# WRAMC US TOO, Inc.
**A PROSTRATE CANCER SUPPORT GROUP**
**SPONSORED BY**
**WALTER REED ARMY MEDICAL CENTER**
# NEWSLETTER

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## ♦ DaVINCI AND ME ♦

**by**
**MARK C. HERBERS, SR.**

**Getting the Diagnosis**

It's October 2002 and time for my regular six-month blood work. My thyroid was removed 15 years ago and I'm on Vitamin L, aka Lipitor. I'm 48 years old, so my doctor says "Let's get a baseline PSA while we're at it." OK, it's just one more vial for the phlebotomist to draw. A digital rectal examination is unremarkable. The blood test results come back OK except for a PSA of 3.0. The doctor recommends a prostate biopsy because a PSA of 3.0 is borderline high for a 48-year-old male. No big deal, I'll get the biopsy. This first biopsy shows atypical cells; a second biopsy three months later is normal. It later would become clear that the cancer was missed during this second biopsy. I'm told to return in a year. I had another PSA done in September 2003—my PSA was now 2.9. However, other major health concerns unrelated to prostate cancer diverted my attention, so a third biopsy was neglected. This judgment, both by medical professionals and myself, haunted my wife Kathy.

Now it's October 2004, my PSA has risen from 2.9 to 6.9 in about eleven months! Another biopsy shows six of ten samples positive for cancer, and a Gleason score of 3 + 4. I'm a candidate for surgery or radiation (probably brachytherapy). Given my life expectancy of 20+ years, the urologist recommends a radical prostatectomy as the more definitive therapy. Now it's time for the Internet and full discussions with my wife and my internist. My wife is an RN and my health advocate.

**Selecting the Therapy**

My cancer has been detected early, it is not aggressive and my health is good, so I should tolerate surgery well. Radiation therapy as an infant left me with three benign tumors in my chest and neck, so additional radiation does not seem prudent. Information begins to pour in from family and friends who have dealt with prostate cancer. I am introduced to the WRAMC Us TOO Newsletter and the first edition we receive contained an article about the DaVinci robotic surgical system by Jason Engel, MD, at George Washington University. In the meantime, our Internet research also leads us to the DaVinci robotic system. I narrow the choice to a conventional radical prostatectomy or the DaVinci procedure. The major considerations are insurance coverage, treatment availability in proximity to Chicago, and recovery time. **(Con't on page 7)**

## ♦ *INSIDE THIS ISSUE* ♦

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## ♦ FROM THE EDITOR'S DESK ♦

Our first person account in this issue is a special one for several reasons. First, the author provides us with a very interesting, almost diary-like, account of his experience in dealing with prostate cancer. Second, his article gives us a patient's insight into the Da Vinci robotic system for the performance of a radical prostatectomy. Finally, we are pleased that the author cited the WRAMC Us TOO Newsletter containing an article by Dr. Jason Engel of George Washington University Hospital who had made a presentation on the Da Vinci robotic system to our WRAMC Prostate Cancer Support Group. No doubt Dr. Engel also will be pleased

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Our speakers for the February 1, 2006, meeting were Ralph and Barbara Alterowitz, noted lecturers and authors on the topic of intimacy. The Alterowitzs' presented a frank and sensitive treatment of a subject of special concern to our readership. This was the Alterowitzs' second appearance before our group and we are very grateful for their continuing support. A summary of their topic, "Return to Intimacy After Prostate Cancer Therapy," begins on page 11.

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### ♦ PROGRAM FOR WEDNESDAY, MAY 3, 2006 ♦

Our program for Wednesday, May 3, 2006, is a change of pace from our usual program. Several years ago we presented a panel of five prostate cancer survivors who described their individual experiences with the various prostate cancer treatments, then answered questions. This approach was well-received and since then we have had requests to repeat the program. So here it is! Join us at 7 PM on Wednesday, May 3, 2006, in Joel Auditorium. Plan now to attend and bring your spouse or a friend. They are always welcome.

**Poverty, Not Race, Explains Prostate Cancer Disparities.** Prostate cancer incidence and mortality rates show racial disparities with African-Americans at particular risk of diagnosis with more advanced disease and higher mortality rates than Caucasians. Whether these disparities are due to racial factors or socioeconomic status needs to be explained. Xianglin L. Du, et al., University of Texas School of Public Health, analyzed 11 years of data from 61,228 men aged 65 or older who had been diagnosed with local or regional stage prostate cancer to identify the role of race in prostate cancer survival. The researchers found that race played little role in outcome. Instead, disparities were explained by such socioeconomic factors as level of education, level of poverty, and income. Similarly, other conventional factors such as age, stage of disease, type of treatment, and number of co-morbidities were less strongly associated with poor survival. The researchers concluded that lower socioeconomic status was significantly associated with decreased survival; while there was racial and ethnic disparities in survival, these disparities were substantially reduced after controlling for socioeconomic factors. (Source: *CANCER* American Cancer Society, on-line February 13, 2006, via the National Prostate Cancer Coalition, February 14, 2006)

**Vitamins and Prostate Cancer.** Taking Vitamins E and C or the nutrient beta carotene does not protect against prostate cancer according to the latest study in the confusing quest to determine when or whether health supplements really help health. Many past studies have examined whether these antioxidants play a role in prostate cancer when taken as pills, instead of being consumed as part of an overall healthy diet. The past study outcomes are often conflicting. Now the Journal of the National Cancer Institute's study of 30,000 men found that 1,338 men (4.5%) were diagnosed with prostate cancer within eight years of entering the study. Supplement users were just as likely to be diagnosed with prostate cancer as nonusers. The study concluded that there is not strong support for population-wide implementation of high-dose antioxidant supplementation for the prevention of prostate cancer. Observers say this latest study is unlikely to resolve the issue. (Source: *The Washington Post*: page A-10, February 15, 2006)

**Effectiveness of the Artificial Urinary Sphincter.** A study reported in the February 2006 issue of *The Journal of Urology* says that the artificial urinary sphincter (AUS) has long-term effectiveness in about 80% of men and women who are treated with the device. Diokno and Petero, William Beaumont Hospital, Royal Oak, Michigan, studied the efficacy of the AUS over 20 years in 108 patients (53 men, 55 women) with stress urinary incontinence. Forty-nine patients had no complications, and the original device remained in place. Forty-seven patients needed partial or total revisions, and 12 patients had the device removed. Out of a total of 168 AUS devices implanted, 76 (45%) eventually failed for various reasons. The proportion of mechanical failures over time was comparable for men and women. Overall, 81% of the men and 84% of the women achieved satisfactory continence, although some did use pads in conjunction with the AUS. Urinary incontinence associated with radical prostatectomy was the main reason for men relying on the AUS. (Source: *J of Urology* 2006; 423-4, 605-609 via Reuters Health Information, February 10, 2006)

**Virus as a Factor in Prostate Disease.** Klein, et al., Cleveland Clinic, claim a remarkable discovery suggesting that disease may be a factor in prostate cancer in addition to genetics and the environment. The virus, previously found only in mice, was found in cancerous prostates removed from men with a certain genetic defect. The researchers warn that they have not found any links between the virus and prostate cancer. Nevertheless, the findings open new avenues for studying the most common cancer among men. Infectious-disease-causing viruses are already blamed for some liver cancers and cervical cancer. The researchers will now develop a diagnostic tool that will allow the testing of thousands of patients and non-patients alike to determine if there is indeed a link between prostate cancer and the virus, which causes cancer in mice.(Source: *The Washington Post*, Saturday, page A-7, February 25, 2006)

**Screening for African-American Men.** Previous studies have suggested that prostate cancer occurs at a higher rate and with greater morbidity in African-American men compared with most other racial or ethnic groups. So it is perplexing that African-American men with a family history of prostate cancer are less likely to be tested for prostate cancer than African-American men without such a history. Studying a group of men who had four or more relatives affected by prostate cancer, researchers at the Medical College of Georgia were especially concerned by the decrease in screening in men age 60-70 years old because the average age at which African-American men are diagnosed with prostate cancer is 65. The researchers urge that at-risk African-

American men be informed of the benefits and limitations of screenings and get actively involved in the decision-making regarding prostate cancer screening. (Source: Cancer 2006; 106:796-803 via Reu-
ters Health Information, February 10, 2006)

**Consumption of Fish Oil and Cancer Risk.** In the laboratory and in mice, omega-3 fatty acid - fish oil - has shown promise against tumors. So will eating fish or taking fish oil supplements protect against cancer? A recent study analyzed dietary data and cancer incidence reports from 38 studies involving more than 700,000 people who were followed for up to 30 years. These prior studies had examined the occurrence of 11 types of cancer - primarily breast, colorectal and prostate cancer. The researchers did find some evidence of both increased and decreased risks, but most often there was no link between occurrence of cancer and the participants' consumption of fish or fish oil supplements. The study concluded that taking supplements was unlikely to reduce the risk of cancer. However, eating fish remains a good source of healthier fat and is thought to be good for the heart. The study was reported in the January 25, 2006, issue of the *Journal of the American Medical Association.* (Source: *The Washington Post*, Tuesday, Feb 7, 2006)

**Biofeedback and Post-Prostatectomy Incontinence.** Behavioral training has been shown to decrease incontinence following prostate surgery. Now researchers have produced evidence that preoperative behavioral training may also be effective. Burgio, et al., University of Alabama, evaluated the effectiveness of preoperative biofeedback to hasten return of urinary control, decrease the severity of post-operative incontinence, and improve quality of life in the six months following radical

prostatectomy. The intervention consisted of one session of biofeedback in which men learned pelvic floor muscle control and received instructions in daily pelvic floor

muscle exercises. Of the 51 men in the intervention group, 70% said they continued doing the exercises at the 6-month follow-up. Median time to continence in the biofeedback training group was 3.5 months. Fewer than half of the 51 men in the control group achieved continence by the six-month follow-up period. Also, severe or continual leakage was still present in nearly 20% in the control group compared to 5.9% of men in the intervention group. The researchers note that even more dramatic results may be obtainable by more intensive preoperative training or by a more regular program of postoperative visits to further maximize outcomes. (Source: *J of Urology* 2006; 175: 196-201 via Reuters Health Information, January 17, 2006)

**Obesity and Prostate Cancer.** Freedland, et al., Duke University School of Medicine, report that technical factors unrelated to underlying biology may make prostate cancer more difficult to detect in obese men in their early sixties and younger. Missing some cancers in younger obese men may lead to delayed detection and the possibility of a later-stage cancer. This situation may be contributing to the worse outcomes now observed among obese men. Also, the researchers note that obesity may be associated with decreased PSA production and prostatic enlargement making detection more difficult. The study examined the relationship between body mass index (BMI), prostate weight, and PSA in more than 1,400 men undergoing radical prostatectomy. In the men younger than 63 years, increasing BMI was associated with increasing prostate weight. Prior studies have shown that larger prostate size is

associated with lower detection rates from prostate needle biopsy. Based on the degree of prostate enlargement found in this study, the researchers estimate that there could be a 20% to 25% reduction in the chances of detecting prostate cancer by biopsy. (Source: *J of Urology* 2006; 175:500-504 via Reuters Health Information via Medscape, February 28, 2006)

**Alternative Therapy Widely Used.** About one third of prostate cancer patients in the United States rely on some type of alternative or complementary medicine to deal with their conditions, according to a recent national study. Approximately 26% report using mineral or vitamin supplements, 16% take herbal products, 13% take antioxidants, and 12% some other type of alternative treatment for prostate health, such as saw palmetto and lycopene. A concern is that up to half of those using these products may not be telling their physicians about their reliance on alternative therapies. (Source: *AWARE News*, National Prostate Cancer Coalition, January 31, 2006)

**Radiation Effective for Early Prostate Cancer.** According to recent research, both brachytherapy and external beam radiation appear to be equally effective for treating low- and intermediate-risk localized prostate cancer. Coen, et al., Harvard Medical School, matched 132 patients treated with high-dose external beam radiation (EBRT) and 132 treated with brachytherapy for localized prostate cancer. The patients were matched for stage, Gleason score, PSA, and age. After a median of 5.4 years for the EBRT group and 4.7 years for the brachytherapy, there were no significant differences between the two treatments in both low-risk and intermediate-risk patients. Both therapies appear to be equivalent regardless of risk category. The researchers conclude that

equal efficacy of the two treatments in biochemical outcome suggests that other factors such as quality of life and complications of the therapies will drive patient decisions in the future. (Source: Reuters Health Information, February 27, 2006)

**Experienced Surgeons Produce Better Results (but we already knew that, didn't we?** The findings from a large study involving nearly 10,000 men who underwent conventional prostate cancer surgery between 1987 and 2003 confirmed what we already knew - the more experienced the surgeon, the better the outcome. The surgeon's skill was just as important as the tumor size and aggressiveness in determining whether the cancer recurred within five years. The study led by Bianco, et al., Memorial Sloan-Kettering, New York, did not specify how many surgeries needed be done to establish proficiency, but 250 radical prostatectomy procedures is a good standard. At five years, 17% of all the patients had a rise in PSA, an indication that a tumor has returned. The researchers urge newly diagnosed men to ask about a surgeon's report card, i.e., his precise rates of cancer recurrence and side effects with his patients. (Source: *Detroit Free Press*, February 25, 2006, via the National Prostate Cancer Coalition, March 7, 2006)

**Prognosis in Biochemical (PSA) Relapse.** A substantial fraction of men who undergo prostate cancer therapy with curative intent (surgery or radiation) suffer a PSA relapse. Understanding the expected outcomes for these patients is very important to determine who needs additional treatment. PSA doubling time (PSADT) has been identified as an important prognostic factor. Patients with a short PSADT have a shorter median time to the development of metastases and to prostate cancer-related death. Until recently, such analyses have used all available PSA data. Pickles, et al., British Columbia Cancer Agency, Vancouver, Canada, did research to see whether PSADT calculated from PSA readings obtained early in the relapse (PSA range of 1-3 ng/mL would be useful for prognostic purposes. They studied 1,850 men treated with radiation therapy, of which 390 men had relapsed. The median PSADT was 9.4 months. There were clear differences in prostate cancer-related survival between patients with PSADTs of less than 6 months, 6-18 months, and greater than 18 months. The researchers concluded that PSADT calculated early in relapse is strongly predictive of cancer-specific survival. The five-year-cancer-specific survival ranged from 60% in the highest risk groups to 90% in the lowest risk groups. (Source: *Advances In Early-Stage Prostate Cancer*, Medscape, page 3, March 1, 2006)

**Statins Improve Brachytherapy.** Statin treatment appears to be associated with improved outcome after brachytherapy for localized prostate cancer. Statins are a group of drugs used to lower blood cholesterol levels. Merrick, et al., Wheeling Hospital, WV, studied the impact of statin therapy on clinical progression and long-term biochemical progression-free survival after brachytherappy in 512 men. PSA, PSA density, percentage of positive biopsies, and stage were significantly lower in the statin group than the non-statin group. The researchers said that since cardiovascular disease is a primary cause of death in men being treated for localized prostate cancer, an agent that could potentially benefit both prostate cancer and cardiovascular disease would be of great utility. (Source: Reuters Health Information via Medscape, January 20, 2006)

**(DaVinci and Me-Con't from page 1)**

My urologist thinks this new robotic surgery has more to do with "marketing" than effective surgical treatment, and there are no major studies about its long-term efficacy. Nevertheless, I am intrigued by the procedure. A radical prostatectomy is major surgery requiring a 4-6 day hospital stay and

a six-week recovery period. The new robotic technique has a 1-2 day hospital stay and a one week recovery time. My job requires extensive travel and I want to be out of action for as little time as possible. Dr. Engel's article helped us to decide on the DaVinci procedure. My urologist accepts my decision and recommends Dr. Mani Menon at the Henry Ford Hospital in Detroit. Dr. Menon is a pioneer in the DaVinci system with much experience with the procedure. My wife is able to contact Dr. Menon directly. After his review of my situation, I'm accepted for March 17th. Its mid-January and I'm going to have robotic surgery! Dr. Menon advises me to lose 40 pounds. At 240 pounds, I can afford to lose some weight. My only problem has always been that I keep finding it again after I lose it! Exercise and diet, exercise and diet. By March 14th, I'm at 215 pounds and packing for a road trip to Detroit.

**Pre-Op Activities at the Hospital**

It's Tuesday. We arrive at the hospital where we are greeted warmly by the staff and escorted to the clinic area to join four other couples each huddled together. First, we review my medical history with a nurse. Next we meet with the billing expert–naturally! Then a senior resident arrives to review the procedure, my specific lab results and answer any questions. My cancer is more aggressive than it was originally thought to be. However, we still are timely in dealing with it.

Dr. Menon joins us for a direct one-on-one conversation about the procedure he will perform on me. He is mild-mannered and attentive to us. I learn the most important job I have in this entire process is just to show up and lie still! This is the first time we hear about nerve sparing. Dr. Menon explains that, in addition to the two neurovascular bundles associated with erectile function, there is a thin veil of nerves surrounding the prostate that also affect erectile function. He refers to it as the "Veil of Aphrodite!" My condition will allow him to spare one of the two neurovascular bundles and the "Veil" on one side of the prostate. Dr. Menon has a wall map of the United States with colored push pins representing his patients from around the country. The meeting ends with Dr. Menon pushing a pin into the map for Naperville, Illinois. I'm on his map–no backing out now! Thursday is the day! My procedure is set for 3 pm.

Nothing more to do but wait. The "Magic Number" is now 1–only one day left for sex as I've known it. Will it be possible after? I understand and fully subscribe to the three objectives of this surgery: (1) get rid of the cancer; (2) restore continence; and (3) return sexual function. I'll take two out of three, and the DaVinci robotic system holds promise for two out of three with a good chance for the trifecta!

**Last Chance! Then Back to the Hospital**

Wednesday. The NCAA tournament is on TV. Lots of basketball to watch and reading to do. We go to bed around 9:30 pm knowing that this is **the last time**! Sleep comes and goes and I'm awake by 8 am. We make the best of the morning and "culminate" a final time. Intimacy has always been as important to my wife as it is to me.

Thursday, the Big Day. It's March 17, St. Patrick's Day—we're hoping and praying for the Luck of the Irish! By noon we are ready to return the hospital. We find our way to the same-day surgery area and encounter two wives awaiting news of their husbands' surgery. Before long we go to the pre-op area. I change into a hospital gown, get shaved on my belly and inner thighs, and wait for the call to the OR at 3 pm. The attempt to remove my rings fails, but with a little tape I'm good to go. Kathy

says good-bye and heads for the waiting room. In the OR I am introduced to the DaVinci machine that the OR staff refers to as "the octopus." Anesthesia begins and I'm unconscious.

**Recovery**

It's now about 7 pm and I'm in my room vaguely aware of people talking to me. I feel pretty good but am so thirsty. I start a personal physical inspection….what works and whoa…I have tubes sticking out of me…one for urine, one for suction and one for the IV. I'm up and walking by 9 pm with additional walks at 11 pm, 3 am and 6 am.

At 8 am on Friday, Dr. Menon visits. He says the surgery went well and the surgical margins were clear. (The final pathology report confirms that the cancer was indeed confined to the prostate. My post-op Gleason is 4+3.) He checks my Foley catheter and my chest drain and asks how I feel. Off he goes and I'm back walking the hallways, comparing urine color with my fellow strolling DaVincis. At 3 pm a nurse arrives to walk us through all the steps we will need to perform the next 4-5 days on our own at the hotel. Now the chest drain tube is ready to be removed. She explains that the tube, while inserted in my left chest, actually snakes across my abdomen to the right side of my chest. I am instructed to take a deep breath and exhale. As I exhale, she pulls the tube out. It feels very funny but not painful, just weird. I am now ready to be discharged.

We could have gone home to Chicago, but decide to remain at the hotel until the following Wednesday when the Foley catheter will be removed. Back at the hotel, I learn to sit with a towel supporting my scrotum that has swollen a bit. Hourly checks of the leg bag require frequent trips to the bathroom to empty it. I walk the hotel hallway hourly and it gets easier and easier. Meals are clear broths, tea, coffee, and all the juice I can pour down my throat. Going to bed is an interesting task because the bag hangs over the bed on the floor. If I move, the catheter pulls and is painful. I sleep OK, but I can't roll from side to side, so sunny side up it is!

My first post-operative shower at the hotel requires some help, but all subsequent showering is on my own. It feels great. I'm steady on my feet and have no trouble with balance or dizziness. This is the first time I get to see the six port incisions that accommodated "the octopus." The tape is still in place and I only have a little bleeding from the largest incision. I put a leg bag on, get dressed and go down to have a regular breakfast - I can eat real eggs! As long as the leg bag is less than one-half full, it is hard to notice. Once it fills up, I can really feel the weight and if it slides down my leg, it pulls—ouch! I soon learn how to manipulate it!

Meals are still clear fluids and soft foods. Shifting gas occurs suddenly and catches me by surprise. The stool softener is working. When its time to go, its time to go! The sensation of sitting on the throne and moving my bowels is weird. The sense of urination is missing. Another adjustment to be made!

By Saturday I feel good enough to try a short outing with my brother and his wife. We venture out to tour the Edsel Home, but after an hour on my feet, I feel pressure in my abdomen and need to sit during parts of the tour. All in all, not a bad day. I sleep better and have figured out how to turn slowly on my side. The pain in my abdomen is not sharp, rather like being sore after exercising. On Sunday I am able to attend church and start eating whatever pleases me.

Monday and Tuesday pass similarly without incident. Everything is becoming routine. No leakage or pain to speak of. Walking is easier and any soreness of the abdomen is soon gone. Swelling in the scrotum also seems to be gone, the bowels are working regularly and the intensity of the cramping diminishes each day.

The Foley catheter has become a noticeable aggravation. I am now anxious for Wednesday to have the catheter removed and be able to head for home. Finally it's Wednesday and we return to Henry Ford Hospital. We again meet the other couples who had surgery on the same day; we share "war stories" while waiting to be released. I am sent to Radiology for a cystogram to evaluate the sutures. A nurse reviews the X-ray with us and everything looks good. She asks if I am ready to have the tube pulled. Am I ever ready! I take a deep breath as she pulls the Foley tube out. I am greatly relieved to have it out–I feel like a free man again! The sense of liberation from the leg bag is wonderful! Next come the post-discharge instructions. We cannot leave the hospital campus until I urinate without difficulty. Now we wait for me "to go." I drink a quart of water and within an hour everything works, just like normal. I have little or no leakage. We return to Chicago on Thursday and I return to work on Monday with its demanding travel schedule, provided I don't lift anything more than 20 pounds. No exercise or bicycle riding of any kind for six weeks. The drive to Chicago is uneventful.

**Back Home**

Wearing pads takes a bit of adjustment. Loose fitting clothing helps. I notice that when I sneeze, cough or flatulate, I will leak small amounts of urine. Whenever I urinate, I practice stopping the flow to help regain my control. By the following Sunday, I feel confident enough to attempt work again and travel. I'm on a regular diet and feeling great. I will have missed only 9 days of work. So far, no real issues with controlling my continence. I am using only one pad per day, mostly as insurance against sneezing, and coughing.

The next two weeks pass with each day getting better and I feel confident enough to stop wearing a pad. No problems! Six weeks after surgery and we're free to try out the sexual responses. The "Blue Pill" is swallowed and 45 minutes later I'm ready. Not as firm as it used to be, but firm enough to proceed. The sensations are different and there's no natural lubrication like before. We're prepared for this and penetration is successful. Orgasm occurs but it happens very fast and is significantly less intense and noticeably without any spurting. My testicles ache and I go limp immediately. Well, at least it's a start! Its definitely not the same. I guess I'll have to settle for more warmth and "feeling close" than sexual stimulation and release. Nevertheless, it sure beats the alternative!

**Looking Back - Kathy's Turn**

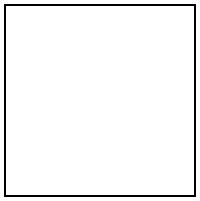
(Now let me turn the story over to my wife Kathy whose love and understanding have been so essential to my coping with the disease.)

It's been thirteen months since Mark's surgery. So how are we doing on the "Big Three," riddance of cancer, return of continence, and regaining potency? Regular PSA tests show that Mark's PSA remains essentially undetectable. His continence has long since been restored. And we thank God for the gift of sex within our marriage even if we require a jump start from Viagra, Cialis, or Levitra. We were told that these medications work differently for different men. It is interesting that one medication will work for us, then a week later not as well. When we change to another

medication, erections improve. Sometimes, medications are not needed at all!

Yes, we decided on a relatively new procedure, but only after at least 60 hours of intensive research and much prayer that we were making the right therapeutic choice. So we had no qualms about selecting the Da Vinci robotic system. And we were blessed to have Dr. Menon, one of the foremost practitioners, perform the procedure. This gifted, self-effacing surgeon simply inspired our confidence in him. It is a measure of his humility that in the immediate post-operative period he invites each family to accompany him to the hospital chapel for meditation or personal prayer. Furthermore, Dr. Menon's staff has been unstinting in its continuing support to Mark and me in the post-operative period.

So, all things considered, it looks like we hit the trifecta after all! Thanks, DaVinci!



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## MARYLAND PROSTATE CANCER COALITION IS BORN!

Prostate cancer advocates from across Maryland assembled on Saturday, March 25th in the historic Marburg Conference Room at Johns Hopkins University Hospital for the first organizational meeting of the Maryland Prostate Cancer Coalition (MDPCC).

The president and vice president of the National Alliance of State Prostate Cancer Coalitions (NASPCC) attended from California and Pennsylvania to provide the group with the tools and resources to develop this new advocacy group organized by prostate cancer advocate Cece Dorough. Those assembled agreed to serve as the initial Board of Directors of MDPCC in order to draft a Mission Statement, Goals and Objectives and elect the first officers of the Coalition.

NASPCC is a significant resource center providing its members with best practices, funding resources and strategic concepts. It seeks to foster networks of prostate cancer advocates across the nation in order to create a stronger voice on behalf of the prostate cancer community. MDPCC, now part of a consortium of thirty-three state prostate cancer coalitions, will complement and collaborate with other organizations, such as US TOO International and the American Cancer Society. MDPCC will focus on advocacy and awareness within Maryland. For more information, contact Cece Dorough at linkstoalliances@comcast.net.

# Returning to Intimacy after Prostate Cancer Therapy

**Ralph and Barbara Alterowitz**
**Authors, Lecturers, and Prostate Cancer Activists**

**(A summary of the Alterowitzs' presentation to the WRAMC Us TOO on February 1, 2006)**

## INTRODUCTION

I am Ralph Alterowitz. Barbara and I are pleased to be with you tonight. Thank you for coming. You are here because you want to have a good love life. I just talked to one man whose wife is not here tonight, and I asked him why not. He said, "Well, I am just exploring this subject and I don't want to go too far, too fast." He is a very cautious guy, but that's OK, too. For those of you who are here with your spouse or significant other, you might start off by sitting closer together. I realize that the armrest presents a problem! At one of our recent talks, I learned afterwards that one of the couples in attendance was "making out" in the back row! Good for them! So if you are in the mood, there is plenty of room in the back row!

People come to our presentations for various reasons. We usually find that the men come to learn about the several medications and other aids to intimacy. Women tend to come because they want to hear about the tender kind of things--the cuddling, the touching, the togetherness. So are there differences between the two partners in coping with impotence associated with prostate cancer therapy? Well, yes, and you are going to hear about both sides tonight! Let's be direct--erections are not enough! We men here tonight are long past the time when we could glance at a pretty face, a nice figure, and be immediately ready for intimacy. So, men, we need both the physical side and the emotional, sensitive side. Tonight we will try to give you the entire package. But let me repeat what I just said--erections alone are not going to be enough!

## OUR EXPERIENCE

How did we get involved in this counseling activity? We got involved because Barbara and I had to work on our own sexuality when I had a radical prostatectomy ten years ago and its aftermath. To be frank, my "plumbing" just was not working. I could not get an erection. Despite many wonderful years of direct and intimate communications, I found myself holding back. I didn't talk about the situation with her because, after all, it was an immense blow to me. I started thinking, am I still a man? Well, what does it mean to be a man? Am I just an erection? Will she still love me as she did before? This became a fundamental issue. Barbara and I did a lot of soul-searching and we reached a remarkable conclusion. I am not my erec-
tion! Big surprise! An erection did not define me as a man. We could still have our strong, on-going sexual relationship with or without it. It came down to this--the essence of our intimate relationship was not that of sex for the sake of sex, but rather it was a matter of expressing our love and feelings for each other with our bodies.

OK, Ralph, my turn. Early on, our search for information was frustrating because there was very little available for the lay person. And frankly, doctors don't prepare patients for the aftermath of prostate cancer therapy when it comes to intimacy. Fortunately Ralph is a zoologist by training, so he understood the medical literature and could translate it intelligently. More than anything, what really helped us was to change our old way of thinking about loving and sex. The old way just didn't work anymore. For couples experiencing erectile dysfunction it is normal to want the erection back. You want the experience to be like it used to be because you thought a good erection equaled good sex. We learned to turn the proposition around. We changed the focus from getting an erection to how can we have good sex. And to our delight and surprise, we found that we could have great sex without the vaunted erection.

## THE "LOVING PIE"

Now we would like to share what we have learned together in our personal journey--how to get erections back, but even more important, how to have great sex with or without erections. Although some will not admit it, most men who have been treated for prostate cancer are going to experience some level of impotence. Nevertheless, a loving couple can still have the intimacy they both seek. You can make love with or without aids or medications because both men and women can experience sexual pleasure and even orgasms without penetration. The key to having great satisfying, sensual sex is to be a team, working to be creative and willing to explore new approaches together. Good loving is a whole-body experience, the physical expression of emotional intimacy. We like to compare it to a pie, the "loving pie." The loving pie consists of three parts. The crust, the element that holds everything together, is the quality of the relationship between the partners. If the crust is ill-prepared, the pie will fall apart and the loving will be no good. Then come the fillings. The key ingredient of the filling is communication, getting reacquainted, getting to know each other sexually and otherwise all over again. And then there are the toppings--the mechanical aids and medications. More about this construct in a few moments. If you watch the commercials, pharmaceutical companies would have us believe that the toppings are all that really matter. But we know better. We know that you need everything working together to make the loving pie--the crust, the fillings and the toppings carefully prepared and served, so to speak. This is our agenda for tonight as we talk about those three elements of the loving pie. But before we do that, let's review the basic facts about impotence and sex. Back to you, Ralph.

## IMPOTENCE AND SEX

Thanks, Barbara. Let's start with the reality of prostate cancer. Many of you know this, but let me refresh your memory. First, impotence or erectile dysfunction is fairly common. At least 70% of the men who have primary therapy for the disease will experience impotence to some degree. For men selecting the radical prostatectomy, ED occurs immediately after surgery, while men choosing radiation therapy likely will experience it later. It is also interesting to note that at least 31% of <u>all</u> men encounter potency

problems sooner or later. So we with prostate cancer are not alone!

Looking at this slide, it is clear why therapy for prostate cancer affects potency, notwithstanding what you may have read about the success rates of the various treatment options. The nerve system in the prostatic area is not like a telephone cable. Instead, think of it more like a spider web on and around the prostate. So, even if a surgeon spared a large nerve, like one of these trunks here, other smaller ones are going to be cut, disrupting the intricate relationships within the neurovascular network. Some doctors may cite impressive results in preserving potency, but what goes unsaid is that these often are based on medicinally assisted erections. As I noted earlier, potency after radiation declines gradually, but when you get to the point about four years after radiation therapy, about 70% of the men also have encountered erectile dysfunction. Let me mention hormonal therapy. About 70 to 75% of men on hormones will have potency problems as well as sharply reduced libido. This same fact applies to men who choose orchiectomy (surgical removal of the testicles).

It's possible to have an orgasm without an erection, but not without arousal. There is a neurovascular channel affecting erections and another affecting arousal and orgasm--two different ones that are not dependent on the other. Of course, recovering potency after primary therapy is affected by other factors. For example, recovery is more likely for younger men who were potent pre-therapy. That stands to reason because they are younger, diet has had less negative impact on them, they likely have fewer accompanying medical conditions, and they are much more likely to exercise, which brings me to my next point.

## EXERCISE, STRESS, AND POTENCY

Exercise is a key to the recovery and maintenance of potency. When you don't exercise, you get overweight, so you feel less attractive, you are less attractive, and your partner is not as stimulated. Furthermore, reasonably vigorous exercise increases sexual stimulation because blood goes to the erogenous zones and that helps maintain the viability of the penis. So how much exercise is necessary? Strive to achieve the endurance for at least a daily two-mile walk regimen. That burns approximately 200 calories. Let me tell you that when you have sex, the energy expenditure is about the equivalent of a five-mile walk. So think of that daily walk as sexercise! Furthermore, thirty minutes of daily exercise can reduce the rate of dying from prostate cancer by 70%. That alone should be a good motivator for regular exercise.

Don't forget that sexual readjustment after prostate cancer therapy is stressful. There are stress scales showing the degree of stress associated with certain life events such as divorce, moving to a new location, getting married, loss of a loved one, etc. Research has found that sexual readjustment ranks at 39 on the stress scale--about the equivalent of getting fired and about half the stress of going through a divorce. So it is not an insignificant kind of event. Get ready for it by being in shape.

Now we get down to the final point. People who make love live longer and are happier. Sex does have a healthful component to it. So have your pie (loving

pie, that is!) and eat it too, even with erectile dysfunction.

## ESCAPING THE RUT

As Barbara pointed out earlier, you need the good crust, the fillings, and the toppings. But there is a common problem that you must address. Even the best of marriages can have a stale aspect to them. Over time you get into this rut where the relationship becomes routine. Everything is the same, day in and day out, and so it is sex. The sex is perfunctory, nothing changes, and interest may diminish. It's like playing the same old card game over and over again. I got a call from a client today, and he said, "My wife doesn't relate like she used to. She is always "busy" doing her own thing. She avoids closeness and my displays of affection. We are just living in the same house." Sound familiar? Is this the case with you? If it is, you need to get out of the **"RUT"** of a Routine, Unappreciated, and Tired relationship. You need to move to what we term a **"CREST"** relationship emphasizing Creativity, Respect, Excitement, Sensitivity and Togetherness. What is Creativity? It's thinking of new things to do, new ways of relating to each other, and rebuilding the intimacy between the partners. Respect-- for each other, for who they are, what they are, what they do, and their values. Excitement--it's waking up in the morning expecting a great day; there is a little bit of mystery in the day, a little bit of anticipation. That's what makes for excitement and enhanced relationship between the partners. Sensitivity-- a concern for other's feelings, an understanding of their needs. Togetherness--the enjoyment of each other's company, doing things together, and acknowledgment of a need for individual personal time. The interesting thing is you can't isolate one part of the marriage from all the others. You can't stay upset with your partner all day and then expect to have romance that evening. So how do you get to a CREST relationship? You need to create an overall environment of love. As the song goes--little things mean a lot--a frequent smile, an unsolicited compliment, an unexpected offer to help, a gentle touch.

Speaking of a gentle touch, the AARP recently had a remarkable article about touching. Did you know that the skin is the largest sex organ! Touching is simply essential. A baby's emotional development can be stunted if they are not touched and held often enough. Why should it be different for us grown-ups? A reassuring touch can help reduce stress and even improve the immune system. Research has identified a condition known as touch deprivation and it is prevalent in the United States. Couples in Puerto Rico and France exchange touches at a much higher rate than do couples here at home.

Enhance your relationship by doing things you both enjoy doing together. Like taking walks, riding bikes, taking dance lessons, swimming, yoga instruction, and going to the gym. Perhaps you have forgotten some of these togetherness activities from the "good old days." Try this--tell your partner you want to find more ways of doing things together, then you each prepare a list to compare. You may be pleasantly surprised! OK, Barbara, your turn.

## COMMUNICATION

Now the hardest part of staying connected, especially when facing a crisis like sudden erectile dysfunction, is how do you talk about it. And that brings us to that important part of the filling--communication. When erectile dysfunction happens it's usually an immediate identity crisis for the man. It is a very big job for the couple to resolve that crisis. The typical pattern is that the woman won't say anything because she doesn't want to embarrass him, hoping he'll broach the subject sooner or later. Well, guess what! He never does! So now they have an important aspect of their life that they can't talk about, but they receive frequent reminders about it. They walk down the street and see people in love, they go a romantic movie, they see people touching and kissing--it's that thing that they avoid talking about. So the little island of silence grows bigger. In many marriages this conspiracy of silence between the partners can have tragic results. I remember a man in one support group who said that for eleven years he and his wife had not touched and had not talked about the problem. Ever since his prostate cancer surgery they had not discussed their feelings toward sexuality and so they simply lost that aspect of their life. That is a tragedy. In assisting couples, we have heard from so many that only when they had the guts to address the issue head-on did they start getting the relationship back on track. One common problem we often see is that men feel "this is my problem and I've got to solve it." I remember well one man who finally realized that his wife felt rejected, hurt and shut out. She was as impacted by this problem as he was, but he never saw it that way. Only when he became aware could they cooperate in solving the problem. Many men feel that having an erection is the only way to please their partners. If they would only ask the question they will likely be in for a pleasant surprise. Why? Because an erection is not necessary to sexually satisfy a woman. The organ that causes her sexual pleasure is external. So, Mother Nature is on your side!

## REASONABLE EXPECTATIONS

(Ralph) Let's say you've had a primary therapy and your relationship is being affected by its side effect of ED. Are you both ready to sit down for a frank discussion of the matter? Are you both ready to resume the physical aspects of your relationship? Good! Review the literature to be aware of the mechanical and medicinal means at your disposal. If you decide to try the medications, have realistic expectations about them. For example, if Viagra was effective only for only 60% of men in the clinical trial, it is never going to be anywhere near 100% effective for prostate cancer survivors. So when you both agree to try mechanical or medicinal aids, have realistic expectations of their efficacy.

## GETTING REACQUAINTED

(Barbara) Get reacquainted. Take the time to touch and to talk, learning about each other all over again, especially about sexuality. What turns you on, and just as important, what turns you off. Many men are very turned on by the visual aspects of sex, while many women respond more to the romantic and tactile aspects. However, this common wisdom may not apply to your relationship. So the partners must make the effort to understand each other sexually. Good loving is a lot more than

the physical act of intercourse; good loving in a long term relationship is based on good communications. Tell and show each other what you want and what you like. Women should avoid the trap that many fall into. They think the best way to support their husbands is to assure them that "its OK, I don't miss sex that much anyway." Now that's a turn-off if there ever was one! A more constructive approach is to work together to find ways to give each other sexual pleasure. Relearning loving together is what we are really talking about here. It means touching a lot, talking a lot, and learning about your own anatomy and your partner's anatomy, not just in the genital area, but all over the body because good sex is a whole body experience. Do whatever feels comfortable to you as a couple. Part of getting reacquainted is also understanding how the other person's chemistry works. For example, the woman's chemical processes are such that in her mind the sex act begins long before penetration!

Age does not have to be a limitation if you are in reasonable health. We can have life-long interest in sex and enjoy sexual relations and sexual pleasure throughout our lives. Partners also get more in sync as they get older. Remember when we were young? The man goes "one, two, three--OK, I'm done." The woman goes "Wait!--"55, 56, 57, 58." As we get older the testosterone levels get closer together. In men the testosterone goes down, and in women it actually rises proportionally. So the men slow down their arousal as the women speed up. What a wonderful gift from Mother Nature that we both can become more highly aroused as we enjoy longer foreplay. And we should use foreplay in quotation marks here because "foreplay" oftentimes can actually be the whole event, wonderful and satisfying in itself. We encourage everyone to learn to make love in a new way, to take the emphasis off the intercourse. Just focus on the fun on the way there, because the key to good sex is to accept those changes that come with time and with illness, and to make the changes work for you.

Change. What else does it mean? Well, change the place where you make love. It doesn't have to be in the bedroom on the left side of the bed or the foot of the bed. It could be almost any place else. Change the way and the places you touch. We talked about that. Change the pace. You don't have to rush into it. Take some time. Change the time you make love. As you get older your body clock changes. Don't start making love at eleven o'clock at night when you are already falling asleep! Do it at six! Do it before dinner! Be spontaneous! Do it any other time. The point is make love anytime, whenever, wherever, however you can.

## SOME SUGGESTIONS

Here are some other suggestions that may work for you. There are also some common sense "home remedies" that we would like to describe quickly. First, the penis and vagina must be well lubricated. There are some well-known products like KY Jelly and Astroglide. Use gravity to your advantage to maintain the blood flow to the penis. If you have an erection, or even a partial erection, stand on the side of the bed with your partner laying on the bed. Or make love in the missionary position to help maintain the erection. You even can use a partial penetration because the penis is somewhat stuffable in that

state. And given the female anatomy, that condition feels very pleasurable to a woman. The partner plays a big role in rebuilding the man's confidence. Her reaction to the suggestion to make love, her support to using medications and aids, and the reaction to leaks are important. Let me talk about leaks for a minute. Unfortunately, incontinence is another frequent side effect of prostate cancer treatment. There are some ways to manage that relatively easily if the man has a slight case of stress incontinence. One is to void completely before making love, but keep some tissue or a towel handy for accidents. Use herbal remedies with caution. There is a lot of marketing hype about them with unproven claims.

## MEDICATIONS AND AIDS

Now we've talked a lot about making love without an erection or with a partial erection, we do want to talk to you also about the medications and aids that are available to help produce erections. These are the "toppings" we mentioned earlier.

Let me very briefly mention the various medicinal and mechanical aids that may assist men in coping with ED. Remember that (1) first and foremost, the advice of your doctor is paramount in helping you decide what aid to use for your circumstances; (2) some aids may not appeal to you aesthetically; (3) all of them have their own pluses and minuses as to efficacy and ease of use; (4) the drugs and devices help you gain an erection, but stimulation is necessary to achieve orgasm. So do your homework and consult with your doctor about options available and suitable for you.

No doubt you are already aware of the oral medications--Viagra, Levitra, and Cialis. There are three items I want to mention here. First, there are disputed reports that Viagra (and perhaps the others) has resulted in blindness in a very small number of cases; second, some men taking cardiac medications are vulnerable to dangerously reduced blood pressure if they should use these oral medications; third, they do not work automatically--arousal is required!

Then there is the intraurethral suppository MUSE. The user inserts a plastic delivery device into the urethra to place a small pellet of alprostadil. Some men find it more effective when combined with a constrictive device that is also available from the manufacturer. Caverject uses a needle to inject alprostadil directly into the penis. Although some may find it difficult to self-inject, Caverject gets high marks for effectiveness.

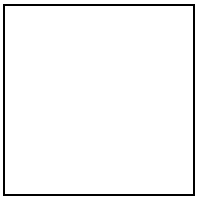
The penile splint is a condom-like sheath placed over a flaccid penis to provide rigidity to facilitate penetration. There are a number of vacuum erection devices available with or without prescription. They can be effective, although some men find them cumbersome. Those obtained by prescription are more likely to be covered by medical insurance. Penile implants have become very reliable and the surgical procedures are much improved. Obviously, they involve the risks associated with any surgery. Users report a high degree of satisfaction with the penile implant. An effective topical gel would be a great breakthrough, but we must await the outcome of the research effort.

Penile rehabilitation after radical prostatectomy is a topic you will be reading more about. Research has found that early initiation of measures to restore blood flow to the penis will help in the recovery of erectile capability. Doctors now recommend injection therapy or oral medications within three to six weeks of the surgery to stimulate the blood flow to the penis to help prevent penile atrophy and fibrosis.

**SUMMARY**

Are both of you motivated to resume loving and to take the necessary steps to make it a reality? We hope we have shown you tonight some ways to do this with or without erections. Now, let's summarize some key points. Number one, impotence doesn't prevent us from having a good love life, and you don't need intercourse to have sexual pleasure and orgasms. If you decide to use the available medications and aids, have realistic expectations. They won't always work perfectly. Keep trying until you find what works for both of you. Next, relearn how to make love and have sensual sex for the sheer pleasure of being together. And always remember that sex is actually an thirteen-letter word--

**C-O-M-M-U-N-I-C-A-T-I-O-N!**



**(Editor's Note:** Ralph and Barbara Alterowitz are recognized authors, certified sex counselors and prostate cancer activists. Their acclaimed book *Intimacy with Impotence*: *The Couple's Guide to Better Sex After Prostate Disease* (2004, Da Capo Press) expands in considerable detail on the concepts summarized above. It is available at **www.renewintimacy.org.)**

**EDITOR'S NOTE:** We regularly receive requests from readers asking that we include family members, friends, and acquaintances on the mailing list for the newsletter. We are pleased to do so. However, we ask that you advise them of your request so that they are not surprised when the next issue arrives in their mail boxes. Thanks.

## ♦ WRAMC US TOO COUNSELORS ♦ (AS OF APRIL 1, 2006)

**(These persons are willing to share their experiences with you. Feel free to call them.)**

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**7 PM**

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## ♦ SPEAKERS ♦

## A PANEL OF FIVE PROSTATE CANCER SURVIVORS

## DISCUSS THEIR PERSONAL EXPERIENCES

## ♦ TOPIC ♦

## "DEALING WITH PROSTATE CANCER - OUR STORIES"