjustment is a bit different, but I hope that you have accepted your stoma. I tell my patients, "You do not have to like the stoma, but you do have to learn to live with it".

### You rule your stoma

You need to take the time to take good care of your stoma but not let it rule your lifestyle. In other words, "You rule the stoma. Do not let it rule you." After all, you are the same wonderful person you were before your surgery.

### Help is available

You need to know some basics to reach a satisfactory point of control over your ostomy. You need to know how to take good care of your stoma and surrounding skin, what information is available to help you and where to obtain sound advice. You also need to take that information and assimilate it to fit into your own lifestyle. One reason you see so many products in ostomy catalogs is not to confuse you, but to help you find the right products so you may personally choose the best way to get on with living. Your local ostomy association is an excellent source of information, advice and support. Use this resource for the benefit of yourself, and for the benefit of others. You know, we want to hear about your story and about your successes.

### Does it hurt?

First, you need to know about your stoma itself. It is red and looks as if it ought to hurt. However, looking at the stoma is actually looking at your intestine's lining, which does not have any feeling nerve endings. Reassure your spouse about this. Your mate may be afraid of hurting you if the stoma is touched. A person with an ostomy may feel rejected because of the mate's fear to touch him/her. If your spouse understands the stoma has no feeling and will not hurt you, he/she will be more at ease to share intimacies.

### Learn to live with it

Your attitude is also important. If you cannot accept your stoma, how can you expect someone else to accept it? Remember, you do not have to like it, but you must learn to live with it. I am sure there are other parts of your body that you would like to change. Maybe you think your nose is too large or your butt is too big. Maybe your eyesight is not what you would like and your teeth are yellow. We all learn how to live with these unique characteristics. Your stoma is just a new part of you that you learn to live with. Remember the symbol of the United Ostomy Associations of America is the Phoenix. The Phoenix is the mythical bird that was raised from the flames after it died. People with ostomies are "raised from the ashes of disease." You do not have to like your stoma, but you do have to live with it. There are people who said, "I could never live with one of those." And you know what . . . they don't.

### Should I worry about bleeding?

The reason your stoma is red and your stoma bleeds easily is that the blood vessels in your intestinal lining, which again is what your stoma is made from, are very close to the surface. This is why it is important for you to be gentle in cleaning your stoma. A small amount of bleeding is normal and do not be concerned about it.

Excessive bleeding should be reported to your doctor or WOC nurse as needed. Excessive bleeding means more than a drop or two. If you touch it with a tissue, you may notice some red on the tissue. This is what is normal. If you have much more than this, meaning you actually witness bleeding, see someone immediately. This is not normal. Anytime we are bleeding, it is not usually good. Check with a health professional about it.

Make sure nothing constricting is riding over your stoma, reducing the blood supply needed to keep this vibrant tissue alive. Elastic belts over your stoma are usually okay, but a leather belt does not "give enough" to ride over your stoma if it is on your beltline. Ideally, your stoma is located below the beltline, but sometimes it cannot be surgically positioned in the ideal site.

### Isn't it supposed to be round?

Stomas come in all sizes and shapes, just as all of us do. If you are worried that your stoma does not fit exactly into one of those cute measuring guides with the perfectly round holes, do not be discouraged. Most stomas are not perfectly round. The measuring guide is just that, a guide. You customize it to fit your personal need. This is a vital

point. The correct size for your equipment is extremely important. Always measure your barrier to the correct size, no matter how your pouching system is built. Just like us, stomas come in all shapes and sizes.

### **The right fit**

Initially after surgery, your stoma is probably swollen. It will decrease in size. Your nurse should show you how to measure your stoma correctly. Measuring is an ongoing concern. Incorrect sizing of the stoma creates most of the problems I see after surgery. You want the opening in your pouch or adhesive to fit as closely as possible to the stoma. Many extended wear barriers do not require any gap between the barrier and the stoma, others, with harder barriers; require leaving a 1/16" to 1/8" border from your stoma.

This is to allow your stoma to change size and shape. Yes, your stoma does move and change size slightly with the normal peristaltic waves of your intestinal tract, of which it is after all a part. A soft pliable substance is usually used directly around the stoma, such as a paste or a barrier seal, to fill in this 1/16" to 1/8" gap around the stoma. It acts as a washer or caulk to protect the skin directly around the stoma and to protect the seal of the pouch to your body. The more liquid the discharge from your stoma, the more important the caulking compound is. Liquid effluent usually breaks down adhesives faster than solid. Note that urine is sterile right out of the body, and it is not caustic.

### **Which pouching system?**

Now that you know what size your stoma is and the importance of skin protection, let us discuss what type of pouching system you will be wearing. Maybe you are still wearing the same type you had when you were discharged from the hospital. This is perfectly okay if you are comfortable with it.

If you are not happy with that type of pouching system, decide what it is that you do not like and try finding another type that is more compatible with you. Take advantage of the great variety of products on the market.

Sometimes it makes a difference where your stoma is located to determine the best pouching system for you. Remember, you are trying to find what will best fit into your lifestyle. You can listen to your doctor and nurse's advice as a guide, but you are the one wearing it. You should be as comfortable as possible. Find what will best fit into your lifestyle.

Most people with an ileostomy wear drainable one-piece pouches, whereas most people with colostomies wear two-piece closed pouches. These all come in different lengths, shapes and materials. Shorter pouches are better for shorter people so the end of the pouch does not rest in an uncomfortable position. Most people in America prefer an opaque pouch material or color, one you cannot see through. (In Germany, people want the clearest pouch they can find.) Also available are pouch covers or "necessities" which are actually underwear to conceal the pouch, and prevent it from adhering to your skin or causing perspiration underneath it. Some people swear by pouch covers. Others have no use for them. Take the time and trouble to find what is most comfortable for you.

Some people like to wear closed end pouches. These are closed off at the bottom, and when they are a third full are usually disposed of and replaced, or emptied and snapped back on. Closed pouches may be supplemented with liners, which reduce the cost of replacing them. Most people find it convenient to wear disposable ostomy systems. Some like to use a mini pouch for special occasions or intimate moments. Unless you have good control of a colostomy irrigation, a mini pouch is designed for short-term use; e.g., for swimming, sexual relations or working out in the gym. A new development has taken place over the last few years. More and more people are using the smaller pouches on a regular, daily basis. They have a sporty look to them and are less intrusive to wear.

### **Can I switch pouching systems?**

A two-piece system is available for anyone to use. These enable you to change the type of pouch you are wearing without removing the adhesive barrier each time. You would also be able to see the health of your stoma more easily. In addition, a two-piece ostomy system utilizes a small flange that protrudes from the barrier. This helps protect the stoma from some injury. Remember, you want to select equipment that best fits into your lifestyle. You want it to be compatible with your activities.

Some people use one- and two-piece system. They change between these because of different activities in which they are engaged, or just for something different. In fact, some people even alternate between manufacturers every time they change their skin barrier to keep the peristomal skin from becoming allergic to one brand. In addition, if you are

able to use more than one system, you are not as dependent on a particular manufacturer making your particular system. They do modify product lines ever so often. You want to anticipate this.

### **Do I need a support belt?**

Any abdominal surgery cuts through abdominal muscles and may weaken them. Peristomal surgical support belts are available in different widths to accommodate different needs. Some people like to wear a support belt for physical activity such as bowling, gardening, working out in the gym or performing physical labor on the job.

Such a belt can help prevent complications, provide support for a peristomal hernia or provide abdominal support just for comfort. Support belts come in 1-, 3-, 4-, 6- or 9-inch widths. They are elastic, fasten with a Velcro like material and have an opening cut especially to fit around the ostomy pouch. Most people with ostomies do not wear belts anymore. They are still made for special situations and needs. Discuss this with your WOC nurse. She will be able to help you determine if a support belt will be of benefit.

### **Peristomal hernias**

A few words about peristomal hernias . . . developing a hernia around the stoma is a common complication because of the necessary weakening of the abdominal muscle. This occurs when the surgeon cuts these muscles during surgery. Even with the newer laparoscopic procedures, the stomach muscles are weakened. The area particularly vulnerable is where the surgeon pulls the intestine through the abdominal wall. Such a hernia is characterized by a large bulging around the stoma. If in doubt about whether you have developed a hernia, check with your doctor or WOC nurse.

Remember, after any type of surgery, the best way to avoid complications is to exercise. When you are able, begin walking two or three times a day. Start out slowly under the advice of your doctor. Gradually build up the distance you walk. Six to nine months after surgery, start other abdominal, arm, leg and body muscle building exercises. Never strain yourself. You will not only gain strength, look good and feel healthy but you will reduce the risk of hernias.

Muscles repair faster and better than fat does. There are health professionals to advise you in this area. Use their help. This is a very important issue. Many problems are caused from lack of physical activity. Eliminate them... exercise.

### **Stomal prolapse**

Another complication is a prolapsed stoma. This happens when the stoma keeps protruding more and more from the abdominal wall. It looks like it is actually growing. It is falling out of the body. It does not hurt because the stoma has no feeling. It is harder to manage because the pouch must be maneuvered more carefully to be applied. As with a peristomal hernia, a prolapse can be cured only by surgery.

It may be contained where additional damage is slowed and is less uncomfortable by wearing a peristomal support belt. Usually, wearing such a belt in this case will increase your comfort. The surgery requires that the doctor repair the tissue around the stoma and rebuild it. This sometimes can be done at the same site. Very often, the stoma must be moved to the other side, lower, or in extreme cases, higher. There are stomas almost to the rib cage. These are very difficult to manage.

### **Summary**

It is test of character. Having an ostomy is not easy, yet it is not really hard. The most difficult part of the surgery is psychological adjustment. If you are able to muster the strength of character to accept your body, then you will have the best attitude to attack the physical issues with more success. Be happy. You've been given a new life.

### **Check Us Out On The Web**

[www.ostomymcp.cpom](http://www.ostomymcp.cpom)

### **Other Websites Of Interest:**

United Ostomy Association of America: [www.uoaa.org](http://www.uoaa.org)

Your Ostomy Community Connection Center: [www.c3life.com](http://www.c3life.com)

## Ostomy Chat Room Weekly Meetings

Yahoo Peoples with Ostomy2\* - Mondays, 8:00 pm US Central time  
<http://clubs.yahoo.com/clubs/peopleswithostomy2>

Community Zero (Ostomy) Support\* - Wednesdays, 9:00 pm US Eastern time  
<http://groups.yahoo.com/group/ostomatessupport/>

Shaz & Jason's Chat\* - Saturdays, 8:00 pm UK time / 3:00pm US Eastern Time  
<http://www.ostomy.fsnet.co.uk/chat.html>

Yahoo UK Ostomy Support\* - 1st & 3rd Sundays, 8:00 pm UK time / 3:00 pm US Eastern Time  
<http://clubs.yahoo.com/clubs/ukostomysupport>

UOAA Chat Sundays 9pm ET / 6pm PT  
<http://www.yodaa.org/chat.php>

Use this form to join our chapter! You do not have to be an ostomate to be a member and/or support the work of UOA. All information on this form will be kept confidential.

Name \_\_\_\_\_  
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Address \_\_\_\_\_  
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City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
 \_\_\_\_\_

Phone# Home \_\_\_\_\_ Work# \_\_\_\_\_  
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Email Address \_\_\_\_\_  
 \_\_\_\_\_

Type of intestinal or urinary diversion: Colostomy \_\_, Ileostomy \_\_, Urostomy \_\_, Ileoanal Pull-thru \_\_  
 Continent Ileostomy \_\_, Continent Urostomy \_\_, None \_\_, Other \_\_

You may use my name in chapter Newsletter & Directory: Yes \_\_ No \_\_

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