Simon Foundation Hosts Meeting on Incontinence in Long-term Care and Assisted Living

It has long been known that upwards of 50% of people who reside in long-term care facilities experience incontinence. Fortunately, over the past few years more attention has been focused upon aging and incontinence. However, all too soon the tidal wave of baby boomers will be increasing the long-term care and assisted living population and America is not ready. There is a desperate need for an increased understanding of the needs of people with incontinence in these settings.

Recently, the Simon Foundation for Continence hosted a two day round table discussion about the state of incontinence in long-term care and assisted living. Experts were brought together from throughout the United States, Canada, and Europe to focus on the impact of incontinence on residents of these facilities and to increase awareness of programs that successfully deliver good continence care.

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THE IMPORTANCE OF WATER

One pundit has claimed that “our bodies are just a way for water to get up and walk around.” Humor aside, it is important to recognize that at every stage in life, adequate hydration is necessary for good health. Adequate hydration means that your body has sufficient water in the right locations and contains the right concentrations of electrolytes such as sodium and potassium.

The benefits of water are numerous. Water helps to: keep skin healthy; flush toxins from the body; cushion and lubricate joints; keep bowels regular; maximize mental function; reduce the risk of kidney stones and urinary tract infections; and regulate body temperature. Water comprises approximately two thirds of the body’s weight, although due to changes in the body’s tissues as we age, the water content will vary. For instance, children’s bodies have approximately 80% water, whereas men and women over the age of 60 show an average of 51% and 43% water content respectively. The decrease of water content in the body as we age is due to loss of lean muscle tissue which holds body water better than fat (muscle tissue is approximately 75% water). There are also diseases which are more common as we age such as heart and kidney disease and diabetes to name a few, which can affect the fluid balance in the body. Small fluctuations in fluid intake can cause proportionately more dehydration in a senior citizen than in a child.

Understanding how to determine if you are drinking enough water is the first step in maintaining a healthy body. First of all, continued on page 2
it is important to drink before you become thirsty. This is especially important for older individuals because age decreases the body's thirst mechanism. In fact, increasing age is one of the major risk factors for dehydration. Experts recommend a fluid intake of 1,600 mls per 24 hours. With the increased number of people who are overweight in America, using a rule of 1/2 oz. of fluid per pound of body weight may be a better indicator of appropriate fluid intake. Any food item which is liquid at room temperature such as ice cream, popsicles, or gelatin should also be calculated as part of your daily fluid consumption.

The body loses water in many different ways: through the skin by perspiration; through the kidneys by urine production; and through the lungs by exhaled water vapor. The human body reacts to insufficient fluid intake in many different ways, including: headaches; kidney stones; low energy and fatigue; dark urine; constipation; muscle and joint soreness; and the misperception of feeling hungry. If you are suffering from any of these symptoms, paying attention to (and if necessary increasing) your fluid intake may alleviate these symptoms.

One way to determine if you are drinking enough is by the color of your urine. Urine the color of water is good and the color of lemonade is OK; however, if your urine is the shade of apple juice you need to drink more fluid and if it is dark like Coca Cola you may need to seek medical attention for dehydration.

Other indications of adequate hydration include: skin that retains moisture and is supple; mouth and lips which are adequately moist; and eyes which have sufficient tearing. Including a variety of fluids in your diet each day may help you to consume adequate amounts of liquid. However, fluids other than water should be substituted in moderation. Soft drinks and sports drinks are high in sugar and may contribute to dehydration as the kidneys attempt to dilute the sugar. Although nourishing, many soups contain a high sodium content. Some individuals find that milk is constipating and an excess of juices can cause diarrhea and alterations in sodium and potassium levels. Caffeine and alcohol act as diuretics.

Dehydration is not only bad for maintaining a healthy body, but can become a medical emergency. Older individuals and their caregivers need to be especially vigilant in guarding against dehydration. People between the ages of 85 and 99 are 6 times more likely to be hospitalized for dehydration. A medicare study indicated that 18% of those over 65 who were hospitalized for dehydration died within 30 days.

The prevalence of underhydration and dehydration in long-term care is estimated at 33%. Underhydration can make older adults more susceptible to urinary tract infections, pneumonia, pressure ulcers, confusion and disorientation.

For individuals at risk of dehydration, increased fluid intake can be made more appealing in several ways. Keeping fresh ice water at the bedside; using larger cups of water to accompany the taking of medications; using pretty glasses which aren't too heavy; and adding slices of lemon to flavor a glass of water may all help to make keeping up one's fluid intake more enticing. Even reminding people that cool water can be very refreshing may also tempt them to drink more often.

Adequate hydration is also very important for individuals who have bladder and/or bowel problems such as incontinence. Although for people who are fearful of being wet in public it is a natural tendency to want to decrease fluids, risking underhydration or dehydration is not an appropriate response to incontinence. An adequate amount of urine is needed in the bladder to stretch the bladder walls, activating nerve receptors which transmit signals through the spinal cord to the brain. These signals warn you when your bladder is becoming full and give you time to seek a toilet. Chronically reduced fluid intake may lower an individual's awareness of bladder sensations. Dehydration may also increase constipation and could result in bowel impaction. In fact, what many individuals experience as bowel incontinence, is really an impaction in the bowel, blocking its normal action and leading to leakage which seems past the impaction.

The International Organization for Standardization reports in their journal that in December of 2003 the UN General Assembly proclaimed the years 2005 to 2015 the International Decade for Action, "Water for Life", beginning with World Water Day on March 22, 2005. The UN called upon organizations and governments to deliver a coordinated response to make "Water for Life" a "Decade for Action". There are still almost 1.1 billion people worldwide who have inadequate access to water.

Slowly, the importance of water and adequate hydration is beginning to get more attention in the media. This attention is increasing public awareness through articles which include interesting facts like the following (taken from the 2004 Water Quality Report "Drinking Enough Water?" - City of Evanston, Illinois): 77% of Americans are chronically dehydrated; in 37% of Americans, the thirst mechanism is so weak that it is often mistaken for hunger; even mild dehydration will slow down one's metabolism as much as 3%; lack of water is the number one trigger of daytime fatigue; the average daily requirement for treated fresh water in the United States is about 40 billion gallons; and one glass of water shuts down midnight hunger pangs for almost 100% of dieters studied in a University of Washington Study.

Is water getting enough attention in your life? You might keep track of your water intake for a few days to be certain. You may find out that the next time you are feeling tired or hungry, simply increasing your water intake will provide a quick and inexpensive remedy.
ONE VOICE, An Editorial

Cheryl B. Gartley
President and Founder

Today on the telephone, one of the most dedicated physicians I know said to me that he felt that in our country "all hell has to break loose before anyone does anything." At the time we were talking about healthcare, and what is going to be needed by the baby-boomer generation as they age at the same time when there aren't sufficient numbers of doctors trained in elder specific needs. At a medical round table discussion which the Foundation organized recently, another highly regarded doctor remarked that the healthcare system is about to implode. These two individuals are doctors who entered medicine for its challenges and rewards and who truly care about their patients. They are both working long hours outside of the time they spend caring for patients to facilitate change. I take their concerns about all of our futures seriously. I hope I can do my part by encouraging you to become concerned also and recognize that there is something that you too can do to be part of the solution, before the medical help we've all taken for granted as Americans is no longer available to us.

The first thing we can do, old and young alike, is to remove our heads from the sand and recognize just how serious is the problem; it's not just the next guy's problem, it's here in our own communities. It's true that not all of us can have a world changing idea; not many of us have the political clout to single-handedly influence decision makers in Congress, and likewise few have the financial wherewithal to build a model hospital...but there are some things we all do have. We have discretion on how we spend our free time - we all have time to volunteer at our local hospital or long-term care facility. We each have the ability to improve our relationships with the people who provide our healthcare and we can insure that we are an example of a patient to whom they enjoy giving care. Most of us can afford stamps to post a letter regarding our concerns and suggestions to our representatives in Washington, and every one of us has the ability to care about the future we are leaving to the generations which follow. Every single person can take some little steps that won't take much time in our busy schedules. For instance, the next time you have something special to talk to your doctor about, tell the person who schedules the appointment that you need a little extra time and ask if perhaps it would be easier for their office to put you in at the end of the day. Or perhaps there is a holiday you wouldn't mind missing, or your family doesn't celebrate? Then get to know the director of volunteers at your hospital and tell him/her that you'd be available to give some time on that day each year when they are most likely to be short staffed in the volunteer department. Are you active in an organization that would be interested in hearing a doctor's or nurse's point of view of what is happening in healthcare today...then invite your favorite doctor or nurse to speak to this group.

A well known author speaking about effective change stated that everyone was capable of deciding to change. People can determine to live their lives in ways they'd always dreamed. The author backed up that assertion with the following logic - "you created the life you have today, didn't you?" Indeed, with some luck and misfortune thrown in, most of us did just that! And as a society there's a lesson in that statement for what we must do as a society. We must decide, each and every one of us, to help to determine what is needed and then to make the changes necessary today to ensure the future health of our nation's system of medical care.

In his book entitled "What your Doctor May Not Tell You About Colorectal Cancer", Dr. Mark Bennett Pochapin states: "Remember: The best person to ensure your good health is not your doctor, but you. That is one piece of lifesaving advice that your doctor may not have told you." He was of course speaking about not waiting for illness to strike you, but working on prevention. We need to all work together to prevent the illness and collapse of our healthcare system and the best person to ensure its good health is you.

REQUEST FOR MEMBERSHIP
Yes, I would like to be a member of the Simon Foundation for Continence.

Please mail me the Foundation's newsletter The Informer.

Enclosed is a check.

☐ $1,000. Life Membership
☐ $15. Annual Membership
☐ $5,000. Corporate Sustaining Membership
☐ $100. Individual Sustaining Membership
☐ $5. Caring Membership
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Your annual membership will begin with the next edition of The Informer.
Contributions and membership in the Simon Foundation are tax deductible.

The Simon Foundation for Continence
P.O. Box 815, Wilmette, IL 60091

NAME

ADDRESS

CITY

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SIMON SAYS:

THANK YOU TO OUR CORPORATE MEMBERS...
Many of the companies who provide medications, devices, and absorbent products for people with incontinence also provide unrestricted financial support to the Simon Foundation for Continence in the form of annual Corporate Memberships in the Foundation. In addition to this form of sponsorship, many of these same corporate members also continue to advance the cause of continence promotion with various grants for specific educational projects. To date the following companies have become 2005 Corporate Members: Eli Lilly & Company; Gynecare; Hollister Incorporated; Home Delivery Incontinence Supplies; Indevus Pharmaceuticals; Laborie Medical Technologies; Pfizer Pharmaceuticals; and SCA Personal Products. Good corporate citizens such as these should be thanked often and by all of us that they continue to help.

VISIT SUNA WEBSITE...
The Society of Urologic Nurses and Associates (SUNA) has recently put its educational "Fact Sheets" online for free download at www.suna.org under the "Resources" section. Current fact sheets include information on the following topics: Benign Prostatic Hyperplasia, Chlamydia, Genital Warts, Interstitial Cystitis, Kidney Stones, Local Estrogen Replacement for Urinary Incontinence Related to Urogenital Atrophy, Overactive Bladder, Prostatitis, and Urinary Tract Infections.

THE CONILL INSTITUTE FOR CHRONIC ILLNESS...
is a not-for-profit organization founded by Alicia M. Conill, M.D. The Institute seeks to instill in every individual an awareness of the well-being that is possible in the presence of chronic illness and disability. Founded in 1998 its inaugural project was a pilot program called the Disability Experience. The program goals include increasing knowledge of the culture, diversity and challenges of people living with disability as well as understanding the cyclical nature of adaptation to disability or chronic illness. The course was first taught to University of Pennsylvania medical students and nursing students at Villanova School of Nursing. To learn more about the Institute log onto www.conillinst.org or write to Conill Institute for Chronic Illness, 3535 Market Street, Suite 4045, Philadelphia, PA 19104.

THE INTERNATIONAL CONTINENCE SOCIETY’S...
2005 annual meeting comes to Montreal, Canada in August. Dr. Jacques Corcos, Chairman of the 35th Annual Meeting estimates that over 2,500 delegates from around the world will attend. The Conference attracts physicians, surgeons, nurses, physiologists and other scientists who have an interest in all problems related to urinary tract functions. Prior to the ICs meeting workshops covering a wide variety of topics including: The Pelvic Floor and Childbirth; Lower Bowel Dysfunction; A Global View of Continence Promotion in Nursing Education and Care Delivery; and Bladder and Bowel: Perfect Harmony or Conflicting Neighbours? - to name just a few - are being held. The ICs meets once each year at various locations throughout the world. Upcoming meetings are scheduled for New Zealand, Europe and Egypt. For further information and registration materials contact www.opus3.com/ics2005 or www.icsoffice.org.

FOUNTAIN REPRESENTS YOU...
Jasmine Schmidt, the Foundation's Director of Education, represented the Simon Foundation and people with incontinence at the April meeting of the National Kidney and Urologic Diseases Information Clearinghouse Coordinating Panel held at the Bethesda campus of the National Institutes of Health. The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) is an information dissemination service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The clearinghouse was established by Congress in 1987 to provide education to the general public. You can learn more about incontinence and other urologic diseases by visiting their website at www.niddk.nih.gov.

THE VERMONT PARKINSONIAN...
is an excellent newsletter for people with incontinence who are also challenged by Parkinson’s Disease. Articles in a recent edition included: "Questions to Ask Before Having An Operation"; "The Miracle of Aspirtin"; "Four-Step Plan for Beating Obsessions & Compulsions"; and "Healthy Foods: Carrots - What's Up Doc?" For a sample copy write to The Vermont Parkinsonian, 1430 Brown Farm Road, Lyndonville, Vermont 05851.

THANK YOU TO OUR CORPORATE MEMBERS...

Professor Alan Weil, M.D., Professor and Chair, Division of Urology, University of Pennsylvania will be chairing a lively and current debate at an upcoming satellite symposium which will be held one evening at an industry sponsored event for attendees of the Montreal ICs meeting. The debate, entitled "Patient Choice or Physician Choice - Which Comes First? A Debate on SUI" will cover the following questions: "How do you most effectively manage patient expectations?"; "Where does the balance fall in the patient choice vs. physician choice debate?"; "What are your thoughts on injectables vs. surgery?"; and "Is surgery the only cost-effective treatment for SUI?"

Dr. Weil is a long time member of the Foundation’s Advisory Board and a world renowned expert on incontinence.

THOUGHTS FOR THE DAY... "Never doubt that a small group of committed citizens can change the world. Indeed it's the only thing that has." — Margaret Meade

"I try to take one day at a time, but sometimes several days attack me at once." — Author unknown.
LETTERS TO THE EDITOR

Hello: I have been very concerned about urine leakage. It is embarrassing to even tell my husband. I haven't seen a doctor so far. I don't know where to start and I don't have insurance. I need to know where to go first. Thank you very much.

Nevada

Dear Nevada:

Urine leakage (incontinence) is a medical problem which affects millions of Americans and is always a symptom of something else happening in the body. Therefore, it is important to have the cause of your incontinence diagnosed. It is understandable that you feel some embarrassment; most people report to us that they do. However, physicians, nurses, and physical therapists who are interested and knowledgeable about treating incontinence will understand your concerns and they will help you feel comfortable when talking about your bladder and bowel. Remember, they see many misbehaving bladders each day in their medical practice.

Depending on the size of the community where you live, you may have many choices of people you can consult, or finding the appropriate medical help may be more of a challenge. There are many different specialty practitioners who treat incontinence, including: urologists, gynecologists, geriatricians, primary care physicians, urogynecologists, nurse practitioners, and physical therapists. If you live in a large metropolitan community, asking at one of the large teaching hospitals for a recommendation may be a good place to begin your search. If you live in a small community, you may know a nurse who would tell you where he or she would send their mother or sister for care. When telephoning for an appointment, be sure to ask if the person you are choosing treats incontinence, and if not, where they send their patients for help.

Dear Simon: Last July I received a letter of encouragement and motivation from your Foundation. It did motivate me to attend a seminar that meets every two months at a local Cancer Center. These seminars are very helpful in understanding incontinence.

Urologists from all over the area are invited to come and express their medical knowledge that pertains to the problems dealing with prostate cancer. Participants explain their situation in a question and answer session. The stories of their experiences are very helpful to fully understand the pros and cons of this medical problem.

A Grateful Reader

Dear Grateful Reader:

There are two main types of incontinence many men experience after a radical prostatectomy due to prostate cancer - stress urinary incontinence (SUI) which is the leakage of urine when you sneeze, laugh, lift or cough; or urge incontinence, the sudden urge to urinate with the inability to reach a toilet in time.

If after allowing for post-surgery healing (most physicians suggest waiting at least one year) you find you are still leaking urine, there are several things that can be done. If you are experiencing urge incontinence, your physician may prescribe one of several medications that are currently available. For SUI, exercises to strengthen the muscles of the pelvic floor, called Kegel exercises, may be of help. Also procedures such as bulking of the sphincter tissue with injections of bulking agents such as collagen, or the implanting of an artificial sphincter, may be suggested. Be sure to report your progress to your doctor periodically. If you stop making progress it is reasonable to explore the possibility that something else is causing the delay. Also, if you experience a full bladder, but you are only able to produce a very slow stream or dribbling, you may be forming scar tissue which is constricting the urethra and needs to be removed.

Dear Mrs. Garlcy: I have some experiences I'd like to share regarding nocturnal enuresis and thought you would be the ideal person to discuss this with, because there is a lot of stuff I'd like to get off my chest. I have dealt with many kids who wet the bed and have read many childcare books on bedwetting. In just about all the books they discourage the use of diapers for older children, stating that "wearing diapers makes a child feel like a baby."

There is an alternative way of looking at this - in a way it's more babyish if you don't wear a diaper. By wearing diapers a child or adult is demonstrating that he or she has the maturity to take responsibility and manage the situation. Furthermore diapers by themselves don't symbolize being a baby - after all babies can't bathe themselves, feed themselves, clothe themselves, etc. If people would just learn to look at it this way, we'd all have healthier attitudes toward the use of diapers.

When I was growing up I tried alarms, medicines, and other methods to stop bedwetting, but none of these methods worked. Finally, I asked my mother if I could start wearing diapers again. I was glad when she said yes, because I felt a lot more comfortable waking up in a dry bed. There are adults who wear braces for their teeth, but we don't stigmatize them like we do with adults who wear diapers for bedwetting.

We as a society have come a long way and matured where a lot of issues and problems are concerned. Unfortunately we still live in the dark ages regarding bedwetting and diapers. You are welcome to print any part of this letter if you think it could help someone else come to terms with their use of diapers to deal with bedwetting. However, I would like to remain anonymous.

An Adult Bedwetter

Dear Friend:

Like all of the issues surrounding incontinence, no matter what the type or cause, the social, psychological and emotional problems associated with incontinence are often as distressing as the actual leakage of urine. Your point about taking responsibility for one's own healthcare is very well made. The Simon Foundation for Continence is drawing increasing public attention to the impact of stigma upon individuals with health challenges with our "Defeating Stigma in Healthcare" campaign and the anti-stigma song "I Am More" which we are working to popularize. Hopefully one day soon, whether we are talking about braces to straighten teeth or absorbent products to manage incontinence, everyone will realize that no one's body is without some imperfection. It's what we do about taking care of our problems that counts. In the meantime, it's adults like yourself who can show children the way. Thank you for taking the time to write.
The goals of the conference were: (1) to identify what current research has discovered regarding achieving continence in older individuals and the frail elderly in residential settings; (2) to identify what is still unknown; (3) to explore model programs of excellent continence care and cultural change which can and should be replicated; and (4) to create the appropriate public educational messages regarding continence care in long-term care and assisted living.

"This round table marks the launch of the Foundation’s programs to address the needs of people with incontinence who reside in care environments and to support the front line workers who provide their care," stated Cheryle B. Gartley, Simon Foundation’s founder. "As movements such as the Pioneer Network address the culture of aging in America, we hope to participate in helping to remove the stigma surrounding incontinence, and to continue to build awareness of how quality continence care improves the quality of life."

The conference was chaired by Professor Christine Norton, Ph.D., R.N. from St. Mark’s Hospital (U.K.) and Mary Radtke Klein, President, Assisted Living Associates (Oregon), both members of the Simon Foundation’s Advisory Board.

Among the experts from various disciplines participating in the round table discussions were: Mary Ann Anichini, APN, GPN, a geriatric nurse practitioner; Catherine DuBeau, M.D., a geriatrician at the University of Chicago; Jeanne Held-Grubman, MSW, Director of Education and Outreach, Alzheimer’s Association; Lorna Myles, CNA, from the Presbyterian Homes; Mary H. Palmer, (CNA) from a task-based working environment to a patient-centered environment, allowing aides and their patients to know each other better; educating families about incontinence and how to understand the institutional system and advocate successfully for their loved ones; encourage hiring practices to include a search for people with a highly compassionate nature; moving continence care into the arena of the culture change movement; improving continence care to help our culture change to a more positive approach to the end of life - to name just a few of the topics covered.

It is well known that motivating system change in corporate environments, where procedures have long been in place, is a tremendously challenging task. Raising the bar for better standards of care for people with incontinence in longterm care (especially when the American public seems to be determined to avoid facing the issues of aging) will take a group of dedicated and committed people from all walks of life. However, it was only two decades ago that a few dedicated individuals began a successful movement to remove both the physical and chemical restraints from nursing homes, proving what can be done to affect change.

Society’s norms and corporate cultures alike can be changed when people care enough to shine a glaring light on the need for improvements. And there is certainly no disagreement the need is there for improvements to be made in the manner that incontinence is addressed in long-term care and assisted living.

Editor’s Note: The round table on Incontinence in Long-term Care and Assisted Living was made possible by an educational grant from SCA Personal Products.