Understanding Incontinence After Radical Prostatectomy

Editor's Note: Incontinence as a result of radical prostatectomy is a devastating complication for many men. Sadly, men are often not warned that impotence and incontinence can result from this surgery. Often the advice they receive, after the fact, is to wait and see if the problem will lessen with time. The following article was written with the intent of helping readers to understand why this advice is so often given.

The number of men who suffer from incontinence after prostate surgery is unknown. According to Gary Leach, M.D., the incidence of incontinence after radical prostatectomy which is reported in the urologic literature, ranges from a low of 2.5% to a high of 87%.

"This large variability emphasizes the need to obtain more accurate scientific studies of this problem," states Dr. Leach in an article for US TOO, The Prostate Cancer Support Group International Newsletter. Whatever the true statistics, incontinence after surgery is a major problem which needs thorough understanding before any action is taken.

There are two components of normal bladder control which may be affected by prostate surgery. When the bladder is functioning normally, it is able to store a normal volume of urine at normal bladder pressure. The sphincter muscle at the outlet of the bladder is also functioning properly. Incontinence after surgery may be related to either a sphincter problem, high bladder pressure, or a combination of both.

It is unclear why men who had normal bladder pressure before surgery, exhibit an inability to store urine at normal pressures post operatively. Since some men have significant improvement of bladder control with the passage of time, it is theorized that some temporary nerve

Foundation's President Receives F. Brantley Scott Award

Cheryle B Gartley, President andFounder of the Simon Foundation for Continence was presented with the 1995 F. Brantley Scott Award before an audience of urologists attending the meeting of the American Urological Association.

This annual award honors the late Dr. Brantley Scott, a urologist known for his vision, tenacity, compassion and entrepreneurial spirit. Dr. Scott helped restore hope

The First Bladder Health Week Planned for Fall

The Bladder Health Council of the American Foundation for Urologic Disease is sponsoring a national campaign focusing on Bladder Health Week, September 10-16.

The purpose of Bladder Health Week is to educate the public on the issue of bladder health, including bladder cancer, urinary tract infections, interstitial cystitis and incontinence. This fall's campaign will
National Parent to Parent Database. If you are a parent of a child with special healthcare needs or rare disorders you might wish to join. If you are a parent looking to network with other families, or to meet with other families, please either contact NPPSIS at 1-800-651-1151 or write to PO Box 907, Blue Ridge, GA. 30513.

INTERNATIONAL CONTINENCE SOCIETY...
Ms. Gartley, President and Founder of the Simon Foundation for Continence has been appointed to a new committee of the ICS which will focus on patient education and public awareness worldwide. The ICS is an international organization of physicians, nurses, biomedical engineers, and others whose primary research interests are in the field of incontinence. The Continence Promotion Committee will make its first report to the general assembly of the ICS at the fall meeting in Sydney, Australia. Members of the committee include Christine Norton, R.N. (England), David Fonda, M.D. (Australia), Peter Lim, M.D. (Singapore), and Linda Brubaker, M.D. (Chicago). Informer readers who would like to contribute their ideas as to effective ways to promote continence worldwide should address their suggestions to the Simon Foundation.

CONGRATULATIONS TO HDIS...
winners of the 1995 Inc. Magazine’s Positive Performer Award. This award recognizes companies who excel in being customer focused. Home Delivery Incontinent Supplies Co. was selected as the nation’s top retail company in customer service. HDIS has been a generous corporate supporter of the Simon Foundation for Continence.

NEW RESOURCE AVAILABLE FOR DISABILITY INFORMATION...
One Step Ahead is a newsletter written by and for people with disabilities. Because many of the newsletter writers know first-hand about living with a disability, their perspectives are unique. For more information and subscription costs, call 800-386-5367.

THOUGHT FOR THE DAY...
“We make a living by what we get, and a life by what we give.”
—Winston Churchill

Award continued

and normalcy to children and adults with urologic abnormalities and dysfunctions.

Ms. Gartley was nominated by the Bladder Health Council of the American Foundation for Urologic Disease. The award is presented to “an individual who exemplifies the spirit of excellence through significant contributions to the specialty of urology.”

Accepting the award Ms. Gartley said: “I am honored to receive this award on behalf of all the staff, volunteers, and board members at the Simon Foundation for Continence. Their dedication and diligent work have brought visibility to a long neglected healthcare issue.”

Other winners of the 1995 Brantley Scott Award were Vicki Ratner, M.D., founder of the Interstitial Cystitis Association, and Katherine Jeter, Ed.D., founder of Help for Incontinent People.

Letters to the Editor

Dear Ms. Gartley:
Last month, I was telling you my “Luciano Pavarotti Concert” story when you were needed on the stage at Continence Awareness Day so I thought I would finish it in writing.

I attended this concert in Central Park last summer. N.Y.C.’s finest were out in full force! We arrived two hours before the concert, but part of my group had been there for hours. Therefore, our “blanket” was in the first section. An hour before show time, the police announced that if anyone left their area they would not be allowed back inside. I immediately became concerned because the port-o-pans were set up outside the barricades. I knew I would need to use one.

Only one friend attending the concert knew of my urological problem. I was born with a congenital birth defect including a deformed urinary bladder. My policy has always been not to mention my dilemma unless absolutely necessary. My friend accompanied me to the “front-line” to help plead my case but talking to the officers was getting us nowhere.

The bottom line, we would be allowed to use the “facilities”, but we would not be able to rejoin our group. At that point I asked to see their supervisor. They laughed as they pointed to him.

I approached and immediately showed my Medic Alert bracelet. No further words were needed. He assigned us a “police escort” who waited while I took care of business and then escorted me all the way back to our blanket! I was so pleased that I wrote a letter of commendation to his precinct commander.

A New Yorker continued on back
damage has healed.

If healing does not occur with time, then it is important to sort out the exact reason for the incontinence. The tests which are done to distinguish what is happening within the bladder are called urodynamics. These tests involve inserting a catheter into the bladder and filling the bladder with fluid while measuring bladder pressure. You may be asked to cough or perform maneuvers which simulate when you have leaked urine under normal conditions.

Urodynamics will tell your physician what is causing the leakage. If high bladder pressures are the cause, medications may help. If the problem is a weak sphincter, then an artificial urinary sphincter may be considered. If both conditions occur simultaneously, medication to normalize bladder pressure will be given first. Once the bladder is responding normally, an artificial sphincter may also be suggested.

According to an article by Judd W. Moul, M.D., exercises for men with post-prostatectomy incontinence (PPI) can be effective if the patient is instructed to perform them properly. Often biofeedback is used to help the patient do these exercises. Periurethral collagen injections may also be a solution depending upon the exact nature of the problem.

Thus, it is important for all men to know that much can be done to restore continence. By waiting to give the body time to heal, you can give yourself the best opportunity for success if a follow-up intervention is needed. If the physician who performed your surgery is not a continence specialist, ask him to refer you to someone who is interested and knowledgeable about incontinence.

**Bladder Week continued**

focus on incontinence. As a prelude to Bladder Health Week, this summer a public service announcement featuring actress Shirley Jones will begin airing on national television.

To further underscore the need to focus attention on bladder health, the Bladder Health Council released a new study at the American Urological Association’s annual meeting. The study, conducted by Yankelovich Partners, surveyed 1,000 women nationwide on a wide range of health issues, including incontinence. The study revealed that personal embarrassment and lack of information are preventing women from getting effective treatments for incontinence.

Alan J. Wein, M.D., a Simon Foundation Board member and co-chair of the Bladder Health Council, said at the AUA press conference: “More than 10 million Americans are affected by incontinence and 85% are women. The study underscores the need to educate the public about bladder health and to empower individuals with the knowledge to seek effective treatment.”

Women who answered the questionnaire reported that:

- they valued their health more than love or money; 89% say that good health is more important than financial security; a good marriage rated 57%
- a majority (52%) say they are concerned about developing incontinence, a proportion similar to those who say they are concerned about osteoporosis (56%) or hearing loss (53%). Yet 58% know “little” or “nothing” about incontinence.

These findings and others speak compellingly to the need to educate individuals about incontinence issues through Bladder Health Week. Shirley Jones, Dr. Wein, Ms. Gartley, and others from the Bladder Health Council kicked off the campaign at a press conference held recently in conjunction with the American Urological Association’s annual meeting. The Simon Foundation for Continence will be actively involved in Bladder Health Week. Ms. Gartley, President and Founder of the Simon Foundation for Continence is also a founding member of the Bladder Health Council.
Letters continued

Dear New York:
I hope more of our readers will consider using a Medic Alert bracelet. It's certainly one way to bring more awareness to the fact that there are many bladder disorders which are disruptive to an individual's life and therefore should be considered disabling. Thanks for sharing your story.

Dear Cheryle:
I don't know if you remember me, but I met you at the Continence Awareness Day in New York City. I am the 40-year-old commercial pilot who is still a bedwetter. I feel like I am the only adult who still wets the bed. It seems all other forms of incontinence are "acceptable" but bedwetting is still taboo and an adult who wets the bed is even worse.
I have dated some very nice girls, but have always ended the relationship when it got to where I would have to tell about the diapers or risk discovery. If you know other adults who are bedwetters and would be interested in corresponding, you may print my address.

Tom Caton
Suite 502
179-9 Route 46 West
Rockaway, NJ 07866

Dear Mr. Caton:
Of course I remember you. I understand and empathize with your reluctance to risk your secret. However, I can assure you there are numerous adults with nocturnal enuresis. Many of them have contacted the Simon Foundation for Continence and shared their stories. They tell us of women who are interested in them as warm, loving partners. I hope you'll begin to take the risk of letting others know about your problem. I'm sure you will hear from many of our readers who will share their stories with you.

Dear Cheryle:
Thank you for your sensitivity in not publishing a portion of my letter without first checking with me. I don't want to reveal my name at this point. Let me tell you about myself so that you might better advise me what to do.

I am 69 years old, have a Ph.D. and for over three decades have been a college professor. Several times each year I travel to various locations to give lectures at professional or public meetings. In the last few years I've found it increasingly difficult to get to a toilet quickly enough when I feel the urge. This challenge is complicated by my being blind, which often requires more time than normal to find a bathroom and locate a toilet inside. I wonder if any of your readers who have faced a similar situation would have some suggestions to share with me.

A reader from Alaska

Dear Alaska:
You and all Informer readers can be assured that we would never reveal a reader's name without their consent. Perhaps you would find it less stressful to travel if at every new destination you shared your problem with at least one associate. This person could be assigned the responsibility or privilege of locating washrooms and giving you clear directions. Two things would be accomplished...you would help spread the word that bladder control problems are common. The second would be to give someone the chance to understand another type of challenge that human beings overcome by determination. We'll send along to you any reader's suggestions.

Dear Informer:
I am concerned about the letter from Oregon regarding signs outside of public restrooms. These signs notify users that it is legal to have the opposite sex bring in disabled people if they are using a wheelchair. People tend to not realize that not all disabled people are in wheelchairs. I am a registered nurse and work in a facility for developmentally disabled individuals. Many need help in the bathroom. Some can't be left unsupervised even if they are not in a wheelchair. Someone also could have a disability or temporary medical condition which interferes with the use of their hands.
The facility where I work has restroom door signs stating that a person of the opposite sex can assist a handicapped person. It has a drawing of a handicapped person in a wheelchair and also standing. I really appreciate your attempts to bring attention to the need for more public restrooms. I have a chronic bladder problem which makes it necessary for me to plan everything that I do in regard to the availability of restrooms. The Simon Foundation is providing a very valuable service and I wish you success in all that you are doing.

California

Dear California:
Your point is well made. In the future when we advocate for better washroom access we will pay special attention to the fact that not everyone who needs help in a washroom uses a wheelchair. I hope all of our readers will write to us with suggestions for more public awareness.