Challenging Health Stigma

Individuals often worry about the stigma that could result when others find out about their incontinence. From the very first days of The Simon Foundation for Continence’s founding in 1982, and throughout the years since, we have observed the many ways that stigma impacts those with incontinence and often delays the acceptance of incontinence as a medical condition just like decreased vision, hearing loss, cancer, and the hundreds of other conditions that attract stigma. We have also seen stigma impact the work of nonprofits that address incontinence, and even the industry working to produce products and devices for incontinence.

For example, when the first attempts were made by manufacturers to advertise absorbent products on television, the networks would not accept these advertisements. The companies were forced to retrench and begin their advertising campaigns by purchasing air time on local stations, market by market, across the country. During that same timeframe, AARP refused to accept print advertisements and even educational articles about loss of bladder and bowel control. When a representative of the Foundation sat down with their then president, we were told the reason for this policy was that they wanted to keep an upbeat image of aging and loss of bowel and/or bladder control was inconsistent with that image.

When the Foundation established an 800-line just prior to our president beginning a 20-week media tour to promote Managing Incontinence: A Guide to Living with Loss of Bladder Control (the first book ever written for the public on incontinence), we ran into many of the same challenges. Radio and television station program directors thought the topic was either not of interest to their audience or too sensitive to talk about. And although the phone rang constantly during the tour, it was not just orders for Alzheimer’s and Incontinence

Alzheimer’s disease is the most common form of dementia and affects an estimated 5.3 million Americans according to the U.S. Centers for Disease Control and Prevention (CDC). Alzheimer’s destroys brain cells causing loss of memory, trouble thinking, and changes in behavior. It is the fifth leading cause of death for people over age 65 in the U.S.

The CDC also notes that 80% of those affected are cared for in their homes and that 15 million Americans provide more than 17 billion hours of unpaid care, 62% of caregivers are women, and 23% themselves are 65 or older. Those caring for people with Alzheimer’s provide care for longer than caregivers of other diseases. According to the Alzheimer’s Association, family caregivers are providing care with an economic value of over $200 billion.

The cost of Alzheimer’s goes far beyond these statistics to the human toll it takes on the family caregiver and the entire family. The demands of care giving cause a greater risk for anxiety, depression, and poorer quality of life than caregivers of people with other conditions.

The three descriptors that are most often used to describe the caregiver’s life are isolation, frustration and exhaustion. According to Joy Spahn, regional director of the Alzheimer’s Association Greater Michigan Chapter (quoted in The Grand Rapids Press): “An older adult that is caring for another with Alzheimer’s has a 60 percent chance of dying before the person they’re taking care of because of the stress.”

Due to the nature of the progression of the disease, care giving is a long and changing journey of challenges. A 2018 Fact Sheet published by the Alzheimer’s Impact Movement (the advocacy arm of the Alzheimer’s Association) states that about one-third of caregivers deal with Alzheimer’s and Incontinence continued on page 2...
books or requests for information (the purpose for which it was established) that the callers wanted. We also received nasty comments and even threats for using the public airwaves to talk about what some callers felt was a private, taboo topic that should be kept in the closet.

Years later, the challenges of stigma remain as revealed in a 2015 online survey conducted by the Foundation. When asked to rank the top most stigmatizing health condition from a list of 30 choices, the 1,200 respondents ranked bowel incontinence 4th and urinary incontinence 8th. Motivated by the ranking of incontinence, knowing that many other conditions were also severely impacted by stigma, and propelled by insights from a targeted think tank, the Foundation took a bold and disruptive step by creating a program that would focus attention on a broad range of stigmatized health conditions. The Simon Foundation for Continence launched Rude2Respect: Challenging Health Stigma (rude2respect.org).

Having been guided for over three decades by the simple but challenging mission statement: "to bring the topic of incontinence into the open, remove the stigma associated with it, and provide hope and help to individuals with incontinence, their families, and the health care professionals who provide their care" we felt it was time to broaden our approach and fight stigma itself and place incontinence (prominently) among the many health conditions that attract the ignorant and bad behavior we experience as stigmatization. The approach also had the advantage of building a wide coalition of individuals and advocacy organizations that might pool their energy to change public behavior.

Thus from the beginning of our work on health stigma, it was intended that the Rude2Respect: Challenging Health Stigma program be widely shared and in November of 2017 we began this effort by hosting the first Health Stigma Summit.

The invited delegates were executives from various nonprofits that address health challenges our survey had shown were highly stigmatized. The Simon Foundation for Continence launched Rude2Respect: Challenging Health Stigma (rude2respect.org).

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The invited delegates were executives from various nonprofits that address health challenges our survey had shown were highly stigmatized. Delegates represented people with: hearing loss, mobility challenges, alopecia, scleroderma, gastrointestinal disorders, HIV, Hep C, loss of vision, facial disfigurement, ostomies, addiction, incontinence, COPD, chronic pain, dystonia, Sturge Weber, MS, spinal cord injury, Spina bifida, dwarfism, epilepsy, liver disease, and fistulas, to name a few. In all, 40 nonprofits were represented.

Two hours into the meeting it was clear what those working on Rude2Respect had believed all along—that we are better advocating together against health-related stigma, and that the stigma experience itself is amazingly similar once the first layer of the onion is stripped away (i.e., the particular health challenge). The Summit’s program featured speakers from England and Canada who deepened the delegates’ awareness of the components of stigma, examined the impact of health-related stigma, and explored existing efforts that have been shown to lessen the stigma around specific health concerns. A powerful panel of individuals with various health conditions (both apparent when meeting them and hidden from view) shared their stories of how they’ve been stigmatized and how they handle the ever intrusive situations that pop up in public interactions with their fellow humans. Not only did the panelists drive home stigma’s impact, but also profoundly illustrated that the ways in which people are stigmatized are strikingly similar.

The first Summit was a beginning. It provided the Foundation with a wonderful opportunity to showcase the initiatives that are already underway; to share the vision for the future of Rude2Respect; and to build broad and strategic alliances. If you, or someone you know, or an organization you work with would like to be part of the next Health Stigma Summit you can contact us at info@rude2respect.org. We need to grow this effort together. Begin by visiting rude2respect.org and take the time to tell us your story.
Alzheimer’s and Incontinence
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incontinence. Incontinence, combined with Alzheimer’s, creates a host of challenges. All Informer readers who experience intractable incontinence will well understand the potential stress that incontinence may add to care giving with challenges like loss of sleep, compromised skin, additional laundry needs, and when needed, the cost of absorbent management products.

Advocates for people with Alzheimer’s warn not to assume incontinence is the issue prior to exploring other possible reasons for “accidents”. Among the other causes: inability to find or recognize the bathroom, difficulty communicating the need for a bathroom, an undetected urinary tract infection, side effects of medications, or inability to undo clothing quickly - and some have just given up because they haven’t received the help they need.

There are many changes in the home that can be made to help. Some find that leaving the door to the bathroom open and a light on at all times serve as an adequate reminder of the toilet location. A picture on the door, or painting the door frame a different color can also help, as can a clear path to the bathroom marked with reflective tape.

Once inside the bathroom, there are also changes that should be made, including installing hand rails, being sure the locks can be opened from the outside or disabling them, and putting lids on wastebaskets and other containers that can be mistaken for a toilet.

People with Alzheimer’s have difficulty recognizing things and seeing the depth of an object, thus making the toilet seat a different color from the surroundings will also help. It is suggested that black and red are the easiest colors for someone with dementia to recognize.

There are many criteria that should be considered when seeking the right absorbent product for incontinence management - sufficient capacity to provide many hours of protection to allow uninterrupted activity (sleep, shopping, family activities, etc.); protection from risks to the skin caused by friction, heat, wetness, unbalanced pH; comfortable design; and fit that protects from leakage (thus avoiding the cost and labor resulting from wet bedding and/or wet clothing).

Mistakes that seem to be common include selecting a product on price alone (without considering important attributes such as absorbency and fit) and not searching beyond the drugstore or big box stores as often home health stores will carry different and more absorbent brands. You can find useful information regarding products and devices at the Foundation’s website www.continencecentral.org.

Resistance to disposable products is not uncommon. The person with Alzheimer’s may react poorly to the introduction of wearing a product because they do not understand the need to manage their incontinence. One Alzheimer’s website suggests placing the products in the underwear drawer and removing the regular underwear.

Perhaps one of the most important resources for those caregivers helping someone with Alzheimer’s is information about respite care.

Respite care is nothing complicated. It is simply breaks from care giving duties, which can help to ward off burnout. It can be provided in home by family and friends, or from a senior care aide, or outside the home at facilities such as adult day care centers, nursing homes, or a local hospice.

An advantage of respite care not often considered is it will help those being cared for to acclimate to having a different caregiver if unexpectedly the usual caregiver is unable to provide care.

The length of respite care varies depending on need and can be as short as two hours for lunch out with a friend, or a long weekend, or even a week’s vacation.

The path of Alzheimer’s disease, although filled with challenges, has opportunities for joy and sharing with loved ones, too. Knowledge gained from the numerous resources to smooth this path can be of immense help.

Consider visiting the websites of organizations that offer care giving tips and information (see resource list below); planning for regular respite breaks; and not hesitating to ask for help when needed. As stated by one caregiver, “The care you give to yourself is the care you give to your loved one.”
Understanding Your Bowel

When the bowel misbehaves, stool and/or gas may leave the body at inappropriate times, called incontinence. Bowel incontinence (BI) may create circumstances that can profoundly change an individual’s quality of life. Nearly 18 million adults in the United States experience loss of bowel control. It occurs in about 6 percent of women younger than age 40 and increases to 15 percent of women aged 40 and older. Around 6 to 10 percent of men have BI, and its prevalence increases slightly with age in men. For older people who develop BI, it can often result in their being institutionalized in a nursing home. The overall prevalence rate for BI in nursing homes in the United States is 45 percent.

Causes for loss of bowel control
There are several known causes for BI. Among them are:

- Damage to the anal sphincter muscles
- Storage capacity loss in the rectum
- Chronic diarrhea
- Diseases or conditions of the small or large intestine
- Pelvic floor disorders
- Constipation
- Neurological disorders

Loss of bowel control is not a normal part of aging, nor is it untreatable. Like all types of incontinence, it will not go away if it is ignored. It is always important to know the reason for incontinence due to the slight chance that incontinence is an indication of something else going on in the body. A specialist will ask your many questions and also do a physical examination. Some of the tests that may be ordered in order to obtain a diagnosis include: digital rectal examination, anorectal manometry, rectal compliance test, MRI, EMG, flexible sigmoidoscopy or colonoscopy, and ultrasound of the anal muscles.

Treatments
There are many possible treatments and ways to manage BI depending upon its cause. The treatments listed here may or may not be appropriate for your situation. In some cases, a combination of treatments may be what is needed. All of these should be used on the advice and direction of your personal healthcare provider.

1. Bowel training – used to develop predictable times to have a bowel movement. The approach may take time to work, and persistence is key.

2. Bowel retraining – a technique for those with frequency and urgency that involves the practice of holding and waiting once you feel the urge (best started while on the toilet and you may only be able to hold or wait for a second or two to start). Like bowel training, it takes time and persistence to learn this approach. Coaching from a healthcare provider or both bowel training and retraining will also help.

3. Pelvic floor strengthening exercises – strengthening the pelvic floor through correctly and regularly done exercises may help. Just like any strengthening program, to keep any positive changes you must continue to do the exercises. Physical therapists often are helpful in teaching you how to do these exercises properly, and can help monitor your progress.

4. Biofeedback and electrical stimulation – if your anal muscles are very weak, it may be very helpful to include biofeedback with or without electrical stimulation as you exercise and gain strength in your pelvic floor and your anal muscles. Biofeedback also helps you improve awareness of sensations in your rectum, helping you coordinate the squeezing of your external sphincter muscle with the sensation

5. Suppositories and enemas – these are used to help start the rectum to empty at a convenient time for you.

6. Laxatives – these may be recommended to help develop a more regular bowel pattern.

7. Antidiarrheal medications – these are prescribed to slow down the bowel and help with control.

8. Bowel irrigation – is when water is introduced into the bowel via the rectum, using a rectal catheter. The water stimulates the bowel and flushes out the stool. After irrigating, the lower part of the bowel is empty.

9. Manual evacuation – if you have a neurological condition where your rectum cannot empty on its own, a gloved, lubricated fingertip might be used to gently help the stool out.

10. Surgery (some of these procedures are done in a hospital, while others can be done in a surgeon’s office):
   a. Sphincter repair – surgical repair of the anal sphincter may be appropriate for people who have not responded to non-invasive therapies who have had an injury to the pelvic floor, or anal sphincter
   b. Sacral nerve stimulator – small electrode implant that provides continual nerve stimulation to help provide bowel control
   c. Sphincter bulking agents – injection of a bulking agent (collagen is an example) in the anus to bulk up the tissue around the anus
   d. Artificial anal sphincter – placement of an inflatable cuff around the anus and implant of a small pump beneath the skin that the person activates to inflate or deflate the cuff
   e. Stimulated graciloplasty – placement of an implanted pacemaker. The patient uses an external device to switch off the pacemaker when it is time to have a bowel movement or expel gas.
   f. Colostomy or bowel diversion – the surgeon creates a stoma (artificial opening) on the surface of the

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Simon Launches Online Support Community

Self-help groups can be found for every disease listed by the World Health Organization. Within these groups, individuals share down-to-earth, experience-based insights gained from first-hand exposures to the same situations. However, attending a group can be problematic for many. They may reside in a large city where commuting to the meeting site means an hour in each direction, or in a small town where they fear being seen by neighbors when they prefer to keep their health condition private; or they live in a rural community that doesn’t offer the option of attending a group. These examples and other challenges that prevent individuals from attending a self-help group need no longer prevent someone from getting the help they need to better cope with incontinence. The Simon Foundation for Continence is excited to offer people with incontinence a new online alternative.

In April 2017, the Foundation launched its first online support community for people with incontinence. Our support community is located on HealthUnlocked at healthunlocked.com/simonfoundationforcontinence. HealthUnlocked is a free, social network platform for many different health conditions. By finding others with similar health backgrounds, people can take on day-to-day health concerns together. And because all the communities are set up and continually monitored by leading health organizations, people have access to credible and safe support.

HealthUnlocked provides a peer-to-peer support network of patients, caregivers and health advocates (like the Simon Foundation for Continence) that are connected safely and anonymously online with guidance from credible sponsoring organizations and institutions. People are able to talk about their individual experiences of their conditions. They discuss symptoms, treatment options, and the health services available for their particular health condition. Information is catalogued in an intelligent database, which signposts relevant content to people based on their profile. 2.5 million experiences have been shared and many more are created every day.

Almost 7 in 10 patients on HealthUnlocked report they had never spoken to another patient with the same condition before coming to its platform. 91% say their interactions have been useful or life changing and 87% state they now feel more confident when speaking to healthcare professionals.

There are over 500 patient advocacy organizations (PAC) on board HealthUnlocked. It is the biggest network for advocates in the world. The Simon Foundation for Continence is happy to be able to provide this safe and supportive community for all with incontinence. Caregivers (those at home and professionals) can also find help in this manner.

Each month the number of people in the incontinence community grows, and more posts and sharing follow. We are providing an environment where all feel free to share and discuss incontinence with those who understand them best. Please visit and become a part of the community!

Understanding Your Bowel

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abdomen. A portion of the bowel is removed and the “new” end is reconnected to the stoma opening. When the stool leaves the body it is collected in an external pouch. This surgical procedure is used only for severe cases and when all other treatments have failed. A colostomy can be temporary or permanent.

11. Diet changes – what you eat can affect how soft or hard your stool is. Eating foods that are high in fiber (fresh vegetables, whole grains, etc.) may help add bulk to stools that are too loose or watery. Add extra fiber to your diet slowly to allow your body time to adjust. If your stool is already well-formed, adding fiber may act as a laxative and make your situation worse. Foods that tend to worsen bowel incontinence, because they speed transit of stool through the bowel, are: coffee, tea and chocolate. Some people find that spicy foods, onions, citrus, and dairy products, cause problems. You may find that eating smaller meals more frequently will help. It is important to include water in your diet to help prevent constipation. Be sure not to remove important vitamins and minerals from your diet, and discuss with your physician when it might be important to then take a supplement.

12. Weight control – recent studies are showing an important role in weight control in reducing the symptoms of incontinence. If you are overweight, discuss a sensible and nutritious weight loss program that may help lessen your symptoms.

Changes that require immediate medical attention

There are certain changes in your bowel that require medical attention quickly. Make an appointment with your healthcare provider if you have any of the following symptoms: blood or color changes in your stool; changes in shape or size of your stool lasting over two weeks; undigested food in stool along with diarrhea or unexplained weight loss; and foul-smelling stools that are accompanied by other symptoms like color change, mucus, fever, pain and/or weight loss.

Join a clinical trial

Watch for news of new treatments and management options that can improve your quality of life. You may also be interested in learning more about clinical trials. Clinical trials are research studies that look at safety and efficacy regarding new ways to prevent, detect, or treat disease. They also may study other aspects of care, such as quality of life issues.

To learn more about clinical trials, why they matter, and how to participate, you can access the NIH Clinical Research Trials and You website at www.nih.gov/health/clinicaltrials and for information on current studies access www.ClinicalTrials.gov.
The Bladder Health Alliance is a coalition of 30-plus organizations that have a shared interest in making sure the American public has access to current, accurate information on the different conditions and diseases that impact the urinary system.

The Alliance began in 2014, and a short two years later the group's efforts paid off with a major achievement - a Congressional declaration of November as Bladder Health Month in the USA.

The group worked together in November 2016 on its first initial national response using social media and website posts that provided a wide variety of information on different bladder symptoms and diseases.

Again in November 2017, the Alliance provided resources and information to the public via Facebook, Twitter and websites on interstitial cystitis, neurogenic bladder, bladder and urinary tract infection, bladder cancer, incontinence, bedwetting and nocturia. The Simon Foundation for Continence participated in providing information on these topics on its Facebook page and also in their new online support community on HealthUnlocked. Information on Congressional budget, and health care legislation that would negatively impact our constituents.

Beth LaGro, the Foundation's VP, represents the Simon Foundation for Continence, and the people with incontinence we serve, at all Alliance meetings. The Bladder Health Alliance is only one example of the many ways that the staff at the Simon Foundation for Continence work tirelessly to enhance the lives of people with incontinence. Ms. LaGro is also active on several other coalitions to represent the product and research needs of people with incontinence including the ITEM Coalition, the Access and Care Coalition, Friends of NIDDK, and the Urology Policy Forum.

Above - Bladder Health Alliance members learn about health care legislation at each meeting.

Below - Bladder Health Alliance members at the American Urological Association headquarters in Maryland, October 2017.
Getting to Know Us...

**Cheryl B. Gartley, Founder and President.** Ms. Gartley is a widely published author with articles in journals such as *The Lancet*, *Urologic Nursing*, *Journal of Clinical Psychology in Medical Settings*, *EP (Exceptional Parent)*, and *Social Work Today*. Articles about the Foundation and her work have appeared in *Time Magazine*, *Good Housekeeping*, and the *Ann Landers Column*. She has traveled extensively in Europe, Japan, Australia, New Zealand, Canada and the USA on behalf of people with incontinence where she presents keynote addresses and has appeared on hundreds of radio and television talk shows, including networks shows such as ABC’s 20/20 and Good Morning Australia (Sydney).

**Elizabeth A. LaGro, MLIS, Vice President of Communications and Education Services.** Ms. LaGro received her Master’s in Library and Information Science from Dominican University. She represents the Foundation at meetings and conferences, speaks and writes to people with incontinence, is the webmaster of - and creates content for - all of the Foundation’s websites and Facebook pages, and represents the Foundation on several patient advocacy coalitions. She is a member of the International Continence Society (ICS). She is a new and ongoing contributor to the journal, *Ostomy Wound Management*. She came to the Foundation in 2009 after 30-years of experience with a global medical device company that develops continence, ostomy and wound care products.

**Twila Yednoch, Director of Special Events.** Ms. Yednoch has traveled throughout the United States representing the Foundation at numerous conferences and meetings as an exhibitor, including annual meetings of the American Urological Association (AUA), Wound Ostomy and Continence Nurses (WOCN), Society for Urological Nurses Allied (SUNA) and the American Urogynecologic Society (AUGS). She has represented the Foundation at International Continence Society (ICS) meetings. Ms. Yednoch is a key part of the preparation and execution of each Innovating for Continence biennial conference meeting since its inception and is the onsite coordinator for each meeting. In 2015 she also participated in the meeting as a panelist.

**Susan Hayward, BS, MS, PCC, Special Projects Manager.** Ms Hayward is the first certified Life Coach to be trained as a Continence Coach. She piloted a Continence Coaching program for the Foundation in 2013. She coordinates and participates in the Abstract review process for the Foundation’s Innovating for Continence biennial conference and in 2015 was also a workshop speaker (How We Think and Draw Conclusions) at the conference. She serves as a meeting facilitator for special meetings of the Foundation, and speaks daily with people seeking information and help in regards to their incontinence. Ms. Hayward is fluent in Spanish, and spent 11 years in Columbia, South America.

**Bridget Bean, Administrative Assistant.** Ms. Bean is a graduate of Kendall College with a BA in History and American Studies. In addition to running the day to day operations of the office, she also provides support for the Foundation’s many Conferences, Think Tanks, and Summits. She has many years experience in administrative work, including working in this capacity at a high-paced Chicago commodities firm and at the first mail-order women’s clothing firm. However, her passion is bringing her organizational skills to the nonprofit world where, when we are not keeping her busy, she spends her free time volunteering for various local causes.
The Simon Foundation for Continence
is dedicated to:

- Bringing the topic of incontinence out into the open
- Removing the stigma surrounding incontinence, providing help and hope for people with incontinence, their families, and the health professionals who provide their care.

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