# DEALING WITH INCONTINENCE AFTER TREATMENT FOR PROSTATE CANCER

Compiled by Charles (Chuck) Maack – Prostate Cancer Activist/Mentor

**DISCLAIMER:** Please recognize that I am not a Medical Doctor. I have been an avid student researching and studying prostate cancer as a survivor and continuing patient since 1992. I have dedicated my retirement years to continued research and study in order to serve as an advocate for prostate cancer awareness, and, from a activist patient's viewpoint, to voluntarily help patients, caregivers, and others interested develop an understanding of prostate cancer, its treatment options, and the treatment of the side effects that often accompany treatment. There is absolutely no charge for my mentoring – I provide this free service as one who has been there and hoping to make your journey one with better understanding and knowledge than was available to me when I was diagnosed so many years ago. Readers of this paper must understand that the comments or recommendations I make are not intended to be the procedure to blindly follow; rather, they are to be reviewed as my opinion, then used for further personal research, study, and subsequent discussion with the medical professional/physician providing your prostate cancer care.

As regards incontinence issues, I would hope that your physician provided you some good instructions explaining kegel exercises to get the pubococcygeus muscle back to performing its job.

In any event, visit the following for directions:

# http://www.kegelexercisesformen.com/

Interestingly, the teacher of a student in a home-schooling class said in their research of health issues they came across my <a href="www.theprostateadvocate.com">www.theprostateadvocate.com</a> website and the student, in noticing I have this paper regarding dealing with incontinence, had also found a reference paper regarding dealing with incontinence and gave it to her teacher asking if this was something that would be of interest in this paper. The teacher emailed me and I found the reference, below, of yet additional interest to those dealing with this discomforting issue, and so I have added it: <a href="http://www.parentgiving.com/elder-care/incontinence-information">http://www.parentgiving.com/elder-care/incontinence-information</a>

Important to be aware is that there can be physical reasons why one is unable to regain continence following surgical or radiation treatment for PC.

I have found that if preferring "pads" while performing Kegel exercises to hopefully eventually strengthen bladder/urethral muscles to end urinary leakage, the purchase of Jockey shorts and inserting a female "pad" works quite well. Pads can be purchased in the thickness that works sufficiently. For those with total incontinence the recommendation would be to purchase men's Depends "shorts" that have their own padding, but insert Poise "Overnight" pads in so that these pads can be changed as necessary throughout the day and/or night while not going through numerous Depend underwear.

If you are experiencing a long period of incontinence, while continuing working at kegel exercises you might want to consider a look into purchasing an Alpha Dry Catheter with Reservoir. The \$7.00 for a sample test is well worth the expense.

ALPHA DRY CATHETER WITH RESERVOIR (Visit <a href="www.urodry.com/">www.urodry.com/</a> then visit index for further explanation, a visual, and how to get a sample). This is one of the most recent products and easily among the best. It is a one-piece, reusable condom catheter with a 600 cc expandable reservoir. It has a very good back flow prevention valve and the heavy duty condom section has built in grippers which make it more secure than the typical condom catheter. It is very comfortable and does not show when worn under ordinary briefs. Medicare supposedly will pay for two of the devices per month (I think that they will last longer than a month). UroDry will send a sample Alpha Dry trial options kit that includes 1Alpha Dry System and 1 pair of long-legged briefs for \$29.95. (There are different "sizes" of condom connections for better fit/holding, as well as different sized briefs, so you should discuss sizes when ordering either calling, or review the sizing chart at the website. I believe they also have a connecting kit for a larger reservoir for bedtime, so ask about that.).

Condom connections come in sizes small/10023, medium/10025, intermediate/10027, large/10030, and extra-large/10034.

Long-legged briefs (gray only) come in medium/32-34, large/34-38, and extra-large/40-42.

Here is contact information:

Phone: 1-888-391-7132 (toll free)

(503) 391-7132

Email: info@urodry.com

Address: UroDry Medical, LLC

1211 Edgewater N.W. Suite 2

Salem, OR 97304

For some men experiencing a withdrawn penis from atrophy/lack of use other than urinary, the Alpha Dry may not adequately stay on the shortened penis. In this case, and for those who prefer other than a external catheter, the following can be considered.

Prostate Cancer survivor Michael Holland who has spent personal research and study of erectile dysfunction as well as incontinence has this to offer to help men experiencing incontinence issues: "What DOES work and what I endorse strongly is the MIC Male Incontinence Clamp (aka PP Stop)"



This is a compact, light, molded plexiglass clamp that goes on and comes off easily and is easily adjusted.

I never have had discomfort or lack of circulation, even wearing for several hours or more.

Since it clamps the top and bottom, but not the sides of the penis, circulation is fine.

You can find these at <a href="http://ppstop.com/">http://ppstop.com/</a> "

The website provides a very comprehensive explanation of is use and instructions for application and care.

Another source of male incontinence clamps as well as pouches is explained below and are available via the website of Community Medical Products <a href="https://www.commedpro.com">www.commedpro.com</a>. I have tried these products and explain as follows:

## **URICLAK:**



Uriclak – The product takes a bit of dexterity to squeeze "open" but once the head of the penis is fitted through the pressure type opening, and the product released, it does provide a reasonable and not uncomfortable pressue on the urethra to retain urine from passing through. If a patient wishes to not have it as tight/constricting as normal, it does, again, take a bit of "work" to insert different size "pegs" (provided) at the ends – particularly if trying to insert the thicker pegs. I had to use a pliers when trying to insert a thicker peg. Had less trouble with the thin pegs, but still helped to have pliers on hand to help "squeeze" the pegs appropriately through and a good idea to have vaseline handy to aid in "re-sizing." The online website instructions for this product are much better than that included with the product and those interested should be encouraged to visit the below for more comprehensive instructions.

http://www.commedpro.com/product/uriclak-male-incontinence-clamp/

## **DRIBBLESTOP:**



Dribblestop – I immediately liked how well the instructions were written and use explained. Product very easy to use and reasonably comfortable when "clamped" in view of the foam padding.

http://www.commedpro.com/product/dribble-stop-incontinence-clamp/

## **ACTICUF POUCHES:**



Acticuf pouches – Certainly reasonable for those who only experience occassional dribble and want safe protection while out and about; not for patients experiencing urine leakage more than occassional dribble. Best for those who experience very light urinary dribble or stress/pressure "squirts" that can result from sudden activity that puts pressure on the bladder. Just a bit "snug" when applying over penis and releasing the plastic "cuff."

## http://tinyurl.com/p2hlp62

The products identified are all reasonable for patients with urinary incontinence issues to consider.

Should your incontinence become uncontrollable by usual methods, you could then consider surgical installation of either a "male sling" or an Artificial Urinary Sphincter.

A patient report of exceptional care when considering the AdVance male sling regarded Urologist Allen Morey, Specialist in AdVance Male Sling for Incontinence, Aston Building, 5303 Harry Hines Blvd., 9<sup>th</sup> floor, Suite 110, Dallas, TX 75390, 214-645-8765.

Here is a URL that when you scroll down gives a pretty good explanation of what is going on and how the artificial urinary sphincter works.

# http://kidney.niddk.nih.gov/kudiseases/pubs/uimen/index.htm

Important to be aware: "Prior Radiotherapy Boosts Artificial Urinary Sphincter Problems." This is important to be aware if considering installation of an AUS but have experienced prior radiation therapy to the prostate/prostatic bed. This paper describes the importance of recognizing that you may experience some serious problems and explains those issues. Please open the following from Medscape, and if subscribing to Medscape is required to open, please note that subscribing is free: <a href="http://tinyurl.com/oczg8ww">http://tinyurl.com/oczg8ww</a>

Interestingly, according to renowned urologist Patrick Walsh 2nd edition book Guide to Surviving Prostate Cancer, p. 303, ".......whatever you do, do not wear an incontinence device with an attached bag, a condom catheter, or clamp! If you use any artificial device, you will hurt yourself in the long run. You won't be able to recover your urinary control, because you won't develop the muscle control you need. Until your urinary control returns completely, wear a pad......or disposable diaper......"

I agree that in the early stages of incontinence it is important to do everything possible to exercise the urinary muscles with kegel and other exercises. Yet, I am aware of many patients who have followed these recommendations but because of apparent internal urinary issues were unable to "stem the flow." When this becomes the case, it is certainly reasonable to consider the "incontinence device with an attached bag" or "condom catheter" to give the patient relief from

continuous and multiple pads while seeking a physician with the expertise to determine what needs to be done to resolve this dilemma of many men.

## **REGARDING INJECTIBLE IMPLANTS:**

http://www.nlm.nih.gov/medlineplus/ency/article/007373.htm

#### AND MORE:

"There are varying degrees of treatments," says Janine Morris, Chief of the FDA's Urology and Lithotripsy Devices Branch. "They go from conservative therapy to surgery. All are for managing symptoms, and all have benefits and drawbacks."

Treatment options fall into four broad categories: behavioral, medications, devices, and surgery.

## Behavioral Therapy

Behavioral therapies are noninvasive, free of side effects, and don't limit further treatment options. These therapies include "retraining" the bladder and doing exercises called Kegels.

Bladder retraining helps the bladder to hold urine for longer periods of time. The individual is instructed to empty the bladder at scheduled times during the day, and then to gradually extend the time between bathroom trips.

For stress incontinence, a doctor may recommend Kegel exercises to strengthen the muscles below the bladder (pelvic floor muscles) that hold in urine. These exercises for women and men involve repeatedly tightening, holding, and then relaxing the pelvic floor muscles. Leng advocates Kegels for patients with mild incontinence. "And like any exercise, it's only effective as long as you continue doing it." Some people can't tell whether they are doing the exercises correctly. "A lot of women try to do the exercises on their own and give up," says Leng, who refers patients to a physical therapist to teach them to use the proper muscles. Specialists may use biofeedback devices that indicate a muscle contraction when the correct muscle is exercised. Some biofeedback devices are sold over-the-counter for home use.

### Medications

Another treatment option is medication, as seen in those "gotta go" television ads. The drugs in those ads are for treating overactive bladder, or urge incontinence, says George Benson, M.D., a urologist in the FDA's Division of Reproductive and Urologic Drug Products. No drugs are approved for stress incontinence.

For many years, only two drugs were approved to treat overactive bladder: Detrol (tolterodine tartrate) and Ditropan (oxybutynin chloride). In 2004, the FDA approved three more drugs: Sanctura (trospium chloride), Enablex (darifenacin), and Vesicare (solifenacin succinate). All of these medications come in pill form, and oxybutynin is also available as a skin patch.

"All five drugs work in essentially the same way to decrease urgency, frequency, and urge incontinence," says Benson. "They block the nerve impulses to the bladder that cause it to contract and leak." Side effects of the drugs include dry mouth, constipation, headache, and blurred vision.

How about considering a natural product for urge incontinence? Here's a surprising revelation among the health benefits of magnesium: Women with urinary urge incontinence (also called overactive bladder) may benefit from taking magnesium supplements (therefore, so should men). In a study reported in Family Practice News (February 1, 2003), 60 women with overactive bladder were divided into two groups, one receiving a placebo and the other group receiving 350 milligrams of magnesium hydroxide daily for one month. Twelve of the 30 in the magnesium group reported improvement in their overactive bladder in one month, along with significantly fewer incidents of urge incontinence, less frequency of urination, and fewer times of being waked at night to urinate. As relatively small amounts of supplemental magnesium effectively relieved urge incontinence in the new study, it is likely that suboptimal dietary magnesium intake is one of the causes of this disorder.

# Nonsurgical Devices

Some men and women with stress or urge incontinence are helped with electrical stimulation devices, which help strengthen the pelvic floor muscles. Mild, painless electrical pulses are sent to these muscles through electrodes temporarily placed in the rectum or vagina. Another stimulation device, available in some urology facilities, is the NeoControl Pelvic Floor Therapy System.

Devices for men include clamps and compression rings that fit over the penis to squeeze the urethra shut. These must be removed to empty the bladder. Possible side effects are pain and tissue erosion when these devices are not used properly.

# **Implanted Devices**

When other treatments have failed, implanted devices or surgery may be effective.

In a 30-minute outpatient procedure, a thick substance--made of collagen, carbon-coated beads, or other particles suspended in a solution--can be injected into the area surrounding the opening to the bladder. The substance, called a bulking agent, helps close the bladder opening to prevent leakage. Bulking agents are approved to treat stress incontinence due to poorly functioning sphincter muscles. The collagen device is approved for both women and men; others are approved only for women.

Repeat injections of bulking agents may be needed because the body slowly eliminates the substance over time. Other potential side effects are urinary tract infection, delayed ability to urinate, painful urination, urgency, frequent urination, and blood in the urine. When men or women with overactive bladder have failed to respond to more conservative treatments, an electrical stimulation device can be placed next to the tailbone. This "pacemaker" for the bladder is marketed as InterStim Therapy by Medtronic Inc. of Minneapolis. The treatment requires a trial period in which a doctor surgically implants a temporary electrode in the lower back. The temporary electrode is attached by a thin wire called a lead to an external stimulation device, which patients carry with them for a few days. The device sends mild electrical pulses to the nerve that controls the bladder and surrounding muscles. Patients can try it first, says Leng. "If there's dramatic improvement, then the device is permanently implanted at a second outpatient surgery, leaving all hardware under the skin."

"In clinical studies, more than one-third of the patients did not receive the implanted device typically because they did not have significant improvement during the trial period," says Morris.

# Other Surgical Treatments

Most stress incontinence in women results from the bladder dropping down, which often occurs after childbirth, according to the NIDDK. Two common surgical procedures for severe stress incontinence are retropubic suspension and sling surgery. These surgeries are usually performed in women, but can be done in men who are incontinent after removal of all or part of the prostate gland.

In retropubic suspension, the surgeon pulls the bladder up to a more normal position by sewing it to surrounding bone or tissue. In sling surgery, the surgeon inserts a supportive strap of material (suburethral sling) to elevate the urethra and bladder neck, anchoring it to each side of the pubic bone. Slings are medical devices made from synthetic material, or they can be fashioned from donor tissue or the patient's own tissue, which is cut from the abdominal wall. Although it is a more invasive procedure, some patients prefer using their own tissue, says Roger Dmochowski, M.D., professor of urologic surgery at Vanderbilt University in Nashville, because synthetic material may erode into the urinary tract and cause infection or reduce effectiveness. Newer techniques for sling insertion are minimally invasive, allowing for smaller incisions and shorter hospital stays. These techniques are "variations on the suburethral sling," says Leng, "and they conceptually work the same way to provide a little hammock for support to the urethra.

Dr. Allen Morey, University of Texas (UT) Southwestern Department of Urology at 214-648-4765

http://www.utsouthwestern.edu/findfac/professional/0,2356,94915,00.html is considered an expert in the installation of the AdVance Male Sling. You can read more regarding this product and installation at thi URL:

http://www.eurekalert.org/pub\_releases/2007-08/usmc-nms082707.php

A website that provides several recommendations including accessing physicians who supposedly specialize in incontinence is found at http://www.malecontinence.com/.

Like any surgery, retropubic suspension and sling surgeries all have

their risks, including infection, injury to the bladder or urethra, and urinary retention. "And none of these surgeries last a lifetime," says Dmochowski, adding that 10 years of effectiveness is what most treatments attempt to accomplish. "New symptoms may cause problems," he says. As a woman ages and her body changes, "pure stress incontinence may become urge incontinence."

That's what happened to Behanna.

Behanna was in her early 30s when she was diagnosed with stress incontinence. A sling surgery solved the problem for about five years, she says. Then she developed urge incontinence. Behanna tried a number of treatments, including Kegel exercises and medications, without much relief.

Desperate for a new treatment that she hadn't tried yet, Behanna sought advice from the doctors at the women's hospital where she works. "Every time a new urologist was hired, I would corner her and say, 'I've been peeing in my pants--can you help me?""

Behanna was presented with the option of the InterStim, and in April 2005, she tried it. During the trial period before the permanent electrode and stimulator are implanted, she had some doubts. She was sore from a large incision in her upper buttock to make a pocket of tissue for the permanent stimulator to fit into. And a temporary long lead was sticking out of her body. "I had to be careful not to catch it on anything," she says.

After a week with no results, the InterStim manufacturer's representative reprogrammed the device. "The second week was better," says Behanna, and she opted for the permanent implant.
"It was all worth it," she says. "I'm so glad I did it. I feel more confident and I'm not wearing pads now." Behanna says she still has some accidents, but her condition is about 90 percent improved.

#### Prostate-Related Incontinence

As a man ages, the prostate typically becomes enlarged. This enlarged gland may squeeze the urethra and irritate the bladder, causing urinary problems. "Men with an enlarged prostate may have many of the same symptoms of an overactive bladder," says Benson, "with urgency, frequency, and urge incontinence."

Prostate cancer and its treatment increase the likelihood of urinary problems. Those who have had the whole prostate gland removed (radical prostatectomy) represent "probably the largest group of men who have

urinary incontinence," says Judd W. Moul, M.D., professor and chief of urologic surgery at Duke University in Durham, N.C.

Increased public awareness and screening are leading to earlier treatment for prostate cancer, says Moul, "so the good news is the cure rates are going up, and the other good news is the risk of incontinence is getting less." Yet, up to 20 percent of men treated for prostate cancer have stress incontinence, he says.

Ray Walsh is one of them. After a radical prostatectomy in 1999, "I leaked the day after my operation and continued to leak for years," says the 70-year-old Annandale, Va., resident. "It was aggravating to walk around wet all the time."

Walsh tried an array of treatments--bladder retraining, Kegel exercises with biofeedback, medication, behavioral modification, and the InterStim--with no significant improvement. So in 2001, he had an "artificial sphincter" implanted.

The FDA approved the device, the AMS 800 Urinary Control System made by American Medical Systems Inc. of Minnetonka, Minn., for men who have stress urinary incontinence due to weakness of the sphincter muscles after prostate surgery. It consists of three parts connected by tubing, all surgically implanted: a fluid-filled synthetic cuff that surrounds the urethra, a pump placed in the scrotum, and a balloon reservoir implanted in the abdomen. To urinate, the man squeezes the pump in the scrotum. This action causes fluid to drain from the cuff into the reservoir, which opens the urethra and allows urine to pass. The cuff automatically refills 90 seconds later, closing the urethra. Walsh says the device gave him "great improvement," at first. "I used 10 to 12 pads a day," says Walsh. "When they put the artificial sphincter in, it cut it down to one to two pads." But several years later, when he started having more leakage, Walsh's doctor gave him some disturbing news. "The cuff cut off some of the blood supply and the flesh under the cuff is atrophied to some degree," he says. "I'm not getting as good closure by the cuff."

Walsh is now considering another surgery to get a second cuff to assist the first one. "The downside of that," he says, "is that the flesh between the two cuffs can atrophy because the blood supply is cut off from both sides." In the meantime, Walsh is taking a bladder-relaxant medication, which is giving him "a little more control," he says. "I'm just destined--until I put that second cuff in--to using three to four pads per day."

The following URL leads to an explanation/description of the entire process of installing the AMS 800 Urinary Control System:

http://www.americanmedicalsystems.com/mens\_how\_works\_detail\_objectname\_male\_AMS\_800.html

If the foregoing descriptive procedure does not satisfy your interest in seeing the actual procedure, there are AMS 800 Video's accessible by typing those words...AMS 800 Video...in the internet search box. However, one must have RealPlayer access or subscribe to RealPlayer in order to view the video. I found the description of the procedure in the above URL brought a sufficient graphic to mind to recognize that the actual visual would likely be disconcerting to any patient planning on the procedure.

## Choosing a Treatment

Experts agree that no treatment is perfect for everyone with incontinence. Treatment depends not only on the type and severity of incontinence, but on an individual's lifestyle and personal preferences. And the success of treatment is an individual perception, says Leng. "Some patients with stress incontinence and active lifestyles expect that 'success' means no more pads. On the other hand, some patients with severe incontinence of a complex nature who have failed multiple treatment options may be thrilled with 50 percent improvement of their bladder control."

"It may not always be a reasonable expectation to be cured," adds Dmochowski. "We try to focus on improvement rate."

Some people are satisfied with the improvement that conservative measures give them. About 70 percent of women with incontinence problems are helped by a combination of simple measures such as bladder retraining, exercises, and medication, says Dmochowski, who specializes in treating women's urology problems. Moul, who treats men, says a combination of pads, medications, and exercise is effective for many men with incontinence problems.

Although Dmochowski thinks of surgery as a last resort, not all of his patients do, he says. "Some younger women with pure stress incontinence are desirous of a one-step procedure, and surgery often provides that.

It's an individual choice."

In any case, says Dmochowski, "people should look at the degree of their problem and their quality of life, seek a consultation, be aware of all the options, and actively participate in the decision process."

#### **INCONTINENCE SPECIALISTS:**

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Dr. George D. Webster, Division of Urologic Surgery, Duke University 919-684-2516, Durham, N.C., (Known for expertise with difficult cases) Website: <a href="http://www.dukehealth.org/physicians/george\_d\_webster">http://www.dukehealth.org/physicians/george\_d\_webster</a>

Dr. Jack McAninch, University of California, San Francisco (UCSF) <a href="http://www.ucsfhealth.org/adult/cgibin/prd.cgi?action=DISPLAYDOCTOR&doctorid=811">http://www.ucsfhealth.org/adult/cgibin/prd.cgi?action=DISPLAYDOCTOR&doctorid=811</a>

Appointments: (415) 476-3372

Dr. Niall Galloway, The Emory Health Clinic, Inc., Urology, 1365-B Clifton Rd., N.E., Atlanta, GA Tel: 404-778-4898

Dr. Rodney A. Appell, Baylor College of Medicine, The Scott Dept. of Urology, 6560 Fannin, Suite 2100, Houston, TX 713-798-4001

Dr. Gregory F. Byrd, Wichita Urology Group, 2626 N. Webb Road, Wichita, KS 67226.

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http://www.ucdmc.ucdavis.edu/urology/ourteam/biodetail.asp?bioid=187

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Dr. Victor Nitti, New York University Medical Center, 150 East 32<sup>nd</sup> St, 2<sup>nd</sup> Floor, New York, NY 10016, Tel: 646-825-6324. Background info: <a href="http://urology.med.nyu.edu/about/physicians/nitti">http://urology.med.nyu.edu/about/physicians/nitti</a>
For appointment contact Dr. Nitti's Practice Manager by email: <a href="mailto:ellen.taunton@nyumc.org">ellen.taunton@nyumc.org</a>

For More Information
National Kidney and Urologic Diseases Information Clearinghouse
(800) 891-5390
<a href="http://kidney.niddk.nih.gov/kudiseases/topics/incontinence.asp">http://kidney.niddk.nih.gov/kudiseases/topics/incontinence.asp</a>
National Association For Continence
(800) BLADDER (252-3337)
<a href="http://www.nafc.org/">http://www.nafc.org/</a>
Simon Foundation for Continence
(800) 237-4666
<a href="http://www.simonfoundation.org/">http://www.simonfoundation.org/</a>

# WHEN ALL ELSE FAILS

Some patients experience complete or near complete closing of the urethra/sphincter at the anastamosis of the bladder neck to the urethra because of extensive scarring resulting from treatment. When this occurs, self catheterization no longer works, stents no longer work, and even an artificial urinary sphincter can serve no purpose because of the blockage. Patients should recognize that when this occurs there are surgical procedures to redirect urine release. The preferred method would be to close off the bladder neck, then from the bladder create an abdominal catheterizable stoma from the umbilicus to the bladder using intestine. This permits continued use of the bladder and catheterization is easily accomplished at the umbilicus.

Alternatively, if necessary the bladder can be bypassed with urinary diversion (ileal conduit/urostomy) wherein the ureters are detached from the bladder and joined to a short length of the small intestine. One end of this section of ileum is sealed off and the other end is brought to the surface of the abdomen to form a small spout – this is the stoma. This is where the urine will come out. It has no muscles to regulate the passage of urine which will need to be collected in a bag.

Though these are procedures one would want to avoid, they are important procedures when all else fails and can be extremely welcome procedures to provide relief to those experiencing the discomfort, pain, and anxiety of long term urine blockage.

Patients experiencing this problem should discuss these procedures with their urologist or be referred to centers/urologists with experience in continent urinary diversion.

I HOPE SOMEWHERE IN ALL THE FOREGOING YOU CAN FIND RELIEF