

MORRIS COUNTY OSTOMY ASSOCIATION OF NEW JERSEY

AN AFFILIATE OF UNITED OSTOMY ASSOCIATIONS OF AMERICA

Ostomy Awareness Day October 3, 2020

“Ostomates Unite and Help Place The Ostomy In A Positive Light! Celebrate UOAA’s Ostomy Awareness Day!” These were the words that were spread across the country when United Ostomy Associations of America (UOAA) announced the first National Ostomy Awareness Day on July 25, 2010. This year marks a decade of shining a positive light on lifesaving ostomy surgery. UOAA continues to sponsor this day annually in the United States by raising ostomy awareness and increasing national visibility for those living with ostomies. Ostomy Awareness Day is celebrated on the first Saturday of October, which coincides with World Ostomy Day every 3 years. This year, National Ostomy Awareness Day will be held on Saturday, October 3, 2020.

Awareness celebrations over the past 10 years have been created around several different themes including Bouncing Back into Life, Navigate the Journey Together, Speaking Out Changes Lives, and most recently Ostomies Are Life-Savers. UOAA also partners with like-minded patient organizations, such as the Crohn’s & Colitis Foundation, and medical professional organizations, such as the Wound Ostomy and Continence Nurses Society, with whom we co-host events such as Facebook Live events, Twitter chats, podcasts, and more to raise national awareness and remove stigma.

As in previous years, UOAA is also engaging the ostomy community in a number of ways and is excited to work with volunteers across the country to inspire, educate, and support people who have had or who may have ostomy or continent diversion surgery.

UOAA’s “Operation Ostomy - A Life-Saver” campaign continues to spread the message that we are saving lives one ostomy at a time. Please use our 10th Anniversary Ostomy Awareness Day logo for your profile picture on your social media accounts. We know you throw that life-preserver to your patients all the time! Use the hashtags #OstomiesAreLifesavers or #OstomyDay2020 and tag UOAA on Facebook @uoaa-inc, Instagram @uoaa_, or Twitter @uoaa.

Source: UOAA

Fall 2020 NEWSLETTER

www.ostomymorris.org

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Critical Legislation And How It May Impact Current Admission Regulations To Assisted Living Facilities

by Daphne Gregory-Thomas

Though many of us are on UOAA'S mailing list, some may not have received or realized the importance of the communications that were sent last year regarding proposed Federal Legislation for The Disabilities Integration Act (DIA) (S117/HR555). Though this legislation would provide protection for all people with disabilities in many areas, it directly relates to protection regarding options for and potential discrimination against ostomates and their admission to assisted living facilities (ALF's). Though this legislation is bi-partisan and was first introduced in the 114th Congressional session (2015-16) it is has been stalled in committees and not seen movement in either the House or the Senate. Attached is a one-page infograph on how legislation is passed, and, thus, how this legislation is being addressed. Here is a link to the actual description of the Act.

<https://adapt.org/wp-content/uploads/2019/01/DIA-Bipartisan-one-pager.pdf>

Though UOAA is not listed on this description, they are listed on the DIA website.

www.disabilityintegrationact.org

Also, I have attached to this document the official UOAA position statement on this matter.

The purpose of the bill is to ensure that people with disabilities have a right to live and receive community care services in their home and to prevent forced institutionalization, thus precluding them from more moderate levels of care needed such as in ALF's.

In order to get an update on this legislation and current issue, I contacted Jeanine Gleba, Advocacy Manager for UOAA, and she provided the following information regarding this issue.

- 1) Currently, assisted living facilities are regulated within each state; there is no universal language or definitions among the states; there is variance in services such as what must be offered, or may be offered and many states let the facilities decide what they will offer. All states are very clear that all facilities can refuse admission to anyone whose needs cannot be met by the facility. So if a facility doesn't want to provide ostomy care, they don't have to.
- 2) Understandably, the big issue facing our community, especially as they age, is that most assisted living facilities across our country will not admit someone with a stable 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. We believe that emptying and changing a pouch does not require skilled care, but rather is a simple activity of daily living that should fall under toileting assistance/hygiene.
- 3) All states have different regulations regarding this issue. In terms of New Jersey, nowhere is having an ostomy mentioned in terms of admission or denial of admission to an ALF, thus making it an arbitrary decision for the ALF.
- 4) So how does this all relate to the DIA? The DIA specifically states maintenance and use of a stable ostomy is a health-related task that is NONACUTE. Many ALFs don't accept patients with an ostomy

because it can arbitrarily be considered a need that is “invasive” and requiring institutional care in a skilled nursing facility, thus denying us the right to choose an ALF. DIA would ensure that folks could not be prematurely forced into nursing facilities because they couldn’t get assistance with health-related tasks. Once the legislation passes, each state would need to address this part of their transition plan. So, an individual who needs help with a stable ostomy but not be at the institutional level otherwise would most likely be able to get it. That would appear to mean the rules would change for people in or going into ALF’s and they could not be forced into a nursing facility.

5) Key definitions in the proposed DIA legislation state the following:

“health-related tasks” means specific NONACUTE tasks such as

(A) administration of medication;

(B) assistance with use, operation, and maintenance of a ventilator

(C) maintenance and use of a gastrostomy tube, a catheter, or a stable ostomy

Thus, the bill has the potential to provide protection for ostomates from being denied admission to an ALF based solely on their ostomy. When the bill passes, people will need to advocate for this as a part of the transition planning process in each state. Even once a law, there is still work to be done. It is important that we make our voices heard regarding this legislation. UOAA has encouraged us to reach out to our representatives in Congress using the link below. It has a form letter embedded into it that can be used or you can write your own letter to send using the link. You can share this with family and friends both in New Jersey and in other states. Perhaps you can encourage them to support you by having them send the letter to their congress representatives as well.

<https://www.votervoice.net/mobile/UOAA/Campaigns/64060/Respond>

You can also access the UOAA Action Center to achieve the same thing. Here is that link.

<https://www.ostomy.org/take-action/>

Here is the form letter:

As a constituent living with an ostomy, I am writing to request that you please support S117/HR555 (DIA). The Disability Integration Act ensures that any individual who is found eligible for institutional placement is also given the option to receive crucial services and supports at home or in the setting of their choosing. States and insurance providers will be required to cover home and community-based services so people with disabilities can accomplish their activities of daily living - such as eating, bathing, medication management and housekeeping - and health related tasks such as management and care of a stable ostomy outside of an institutional setting.

In addition to allowing disabled people to lead independent lives, these home and community based services will save taxpayer dollars when compared to the cost of institutional settings. Most importantly, these services will ensure that people with disabilities in the U.S. can exercise the liberty that is the birthright of all Americans.

As my elected official I urge you to sign-on as a co-sponsor and if you already have, I thank you for your support and hope you continue to push for passage of this ground-breaking legislation with your colleagues. Please let me know your support.

Less Is More—Are You Using Too Many Ostomy Supplies?

by Lauren Wolfe RN, BSN, CWOCN;
via Vancouver (BC) *Ostomy HighLife* January 2020

Pouches, barrier rings, adhesive removers, adhesive sprays, ostomy powder, skin prep...I could keep listing products that could be used to manage your stoma. The big question is; do you need to be using all these products?

When it comes to your skin and stoma you will find that most stoma nurses (WOCNs) have the philosophy that less is more. What this means is that you only need to use products that ensure you don't experience a leak and your skin remains healthy. Using many different accessories can cause confusion when you experience a problem and sometimes may even cause problems.

Problems can be skin reactions, your pouching system not adhering causing leaks or decreased wear time. Even the simple fact that you may be complicating your change using too many added products. A change that could be 5-10 minutes is taking more than 30 minutes. On another note, accessory products can be expensive and if they are not helpful to you then best not to use them.

So, when do we use accessory products?

Adhesive removers are designed to help remove the pouching system without causing trauma and skin tears to your skin. They also help to remove any sticky residue that may be left on your skin after removal of your pouching system. I find that the spray works well to remove the pouching system and the wipes help to remove any left over barrier from the skin.

Skin Preps: In the past, everyone was advised to use skin preps to help keep your skin healthy and ensure the ostomy wafer/baseplate/flange adheres to your skin. In recent years, with the advancement of technology, the barrier composition allows for the barrier to adhere directly to your skin without using skin prep. In fact, using skin prep can decrease how well the barrier adheres to your skin. Skin prep is commonly used with stoma powder when treating denuded/raw skin by following a "crusting" procedure until the skin is healed.

Ostomy Powder: Similar to skin prep, ostomy powder was used for many years as part of the application process for ostomy barriers. In fact, the

ingredients in Ostomy powder are similar to the wafer/flange, the goal being to absorb moisture. Unless you're extremely sweaty, I would suggest forgoing the powder and seeing how your ostomy flange adheres to your skin; you may be quite surprised.

Barrier rings: These serve a very important function. They can help to fill in creases or dips and valleys in your abdominal contours or, for some, they can add to the wear time, allowing for less frequent changes. However sometimes, as your stoma settles down post surgery, it may be worth discussing with your WOCN whether you need to use a barrier ring or not. In my experience, I often use them if you have an ileostomy but for colostomy and urostomy I may try to see if we can remove them.

Ostomy Belts: Ostomy belts provide added support for the pouching system at 3 and 9 o'clock, i.e., on the sides. It is not uncommon for people who have a challenging stoma to need to use an ostomy belt to add more support to prevent a leak. For some, it is also peace of mind that the appliance will stay on or perhaps it helps with the weight of the pouch if it's a little too full when a bathroom is not nearby.

Barrier extenders / Adhesive tape barriers: This accessory product is new to the market and has a place for some individuals. I tend to recommend it for people who are using a smaller flange and need to increase the surface area if they are perhaps a larger person. Another use is to provide peace of mind when showering or swimming by adding an area of water resistance to the edge of the flange. For some people, it's just a comfort helping to prevent a leak. However, from a WOCN perspective, these DO NOT prevent a leak; they camouflage a leak, as a leak starts immediately around the stoma. By the time it reaches these barrier extenders, your pouch has been leaking for a while causing potential skin damage.

In conclusion, if you are unsure if you need to be using all the accessories, see your WOCN and discuss what you need and what may be nice to have. Less is best; our skin is sensitive and we do not need to use more products than necessary.

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 2020 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.

However, because of Covid-19 social distancing the meetings will be online via Zoom until further notice. They will still take place on the third Wednesday of the month, starting at 7 p.m.

Announcements will be sent to all MCOA members on our email list. Members just have to click on a highlighted URL to join the meeting.

SEPTEMBER 16-ERIN MACKLIN, EDGE PARK
OCTOBER 21-PAMELA GIORDANO,
PHARMACIST AT ATLANTIC HEALTH
NOVEMBER 18-JEAN MARIE ROSONE,
INTEGRATIVE MEDICINE AT ATLANTIC
HEALTH



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