

MORRIS COUNTY OSTOMY ASSOCIATION OF NEW JERSEY

AN AFFILIATE OF UNITED OSTOMY ASSOCIATIONS OF AMERICA

Does an Ostomy Qualify as a Disability? Support the Disability Integration Act

From Jeanine Gleba UOAA Advocacy Manager and Sue Mueller, BSN,
CWOCN, via UOAA April 2019 E-News

Does an ostomy qualify as a disability? This is a question that UOAA receives on occasion. You are living with an ostomy, you feel pride that you are independent with your ostomy care, that you are able to problem solve the glitches that arise, you have resumed your former activities and tried a few new ones...life is good. So it's confusing when you hear someone tell you that you qualify under the Americans with Disabilities Act (ADA) as having a disability. Perhaps you can walk and talk and see and hear and are independent with your care. You may envision a disabled person as someone who needs help with care, uses a wheelchair or a walker; someone obviously disabled. You do not have a visible disability, but not all disabilities are visible.

Well, elimination of waste is a major body function and your elimination of waste has changed; in fact you need to wear a prosthetic device (ostomy appliance) to manage this change. You have a record of an impairment of a major body function.

You are protected by civil and disability rights legislation such as the Rehabilitation Act of 1973, the ADA, Olmstead vs LS, case law and provisions of the Affordable Care Act. But because the institutional bias in service provision has not been eliminated and the services needed to support non-institutional living have not been created.

As a result, DIA [www.disabilityintegrationact.org] has been proposed in both the US House and Senate as a measure to end institutional bias and promote services in the community and extend the principles established in previous legislation.

An issue facing the ostomy community especially as they age is that most assisted living facilities (ALF) across our country will not admit someone with an ostomy or in the rare cases where they do, the ALF no longer needs to retain them once the individual can no longer perform self-care with emptying or changing their pouch. Once the door to assisted living is closed the only option is placement in a long-term care facility/nursing home.

It is a civil rights issue and is exactly what the DIA is trying to address. UOAA supports and advocates for this landmark legislation and encourages the ostomy community to take action at www.ostomy.org/take-action/ to help us garner legislator support and pass this in 2019.

Source: Ostomy Outlook of North Central OK

Summer 2019 NEWSLETTER

www.ostomymorris.org

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Principals of Ostomy Care

by Jan Colwell RN, MS, CWOCN, FAAN; in
Friends of Ostomates Worldwide (www.fowusa.org)
Newsletter, Spring 2019

Let's talk about the basic principles in ostomy care. The first and perhaps the most important principle: find a pouching system that provides a consistent wear time that maintains intact peristomal skin. So, what does that mean?

A pouching system should not leak from the time it is placed on until it is taken off or changed and this is called "wear time." Wear time varies from person to person with an ostomy. A group of people with an ostomy were asked how long they wore their pouching systems; the average wear time was at or about 4 days. But that is an average; some people wore their pouching system for 3 days, some for 5 days.

There are several items to consider when determining wear time. The adhesive or seal on the pouch is made out of a material called hydrocolloid. A hydrocolloid absorbs moisture over time and slowly loses the adhesive seal, causing the skin around the stoma to be sources, including from the skin from sweating and from the stoma output (the more liquid the stool the quicker the hydrocolloid absorbs moisture; the same happens with a urostomy).

So, what does this all mean? When the pouching system is removed it is important to look at the back of the pouching system adhesive to check for erosion or softening of the hydrocolloid. If the opening in the skin barrier is much larger than it was when it was placed on (i.e. erosion), the larger opening could allow the stool or urine to contact the skin and cause skin injury. It might be advisable to decrease the wear time by one or two days if erosion is present. Wearing the pouching system too long can also cause leakage, allowing the stoma output to get under the adhesive seal.

Another important principle is that the size of the opening in the skin barrier should be the same size as the stoma. The skin barrier opening should be at the junction of the skin and stoma to cover all of the skin around the stoma to prevent the stoma output from contacting the skin and causing injury.

Skin barriers are available with cut-to-fit stoma openings or (round) pre-cut openings in a variety of sizes. If the stoma is round the opening in the skin barrier should be round; if the stoma is oval the opening should be oval. There are some skin barriers that you can mold to fit, by stretching the skin barrier opening to fit the stoma.

It is advisable to periodically measure the stoma as stomas can change with weight gain or loss or just with aging. A third principle is that a pouch should not be allowed to be more than ½ full because the weight of the stool or urine can pull the adhesive from the skin, another cause of pouch seal failure

Effects of Using a Moldable Skin Barrier

From Maria Teresa Szewczyk, Grazyna Majewska,
Mary V. Cabral, Karin Hölzel-Piontek
in *Ostomy Wound Management*, 2014

Peristomal skin problems are the most commonly experienced physical complication following ostomy surgery and often are caused by leakage or a poorly fitting skin barrier. A prospective, multicenter, observational evaluation of persons with a colostomy, ileostomy, or urostomy was conducted to assess the incidence of peristomal lesions and level of patient satisfaction with moldable skin barriers.

During a period of 12 months, 561 patients from 90 centers in 3 countries were enrolled in a study of treating skin issues. Participants included 277 new stoma patients and 284 patients with an existing stoma who experienced skin complications using a traditional skin barrier (ie, a solid or flexible barrier with precut opening or one requiring cutting an opening to accommodate the stoma).

Among the many challenges faced by persons with a stoma is the risk of developing complications relating to the skin around the stoma. The majority of stoma complications are related to leakage, which allows effluent to come into contact with the skin. A skin barrier, which attaches the ostomy pouch to the abdomen, is designed to protect the skin from stomal output, but an ill-fitting barrier can allow effluent to come into contact with the skin, causing peristomal skin breakdown.

A person with a stoma who develops compromised peristomal skin can experience a vicious cycle of suboptimal barrier adhesion, continual leakage, and further peristomal skin breakdown. Accordingly, healthy peristomal skin is essential to achieving a secure seal between the barrier and the peristomal skin; conversely, a secure seal is essential to preventing leaks.

The study results found reduced leakage with use of the moldable skin barriers. From baseline to 2 months, the number of patients who reported leakage as the usual reason for changing the skin barrier decreased from 78.2% to 3.2% in persons with a colostomy, from 88.0% to 8.4% for ileostomy, and from 70.0% to 6.7% in urostomy patients.

The results of this study demonstrate moldable skin barriers are effective at maintaining and improving peristomal skin integrity. Comfort; ease of preparation, application, and removal; and reliability were scored high by the vast majority of patients. Moldable skin barriers may provide multiple benefits to new and existing patients.

I Am an Ostomate and I Can Do Gymnastics!

By Megan Herrett, Boise ID; via Inland NW (ID&WA) *Insider*

We'd like to introduce you to Maggie Herrett, a 10-yearold gymnast from Boise, Idaho who has an ostomy. Maggie was born with a rare liver disease, which necessitated an ostomy to eliminate bile from her body. When Maggie was 7 years old, she enrolled in a recreational gymnastics program and shortly after, was asked to try out for a competitive gymnastics team. Initially, the gym was concerned about her ostomy.

Through trial and error, Maggie learned some tips and tricks to keep her ostomy from interfering with the sport she loves so much. Because gymnastics can be a high impact sport, especially on her abdomen, she makes sure to empty her pouch multiple times during practice to avoid it from "popping." To stay hydrated, she uses Hydralyte tabs in her water – she loves the effervescence! She also recently discovered closed-bottom pouches – because there is no spigot or rolled closure, her pouch is seamless and you can hardly even notice it under her leotard!

Spending twelve to sixteen hours per week in the gym has paid off for Maggie. At the 2019 Idaho State Junior Olympics Gymnastics Championship, Maggie placed 4th on Vault, 3rd on Beam, 1st on Bars and Floor, and 1st place All-Around in her age group! WOW!!



And for the last three years, Maggie and her younger brother Winnie, also an ostomate, participated in the UOAA-sponsored Run for Resilience Ostomy event in Boise which was started and has been managed by their mother, Megan, with help from their father Matt. Lastly, Maggie will attend the 2019 Youth Rally (www.youthrally.org), a weeklong youth camp for children with ostomies, to be held in Seattle.

Source: Insights: Ostomy Outlook of North Central OK

OBJ Pouch Covers



I'd like to share news about our pouch covers for ostomates that are designed for intimacy. I'm hopeful they will help your members in their sex life since their design focuses on keeping the ostomy pouch out of the way during intimate moments. You can view them at www.objpouchcovers.com.

Our pouch covers utilize modern designs and a soft wide band to provide style and comfort for ostomates. An OBJ pouch cover holds the ostomy pouch in a horizontal orientation to keep it out of the way from the genitals area. The pouch remains hidden behind a stylish cover while not being a possible distraction during sex.

I know an ostomy pouch is nothing to be ashamed of, and as an ostomate myself (ileostomy in 2006 from Crohn's Disease), I owe so much to my stoma and pouch. But there are times when a dangling ostomy pouch isn't ideal, and for me, and likely for many other ostomates, this includes during sexual activity.

Brent Mitchell | Founder



UOAA National Conference
August 6-10, 2019
in Philadelphia PA

for more information
www.ostomy.org/2019-

[https://www.ostomy.org/2019-](https://www.ostomy.org/2019-uoa-national-conference/)
[uoa-national-conference/](https://www.ostomy.org/2019-uoa-national-conference/)

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.

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.

DUES

Dues for 2019 are now current. You may send a check or cash for \$20.00 to:

George Salamy
30 Wyckoff Way,
Chester, NJ 07930

Meeting schedule

Meetings start at 7:30 p.m. and end at 9 p.m.
in the Carol Simon Center
of the Morristown Medical Center.

JUNE 19, 2019
JEAN ROSONE, MSW
COORDINATOR ONCOLOGY SERVICES,
ATLANTIC HEALTH

JULY 17, 2019
RUBEN MERA
HOLLISTER REPRESENTATIVE

NO AUGUST MEETING

SEPTEMBER 18, 2019
JULIA WASSERBACK
COLOPAST REPRESENTATIVE

NOVEMBER 20, 2019
DETAILS TO COME

DECEMBER 18, 2019
HOLIDAY PARTY
SCHERING PLOUGH CONFERENCE ROOM
6:30 PM



MCOA

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