Managing Life with Incontinence

Medical science is gradually catching up with the intricacies of the workings of the human bladder and bowel. There are an increasing number of possibilities for breakthroughs in the future as research progresses. However, until a cure is available for everyone there are millions of people who not only live with the daily challenge of managing their leakage, but also struggle as to how to manage a life that can end up being governed by incontinence.

Managing Life with Incontinence, a 232-page book from The Simon Foundation for Continence, sets out to help people improve their quality of life. The book contains chapters on: body image; communicating with family, friends, and health care professionals; creating an

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Continence Central: A Website You Should Not Miss

One of the most asked questions to The Simon Foundation for Continence regards how to select the right product or device to manage incontinence. In response to this demand for information we have created a special website for both individuals and professionals to learn about all the various continence management products available in the US; how to select the most appropriate product(s) based on individual need; where to purchase these products; and information regarding reimbursement.

Continence Central is one of several Foundation websites specifically

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Underactive Bladder Syndrome

Over the past few years, advertising and media attention has focused upon overactive bladder (OAB) or detrusor overactivity. However, an equally serious and common bladder condition is underactive bladder (UAB) or detrusor underactivity. Underactive Bladder Syndrome is characterized by urinary symptoms including hesitancy, straining, and incomplete bladder emptying in the absence of anatomic obstruction.

An underactive bladder is a chronic disease where the bladder holds large amounts of urine, yet the individual cannot feel when the bladder is full, nor does the bladder muscle contract sufficiently for the bladder to empty completely. Other names for UAB besides detrusor underactivity include hypotonic

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improved quality of life; how the bowel and the bladder work; exploring products and practical management techniques; stigma and taboos; and a look at prevention...
to name just a few of the topics.

Chapters are woven together with “Lived Experiences” which are personal stories written by individuals from around the world (Sweden, Israel, Japan, England, Canada, Brazil, and the US) who have moved past their initial reaction to incontinence and created a life of their choice. They share their feelings, their successes, and how they made the changes necessary to get back into life.

Among the people you will meet in this book is Paul from Canada who went from being a recluse in his twenties to taking up marathon running in his fifties.

Paul LaPorte

You will also meet Louise, a happily married nurse midwife who found herself dealing with incontinence following the birth of her first child and how it deeply affected her life.

Perhaps most moving is Kasai-san’s story. He is a Japanese gentleman who happened upon the Japanese translation of the Foundation’s first book, Managing Incontinence, in a bookstore in Tokyo, and traveled to the America to receive help from the Foundation. He writes “19 years have passed since that meeting. After coming back to Japan, I became involved with volunteer activities to support people who suffer from incontinence...to fulfill the promise I made during that trip to America so long as I live. It would be a joy to me for my story to provide the leg up that saves you.”

Research has shown that the psychological, emotional, and social impact of incontinence is often not correlated to the amount of leakage a person experiences. Some individuals may leak just a small amount once a day and feel greatly distressed by this change in their body, while others may have substantial challenges with incontinence and yet find that few aspects of their life are impacted by the leakage.

This book is for those individuals who have sought professional medical attention for incontinence, but who are still living with the symptom of bladder or bowel leakage. So often people with incontinence begin sentences with “I used to”: I used to sail, I used to go to church, I used to love to hike. If you find that “I used to” is part of your vocabulary, or someone you know, then this book is for you.

More personal stories, a complete listing of chapters and the expert authors who created this book, and purchasing information can all be found at www.managinglifewithincontinence.org.

Thank You

(Editor’s Note: This issue of The Informer was underwritten by an educational grant from NorthShore Care Supply. The Simon Foundation for Continence does not endorse specific incontinence products or medical treatments. Inclusion in this column in no way implies endorsement.)

Bladder and/or bowel leakage is a medical condition affecting millions of Americans. And for millions more, people giving care for a loved one who develops incontinence, it can make things more complicated and stressful – for both of you. The first step to take is to obtain a diagnosis to see if there is a treatment available. Do not assume that incontinence is a permanent change and that nothing can be done.

At NorthShore Care Supply, we are experts in home care products specializing in incontinence and personal care supplies. We have carefully selected only the top quality brands available. Founded in 2002 by its President Adam Greenberg to offer a better quality of life for its customers, the company provides absorbent incontinence supplies including, adult diapers, underpads, baby diapers, youth diapers, wipes, and mattress protector and prides itself on award winning customer service and guaranteed discreet home delivery.

CAREGIVER RESOURCES:
National Institutes of Health Caregivers

Caregivers’ Resources
www.usa.gov/Citizen/Topics/Health/caregivers.html

Continence Central Resources
www.continencecentral.org/Resources.html

NorthShore care supply
The Incontinence Supply Experts
Nationwide Discreet Home Delivery
www.northshorecare.com
The conference’s accomplishments included: defining prevention as it applies to incontinence; developing recommendations regarding “Healthy Bladder Habits”; and creating a call to action for research in this area.

For most people, prevention means taking steps to make sure that something like incontinence never happens in the first place (called “primary prevention”). However, prevention can also include preventing incontinence from worsening or from causing complications (such as skin problems). Steps that are taken after a health issue like incontinence has already arisen are referred to as secondary prevention.

The concept of prevention needs to be stressed. Until medical science is able to cure all incontinence, there are many things that can be done to lessen incontinence. Giving attention to secondary prevention now, will in turn lessen incontinence’s impact on the quality of life in the future.

Some of the following suggestions have scientific findings to substantiate the theory that they help to improve or prevent the worsening of incontinence. Other suggestions are what health professionals call “anecdotal,” meaning that many individuals have reported that the suggestion has been of help to them.

In addition to “proven” methods of prevention, anecdotal ideas, which may or may not draw the attention of scientific research in the future, may also be worth trying in order to determine if they are of help.

FOR URINARY INCONTINENCE:

Stop smoking because nicotine can irritate the bladder. Also, chronic coughing caused by smoking may cause stress urinary incontinence.

Maintaining a healthy weight will put less pressure on your bladder. Even a 5% to 10% weight loss in those with an unhealthy BMI has been shown to reduce incontinence episodes. A major weight loss program should be supervised by a healthcare professional.

Determine the proper amount of fluid intake that is right for your body. Find a balance, not too much or too little, by drinking when you are thirsty and checking to see that your urine is not too dark, but rather a pale yellow.

Avoid bladder irritants in your diet first by learning what is known about the foods and drinks that irritate the bladder (such as caffeine, alcohol, highly spiced food, etc.) and then one by one eliminating them from your diet. If you see no improvement, resume eating or drinking that particular item and move on to test the next one on your list. Also check the labels on over-the-counter medications you are taking to be sure they do not contain caffeine.

Keep your bowels regular and avoid constipation. Straining to have a bowel movement can weaken the pelvic muscles.

Try substituting low-impact exercises (activities in which one foot is always on the floor) rather than participating in high-impact activities such as running and high-impact aerobics because these exercises may further weaken the pelvic floor ligaments if they are already weak, as they cannot withstand these forces for prolonged periods.

Never ignore symptoms of BPH (benign prostatic hypertrophy) such as urgency, frequency, difficulty starting the urine stream, or a weak urine stream. These changes in urination may be a result of an enlarged prostate gland in men that is pressing upon and narrowing the urethra, which then causes the bladder to have to work harder to expel urine. Eventually the bladder muscle simply “gives up” and overflow incontinence results.

Overflow incontinence is when urine dribbles from the bladder without your feeling the sensation of bladder fullness. Seeking timely medical help with prostate enlargement can prevent this type of incontinence.

SECONDARY PREVENTION OF FECAL INCONTINENCE

Working to re-establish bowel control also means working to strengthen the pelvic floor muscles, as they support this area of your body too. In addition, understanding how the bowel moves the digested food through your system will help you to train your bowels.

Do not skip breakfast because the bowel is stimulated when you wake up in the morning and is further stimulated by eating and drinking. You can take advantage of this natural awakening of the bowel each day and try to empty the bowel about twenty to thirty minutes after breakfast. Try to make sure your bowel is empty before you start the rest of your day.

Learn to use the muscles in your abdomen to move your bowels rather than straining, which risks weakening your pelvic floor muscles.

Experiment with fiber in your diet to understand if you have better control with a diet low in fiber or with a diet high in fiber.

Stop smoking because nicotine stimulates the bowel as well as the bladder.

Finding an over-the-counter aid that works for you among suppositories, enemas, laxatives, and anti-diarrhea medications might take time and experimentation. However, it may be time well spent if you can find an aid that allows you to choose when your bowel will empty.

Watch your weight because there is some scientific evidence that heavier people are more prone to bowel incontinence.

Annual physicals or check-ups are routine for many people, and your incontinence should be reevaluated on a routine basis too. This is because your incontinence may change over time, and therefore the possibility of the occurrence of underlying health issues should be carefully monitored. Also, your management strategies may need to be modified to meet changing circumstances.
targeted to the needs of the people we serve. Continence Central provides information critical to the product selection process.

Although Continence Central is designed to help people manage incontinence, the Simon Foundation for Continence always communicates the message that incontinence is a symptom of something else going on in the body.

For that reason, it is vitally important to see a physician who is interested in and knowledgeable about incontinence to learn the cause of the incontinence and to determine if there are treatment options available that can either cure or lessen the incontinence.

Embedded within the Continence Central website visitors will find a link to the Continence Product Advisor, a website created for a worldwide audience by an editorial team based at University College London and the University of Southampton in England. This team is led by Professor Alan Cottenden, a long-time board member of The Simon Foundation for Continence, in partnership with the International Continence Society (ICS).

The content of the Continence Product Advisor is based on the findings of the 5th International Consultation on Incontinence (ICI). The ICI creates a state of the art book for health professionals. Ms. Gartley, founder of The Simon Foundation for Continence, is one of the many authors of the most recent edition. The Continence Product Advisor aims to make independent, evidence-based advice accessible to users and healthcare professionals who wish to become more knowledgeable regarding management techniques.

Once the visitor to the Continence Product Advisor supplies information regarding their own situation, they will be helped to determine the best products to suit both the user’s lifestyle and specific incontinence type.

Products are referred to generically (not by brand names) and divided into the following categories: pads; female devices; male devices; catheters; urine drainage bags; fecal devices; toileting aids; bed and chair protectors; and clothing, odor control, and skin care. Visitors are then referred back to their own countries in order to find what specific branded products are sold in their country.

The Simon Foundation for Continence’s Continence Central is the first national website developed specifically to integrate with this international project. The concept and partnership resulted from ideas first discussed at the Foundation’s international conference series, Innovating for Continence: The Engineering Challenge in 2011.

“Continence Central is an ongoing project and we are frequently adding new companies and products,” states Elizabeth LaGro, Vice President of Communications and Education Services at the Foundation, and creator of Continence Central. “The website has grown tremendously since it first launched and we are delighted in the extraordinary variety of products represented. This website truly provides consumers and caregivers a wide range of options.”

Continence Central is designed to help individuals with incontinence select and find products at all the possible sources, including online product distributors, large discount retailers, local pharmacies and grocery stores. In addition, the website is a resource for information on other relevant incontinence topics such as books on incontinence, diaper banks, and US-based organizations helping people with incontinence.

“Many individuals are unaware of the fact that retail stores display only a portion of the many products and devices available today to manage incontinence,” commented Cheryle Gartley, the Foundation’s President and Founder. “This website offers an opportunity to explore additional options available and to learn about new products just entering the marketplace.”

Getting to Know Us...

Elizabeth LaGro, Vice President of Communications and Education Services has a master’s degree in library and information science and has been with the Foundation since 2009. She maintains and writes content for our four websites; interfaces with people who request our resources; assists and speaks at the I Will Manage education program; and represents the Foundation at various meetings. Beth states: “The highlight of my day is when I can help someone locate a local resource, such as a specialty physician or product resource.

Getting the right information to someone, when they most need it, is my daily goal. To do that, I need the collaboration and cooperation of a wide range of sources, organizations, and people. We are so fortunate in being able to provide that to people coming to us for assistance.”
Diabetes and Incontinence

Having diabetes is a risk factor for developing incontinence. Type 2 diabetes, which used to be called noninsulin-dependent diabetes, is a chronic condition where your body resists the effects of insulin or does not produce enough insulin to maintain a normal glucose level in your body. Diabetes increases your risk for both urinary and fecal incontinence.

One of the main reasons for this is that an unhealthy weight, often associated with diabetes, can cause incontinence from the increased weight placed on the pelvic floor muscles.

One of the common symptoms of diabetes is frequent urination. This is because excess glucose that is building up in your bloodstream causes fluid to be pulled from your tissues, leaving you thirsty. As a result, you drink increasing amounts of fluids in an attempt to quench your thirst, making you urinate more than normal.

In addition, your body is also trying to get rid of the extra glucose by excreting it out of your body in your urine. This process also causes a large increase in the amount of urine produced.

Diabetes can lead to nerve damage, which includes the nerves in the bladder and bowel. Nerve damage may lead to several changes. The most common occurrence is an overactive bladder (OAB), which can lead to urgency and urge urinary incontinence (UUI). Another change is decreased bladder sensation, leading to little or no warning that the bladder is becoming full until you feel the sudden urge to urinate, which can lead to episodes of incontinence.

In persons with severe and/or longstanding diabetes, the bladder muscle may become so weak that you do not completely empty the bladder each time you urinate. Eventually the bladder may not contract, causing it to fill and then overflow, called "overflow incontinence." Another repercussion of the bladder not emptying completely is called residual urine. Having urine left in the bladder increases the likelihood of developing a urinary tract infection (UTI). A UTI may also lead to increased frequency and urgency.

Constipation, which affects nearly 60% of persons with diabetes, can also make it difficult to empty your bladder.

Congestive heart failure (CHF) from diabetes-related coronary artery disease can cause your legs and feet to retain water, and can cause your body to create too much urine at night. This can lead to getting up many times at night to urinate (nocturia), and to experiencing incontinence at night.

Stroke from diabetes can affect bladder sensation and your ability to hold back from urinating. Additionally, mental impairment can make it difficult for an individual to toilet himself or herself (and when severely advanced, even toileting with assistance becomes difficult).

Mobility challenges due to diabetic neuropathy, peripheral vascular disease, and amputation can prevent you from reaching a toilet or removing clothing "in time." This is called "functional incontinence."

Some medications for the treatment of diabetes, or for the treatment of the complications of diabetes, can impair continence or complicate its treatment. For instance, some may cause fluid retention in the legs and feet. When you lay flat at night, it is easier for the body to rid itself of these fluids, leading to an increased production of urine and nighttime incontinence.

It is important to note that incontinence in persons with diabetes is not always related to the diabetes. Incontinence could be caused by completely separate factors. This is why all changes in your toileting habits should be reported to your healthcare professional and basic prevention, such as avoiding alcohol and smoking, should be observed.

The best way to prevent incontinence that is associated with diabetes is to prevent the diabetes itself by maintaining a healthy weight, eating a healthy diet that reduces blood sugar, exercising regularly, and using prescribed medication.
In 2005, a small group of individuals passionately dedicated to increasing the creativity and rate of development of products and devices for the management of incontinence, met to develop the first in a series of unique conferences. And from this think tank Innovating for Continence: The Engineering Challenge was born.

The Innovating for Continence Conference Series is held in Chicago in April of odd numbered years. It is a unique, international meeting for engineers, nurses, physicians, people with incontinence, academics, industry executives, and entrepreneurs. From the very first conference, Innovating 2007, the meeting has attracted delegates from around the world including Japan, Israel, England, Ireland, Sweden, Germany, Switzerland, Australia, Brazil, Canada, the Netherlands, New Zealand, the Philippines, and throughout the US.

The concept of the conference series is to feature an unusual mix of speakers. The conference includes experts in areas of technology that have yet to be applied to incontinence. Speakers also include patients and caregivers whose presentations will challenge experts to brainstorm ways in which unique technologies could be applied to incontinence issues; and physicians, nurses, and other healthcare providers whose clinical experience will enlighten meeting attendees on medicine’s limitations and successes.

Professor Alan Cottenden is the ongoing chair for the conference series. He is Professor of Incontinence Technology at University College London in England. Professor Cottenden, a board member of The Simon Foundation for Continence, has been involved in continence technology for almost 30 years, working on clinical and basic science aspects, as well as product development and international standards work (ISO). Honorary Presidents from each conference also bring a wealth of experience. They include: Mr. Ray Laborie, founder of LABORIE Technologies (2007); Mr. Al Herbert, Chairman and CEO, Hollister Incorporated (2009); Christopher Payne, MD, a leading urologist from Stanford University (2011); Professor Robert Linsenmeier, a world renowned biomedical engineer at Northwestern University (2013); and in 2015, Professor Christine Norton, RN, PhD, an international expert in bowel incontinence.

“People with incontinence would like to be cured, but when complete cure is not achievable – as is often the case – delivering the best quality of life possible through effective management is a goal just as worthy of our strenuous efforts,” states Professor Cottenden, Chair of the Innovating for Continence conference series.

Delegates who return year after year to this meeting report that one of their key attractions to Innovating for Continence is the opportunity to network with a group of experts from around the world. In addition, they cite the opportunity to learn from speakers regarding the unique areas of technology that might be applied to products for incontinence, and to hear directly from individuals who live with incontinence on...
badder, lazy bladder, detrusor hypoactivity, and flaccid bladder. UAB has no known cure. The management of underactive bladder syndrome focuses on: reduction of residual urine (the amount of urine left in the bladder after voiding); avoidance of over distension of the bladder; and prevention of upper urinary tract damage. The upper tract of the urinary system consists of the kidneys and ureters (tubes that lead from the kidneys to the bladder). Too much pressure in the bladder can cause urine to flow back up these tubes into the kidneys, causing potential damage to both.

Normal voiding depends upon a coordinated interaction, the bladder muscle contracts while at the same time the bladder neck opens to allow the urine to flow out of the body. There are many problems within the body that can interfere with this interaction leading to detrusor underactivity. Among the risk factors contributing to underactive bladder syndrome are: damage to nerves; diabetes; pelvic surgery which may cause injury to the bladder nerve supply; changes caused by aging; urinary tract infections; medications that cause the bladder muscle to relax (antidepressants, antihistamines, and muscle relaxants); and spinal cord injuries (depending upon the level of the injury).

One of the myths surrounding incontinence is that it is a normal part of aging. Aging in and of itself does not cause incontinence. Millions of people reach old age with functioning bladders and bowels. However, changes that occur in the body with aging may help to precipitate bladder problems. For example, as we age the volume and elasticity of the bladder muscle tissues changes, as well as the number of nerves to the bladder muscle.

Currently, help for UAB includes prescription medications, scheduled voiding, and double voiding. The use of intermittent catheterization to empty the bladder completely is often the prescribed management option of choice. Hope for the future for this type of incontinence may come from research looking at stem cell therapy and neurotrophic gene therapy.

For more information about UAB, visit the Underactive Bladder Foundation’s website at www.underactivebladder.org.
ONE VOICE
An Editorial

Cheryle B. Gartley
President and Founder

The challenges of healthcare in America, and for that matter, throughout the world, affect us all. With all the change that is occurring there is plenty of blame, hope and advice going around.

With that in mind, after a recent visit to my own physician, the thought occurred to me that it is also up to each of us to be a part of the solution, or to paraphrase President Kennedy’s often quoted statement: “Ask not what your physician can do for you, but rather ask what you can do for your physician.”

It is going to take everyone working together to create better care. As patients, we need to be concerned about the projected demands that will be made upon our doctors and nurses as the need for healthcare increases as the US population ages and expands.

You may have already observed that your physician and others providing your care are showing signs of strain. In fact, many are retiring early. Others are looking for new ways to make adjustments to increase efficiency including: trying group appointments, establishing concierge practices in order to spend more time with their patients, and/or putting more responsibilities into the capable hands of well-trained physician assistants and nurse practitioners.

However, training us, their patients, is one thing that hasn’t been tried, at least to the best of my knowledge. So how can we, as patients contribute? No matter the changes or reasons for them (healthcare policy changes, physician shortages, an aging population, the increasing cost of physician and nurse training, etc.) we must be in it to win it, and patients have a significant role to play.

The following are a few thoughts about increasing our role as patients in this challenge. To begin with, each of us can increase what I’ll term our “patient efficiency.”

For instance be sure to show up on time for appointments (prepared with work or a book in order to remain patient in case of a wait) and give plenty of notice if a change or cancellation is necessary.

If you are a new patient, consider writing or e-mailing ahead of time with some of your relevant medical information (surgeries, current medications, reason for consultation, and a brief list of the questions you hope will be addressed at your appointment, with your most important ones first). By planning ahead in this manner your appointment can be focused on your concerns and any additional information your physician needs.

Be sure to ask at the beginning of the appointment how much time has been allocated for your visit, provide a written list of your concerns, and offer to schedule a second appointment if you start to run out of time before all your questions are answered.

An efficient patient also tells his or her doctor or nurse if the recommendations or treatments being prescribed are not something the patient can or wants to do. Healthcare providers call this compliance (or non-compliance depending on if the patient follows the treatment plan or not). Compliance is a very important factor in the relationship between patient and provider, and one that is often not addressed.

If your physician believes you have followed the treatment plan and you have not returned for further care, then an assumption that the treatment or medication prescribed has worked is likely to be made. Honest communications regarding your compliance is not only efficient regarding regaining your own health, but equally important because when you tell your physician or nurse the outcome of their advice, it will allow them to draw the correct conclusion about whether their treatment plan has been efficacious. These correct conclusions affect the healthcare of us all.

There is even more each of us can do to contribute for the good of great healthcare for everyone. For instance, you might carefully check your list of questions to determine if some of them can be answered by your pharmacist. Consider volunteering to be part of a clinical trial for which you might qualify and feel comfortable participating in. More volunteers for clinical studies would help bring down the expense of recruiting patients and help reduce the delays in bringing much needed devices and medications to market.

Lastly, consider concluding every medical appointment with questions like the following that could improve both your care and your future doctor/patient interactions: “Is there anything I didn’t ask today that would help improve this situation?”; “Would you kindly comment on how I can be a more efficient patient for you in the future?”; and “If questions arise between my appointments, how (and when) is the best way to reach you?”

Regardless of race, religion, social economic status, or political preferences, healthcare is something few people leave the planet without needing at some point in their life. It behooves us as patients to do our part to contribute to improving healthcare for everyone.

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