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

VOLUME 15	NUMBER 1	FEBRUARY 2006

♦ A SAGA OF POST-SURGERY INCONTINENCE ♦

by Bernie Parrette

I always read the personal accounts presented on these pages with considerable interest. A personal story in a previous issue prompted me to contribute my own experience in dealing with prostate cancer, especially incontinence, in the hope that it may be useful to the readership of the WRAMC Us TOO Newsletter.

I have made use of the facilities of a major medical facility for nearly two decades. During a routine physical examination in 1992, the doctor detected a hard spot on my prostate in the course of a digital rectal examination. A blood test revealed a PSA of 6.5, so I was advised to have a biopsy. I neglected to get one because I had read about the dangers of "big needle" biopsies and the risk of hemorrhage associated with them. I did not learn until three years later that "big needles" were no longer being used and that the risks associated with biopsy were minimal. In the meantime, my urologist had told me that if my PSA remained stable, I needn't worry about it - a remark that influenced my decision to delay biopsy. (I doubt I would get the same advice today!)

Three years later my PSA did rise and I had a biopsy that produced a Gleason score of between 6 and 7 (there was some professional disagreement about the score). I sought a second opinion at another hospital where the urologist recommended "wide margin" surgery, i.e., removal of lymph glands and nodes together with the prostate. Unfortunately, no one advised me that the wide margin procedure would likely have an adverse effect on potency. That was indeed the outcome in my case. I never recovered potency after the surgery. Only later did I read literature about the implications of wide margin surgery. I often think about whether better pre-operative knowledge would have influenced my treatment choice.

(Continued on page 8)

♦ *INSIDE THIS ISSUE* ♦

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♦ FROM THE EDITOR'S DESK ♦

We are fortunate again in this issue to present another first person account in dealing with prostate cancer. Reader reaction to these articles has been positive, so we will continue to provide them as long as readers keep them coming! If you think your own experience would be helpful to other men coping with prostate cancer, please contact the editor. He will discuss the topic with you, even make editorial suggestions, and provide the draft to you for your final approval. Your article may be signed or anonymous, as you prefer. Let's hear from you!

Our speaker for the November 2005 meeting was Steven J. Tulin, Ph.D., Clinical Psychologist at WRAMC. Dr. Tulin works closely with the Center for Prostate Disease Research so he has considerable experience and very useful insights to help men deal with prostate cancer. His topic was "Psychological Factors in Helping Men with Prostate Cancer." A summary of Dr. Tulin's remarks begins on page 10.

♦ PROGRAM FOR WEDNESDAY, FEBRUARY 1, 2006 ♦

Our speakers for Wednesday, February 1, 2006, are **Ralph and Barbara Alterowitz**, authors of the acclaimed **"The Lovin' Ain't Over, The Couple's Guide to Better Sex after Prostate Disease."** A survivor and his partner who speak and write for other survivors and partners, the Alterowitzs treat a sensitive topic in a frank and compassionate manner. Involved in prostate cancer activism and health care for over twenty years, they have educated and counseled hundreds of couples on the restoration of intimacy after prostate cancer therapy. **Don't miss them!** Join us at 7 PM on Wednesday, February 1, 2006, in Joel Auditorium. Plan now to attend and bring your spouse or a friend. They are always welcome.

You Have Time To Consider Your Options. If you are considering surgery as your therapy after getting a positive biopsy, the procedure need not be performed immediately, according to Eastham, et al., at Memorial Sloan-Kettering Cancer Center. The researchers analyzed data on almost 4,000 patients who had a radical prostatectomy within a year of diagnosis. They found that time between biopsy and surgery did not affect recurrence. They said that most surgeons prefer to wait a minimum of two months after biopsy to allow post-biopsy inflammation to resolve, so patients have time to gather information to make an informed decision without concern about the effect on outcomes. (Source: *The Washington Post,* Health Section, page F-2, October 25, 2005)

Quality of Life after Radiation. A recent study by Jo, et al., Kawasaki Medical School, Japan, says that in men with localized prostate cancer, high-dose rate brachytherapy with external beam radiation provides a better outcome for sexual life than does radical prostatectomy (RP). Given the good 5-year relative survival rates associated with both therapies, quality of life issues are key to deciding among treatment options. The researchers followed 89 men who underwent RP and 93 who had high-dose brachytherapy with external beam radiation. A general health questionnaire showed similar outcomes for both therapies, but disease-specific quality of life questionnaires showed that men who selected radiation had significantly better urinary function and sexual function than men who selected surgery. Conversely, men who selected surgery were less affected by "bowel bother" than those selecting radiation. (Source: *BJU Inter* 2005;96:43-47 via Reuters Health Information July 19, 2005)

Absorbable Sling Enhances Early Continence After Radical Prostatectomy. Placement of an absorbable sling immediately after RP hastens the return of continence. Jones, et al., Cleveland Clinic Foundation, say pilot data for patients at high risk for incontinence after surgery indicate that continence can return within days or weeks rather than months. The researchers evaluated 15 men who had absorbable slings emplaced at the time of surgery. Five patients regained continence within an average of 5.8 weeks. The other ten patients regained continence within 2.6 weeks when slings with additional tension elevated the urethrovesical anastomosis (connection) slightly. Four patients in the latter group were dry within 24 hours! All but one of the sling patients were dry at three months, compared to 7 of 15 patients in a control group that did not receive the sling. Placement of the absorbable sling added about 15 to 30 minutes to the RP procedure, but there were no complications associated with the sling placement. The researchers recognized that most men eventually recover continence in the long run after RP, but even temporary incontinence is poorly tolerated by most men, so any technique that hastens return to continence is important. (Source: *Urology* 2005;65:1163-1167 via Medscape, July 22, 2005)

Prostate Size and Aggressive Cancer. In men with prostate cancer, smaller prostate size is associated with higher grade, more advanced prostate cancer, and a greater risk of biochemical progression, according to a recent study. Freedland, et al., Duke University Medical Center, evaluated the association of prostate weight with tumor grade, positive surgical margins, and seminal vesicle invasion with biochemical progression among 1,602 men treated with radical prostatectomy. They found that smaller prostate weight was associated with increased odds of high-grade disease, positive surgical margins, and extracapsular extension. Smaller prostate weight was also associated with significantly increased risk of biochemical progression. Overall, the researchers believe that small prostate size can be a predictor of cancer aggressiveness. This has implications for watchful waiting for men with very small prostates. Similarly, candidates for watchful waiting who have large prostates may have an additional reason to adopt a wait and see approach to therapy. The researchers conclude that men with small prostates might need close follow-up regardless of the primary therapy they choose. (Source: *J Clin Oncol* 2005; 23:7546-7554 via Reuters Health Information, November 17, 2005)

Penile Prosthesis and Quality of Life.
Surgery for prostate cancer is often associated with postoperative sexual dysfunction. One of the options that has been successful is immediate sexual rehabilitation by placement of a penile prosthesis at the time of the surgery. This is particularly appropriate for men who were not eligible for a nerve-sparing procedure. DeWolf, et al., at Boston University, surveyed 51 men who had undergone the dual procedure five years earlier and 47 men who had radical prostatectomy alone. The men who had a penile prosthesis implanted at time of surgery reported greater quality of life, erectile function and more frequent sex activity than those men who had only surgery. Also, the penile prosthesis patients had better depression, anxiety, and emotional scores than a subgroup of men who had nerve-sparing surgery. The study demonstrates the importance that sexual rehabilitation has on quality of life following treatment for prostate cancer. (Source: *J of Urology 2005; 174: 1395-1398* via Reuters Health Information, November 14, 2005)

Tomatoes Get Canned - Well, Almost!
Producers of tomatoes, tomato sauce and dietary supplements containing lycopene often cite their products as helping to reduce the risk of many forms of cancer, including prostate cancer. The FDA recently ruled that such products may not be so advertised. The FDA will permit producers to suggest a very limited link between tomatoes and tomato sauce (but not lycopene supplements) and a lowered risk of prostate cancer; however, product labels must include an FDA disclaimer so onerous as to discourage producers from making such health claims on their labels. Advocacy groups had sought FDA recognition for their health claims. (Source: *Houston Chronicle,* Saturday, November 12, 2005, via The National Prostate Cancer Coalition's *AWARE*, November 15, 2005)

Brachytherapy and Conception. More younger men are selecting brachytherapy as their primary therapy for dealing with their prostate cancer. The common wisdom has been that men selecting brachytherapy for prostate cancer were rendered infertile by the procedure because it reduces semen volume and alters the viscosity. It also often results in

erectile dysfunction. Grocela, et al., Massachusetts General Hospital, recently reported three unintended pregnancies that occurred after the male partners underwent brachytherapy. The men had low semen volumes and sperm counts, but their sperm still met World Health Organization criteria for "normal." The researchers recommend that men considering brachytherapy be counseled about the possibility of continued fertility. (Source: *BJU International,* October 2005, via Reuters Health Information, November 9, 2005)

Impotence Gel May Be in the Future.
A British pharmaceutical company has announced it was on schedule to develop a non-prescription treatment for impotence. Futura Medical, which specializes in sexual healthcare products, said many men using experimental topical gels in a clinical trial experienced changes in blood flow to the penis consistent with those observed during sexual arousal even without stimulation. The company will now proceed to a Phase III clinical trial during 2006. Futura Medical is also working to produce a condom that will help maintain an erection during intercourse. (Source: Reuters Health Information via Medscape; November 21, 2005)

Surgery for Older Men. Men older than 70 often are not considered good risks for radical prostatectomy. The question is whether the risks of surgery outweigh the benefits for men in that age category. A study analyzed the records of all residents of a Canadian province who had a radical prostatectomy during the 1990s - a total of 11,010 men. Within 30 days of surgery, 53 men (0.5%) had died and 2,246 men (20.4%) had at least one complication. Older men had a slightly greater risk of dying, but even for those aged 70 to 79, the chances of death were a low 0.66%. The presence of other diseases and medical problems had a stronger effect on increasing complications, regardless of a man's age. The study may underestimate the overall risk of prostatectomy because older men with serious diseases or complications may not have been selected for surgery in the first place. Also, the study did not consider possible long-term complications such as erectile dysfunction and incontinence. (Source: *The Washington Post*, Health Section, page F-6, October 25, 2005)

Group Asks for Greater Blindness Warning on Erectile Dysfunction Drugs.
In July 2005, the FDA ordered that warnings be placed on the labels of Viagra, Levitra, and Cialis following reports that a small number of persons taking these erectile dysfunction drugs had developed NAION (nonarteritic anterior ischemic optic neuropathy), a loss of vision that is often irreversible. NAION is one of the most common causes of sudden vision loss among the older population, causing anywhere from 1,000 to 6,000 cases a year. Public Citizen, a consumer advocacy group, wants the FDA to impose its most stringent label warning, the so-called "black box" warning. The group believes the evidence more closely associates the risk of blindness with impotence drugs and it is greater than the FDA has acknowledged to date. (Source: AOL News, October 20, 2005)

Viagra May Improve Urinary Tract Symptoms. McVary, et al., Northwestern University, report that Viagra improved urinary tract symptoms in men with erectile dysfunction and benign prostatic hyperplasia BPH). Citing the improvement in urination as "dramatic," the researchers say the improvement in BPH symptoms was better than that found in other medications. Earlier reports had shown that more than 70% of men

with lower urinary tract symptoms (LUTS) related to BPH also had erectile dysfunction. The researchers randomized 300 men with such symptoms to receive Viagra or a placebo for twelve weeks. The group taking Viagra reported improved erectile function, higher self-esteem, and quality of life. These men also were more likely than the placebo group to experience a reduction in irritative and obstructive LUTS. The researchers concluded that LUTS and erectile dysfunction may be manifestations of the same central problem; a single enzyme system, the nitric oxide system, may be to blame for both LUTS and ED, but larger studies are required. The study was funded by Pfizer, Inc., maker of Viagra. (Source: Reuters Health Information, November 21, 2005)

High Intensity Focused Ultrasound (HIFU). High Intensity Focused Ultrasound (HIFU) is a precise, non-invasive treatment which uses high intensity focused ultrasound to eliminate localized prostate cancer. The Ablatherm-HIFU technology has been used extensively in Europe over the past 10 years. The Food and Drug Administration has not approved the procedure for use in the United States and there is no assurance when or if such approval will be forthcoming; however, HIFU is now available to prostate cancer patients in North America in Toronto, Canada. Ablatherm-HIFU is performed under a spinal anesthetic and a treatment lasts between 2 and 3 hours. An Ablatherm-HIFU probe is placed into the rectum and a high-intensity, focused beam of ultrasound is directed into the prostate. The rapid rise in temperature causes the death of the targeted prostate cells. Computer imaging directs the beam throughout the prostate successfully killing the tissue without blood loss or exposure to radiation. Most patients are discharged a few hours later. Clinical studies from Europe indicate that HIFU compares favorably in terms of outcomes and side effects with other primary therapies. Ablatherm-HIFU may be used not only as a primary therapy for patients whose prostate cancer is confined to the prostate, but also as a salvage procedure in those patients whose initial therapy has failed. Further information about HIFU may be found at www.hifu.ca. (Source: Patient Brochure, Ablatherm-HIFU; included in this issue by the editor to make readers aware of the therapy.)

At Last! A Supplement I Can Use - Beer!

You've read the frequent news items about lycopene, green tea, and other supplements and dietary items that reportedly affect prostate cancer cells, but now there is one that many can applaud - beer! Scientists are examining the flavonoid xanthohumol which may slow the growth of cancer cells under laboratory conditions. Xantholhumol is found only in hops, a basic ingredient in beer. But before you rush out to buy a case, be aware that drinking beer to prevent prostate cancer may not be enough; a supplement would likely be necessary to ingest a sufficient concentration of the substance, if indeed, it does prove to be effective. Oh, well! (Source: *Hops in Beer May Be Healthy*; Associated Press, November 15, 2005)

Proton Beam Therapy Center at Hampton University. Hampton University has announced it will construct a Proton Beam Therapy Center, most likely in the Hampton Research Park, Hampton, VA. Proton beam radiation therapy is a form of external beam radiation therapy that shapes the beam to provide a more targeted dose to the tumor. There now are only three proton beam facilities in the United States - the University of Indiana, Loma Linda Medical Center, California, and Massachusetts General

Hospital in Boston. Hampton University is partnering with other regional hospitals and medical institutions in developing the center. When complete, the new facility will make it easier for persons in the mid-Atlantic region to take advantage of proton beam therapy. (Source: Office of University Relations, Hampton University, March 31, 2005)

Low Testosterone and Prostate Cancer Outcomes. Low testosterone levels may be associated with a higher risk of positive surgical margins on radical retropubic prostatectomy (RRP) according to a recent study. Da Rosa, et al., Santa Casa Hospital, Porto Alegre, Brazil, investigated the association between testosterone levels and prognostic factors in 64 patients with localized prostate cancer who had an RRP. About 40% of the men with low testosterone had positive margins compared with 14.6% of men with normal testosterone who had positive margins. Gleason scores, pathological stage, and seminal vesicle involvement did not significantly differ in men with normal or low testosterone. Since low testosterone may predict positive surgical margins, the researchers say that such patients are more prone to have prostate cancer recurrence and to require adjuvant treatment. They also acknowledge the need for more extensive research into the association between testosterone level and positive margins. (Source: *J Urol* 2005; 174:2178-2180 via Reuters Health Information, December 29, 2005)

Effect of Screening on Advanced Prostate Cancer. Researchers in Canada report that middle-aged and older men who have PSA screening are less likely to be found with prostate cancer that has spread to other sites. Kopec, et al., University of British Columbia, Vancouver, studied 236 men with metastatic prostate cancer compared to 462 similar men who did not have metastatic prostate cancer. The rate of PSA screening was significantly lower in men with advanced prostate cancer than in the comparison group. In men between 45 and 59 years of age, screening reduced the odds of having metastatic cancer by 48%, and in men between 60 and 84 years, by 33%. The researchers acknowledge that their evidence is indirect in that the outcome they examined was metastatic cancer rather than death. Noting that the value of PSA screening is still undecided, they think their study offers new evidence that PSA screening can reduce the risk of death from prostate cancer. (Source: Reuters Health Information, August 26, 2005, via Us TOO *Hot Sheet*, October 2005)

Relationships Help. Among men with prostate cancer, those who have a supportive spouse or partner are likely to have a better quality of life than those who don't have such a relationship. Researchers at UCLA followed 291 prostate cancer patients and found that those in a supportive relationship had much better psychosocial and spiritual health and fewer cancer-related problems. These same men also were able to tolerate symptoms associated with the disease and its treatment. Earlier research has shown that quality of life can effect survival positively. (Source: *Health Day News*, May 25, 2005, via Us TOO *Hot Sheet*, July 2005)

(Personal Account - Cont'd from page 1)

The surgery itself went well, and for the next two years my bladder control seemed to improve. But then it began to deteriorate and I had to resort to the Cunningham clamp to prevent leakage. In the meantime, I tried every available incontinence medication without improvement. I also sought consultation at other local hospitals. The several urologists convinced me that an artificial sphincter was the solution. Accordingly, I had one successfully implanted in 2003. The artificial sphincter is an incredibly simple plastic device that constricts the urethra, controlled by a compression device implanted in the scrotum. To urinate, one simply presses the scrotum button to empty the bladder, then releases it to restore bladder control. It caused me no problems whatsoever, and I used the men's room urinals with the continent men without embarrassment!

Bad news in 2004! I underwent triple bypass heart surgery, and despite my warning bracelet, a Foley catheter was inserted through my penis without regard to the implanted artificial sphincter. Afterwards, I began leaking again. More bad news. My penis began shrinking to the point where I had difficulty aiming it accurately. My urologist now recommended a malleable penile implant which was inserted in May 2005. While such implants are normally inserted to alleviate impotence, mine was not. In my case, the artificial sphincter required three hands for efficient use - one to steady the sphincter, one to activate it, and one to aim the organ. Since I have only two hands (!), the prosthesis helped me to aim the penis more easily (and more accurately!), leaving two free hands to activate the sphincter. During the penile implant procedure, it was discovered that the sphincter had been dislodged and it was eroding the wall of the urethra. Additional surgery was required to remove it, and I would have to wait for six weeks of healing time before a new sphincter could be inserted. Talk about "it never rains, but it pours," - I could not temporarily return to the Cunningham clamp because it would impair healing, so I had to resort to diapers which caused a rash requiring that the sphincter surgery be delayed to avoid infection. But wait, it gets worse! Hurricane Katrina intervened and my surgeon was diverted to service in that tragic event which totally disrupted his local surgical schedule.

It was November 2005 before my replacement surgery could be scheduled, so I was in diapers with an open sphinter for a full six months - a very awkward situation, to say the least, because I work full time. The replacement surgery went well, or so I thought, and initially I received another suprapubic catheter, but it came out; so I probably contributed to some diaper manufacturer's record sales in 2005 until the surgical incisions could heal! Unfortunately, I continued to leak despite the new sphincter and I ended up spending two more days in the hospital.

It was finally determined that the new sphincter was misaligned. The surgeon was able to adjust it; however, he had to use a sphinter with a larger control module, so the new sphincter is harder to use than the old one (it requires more pressure on the scrotum). Being able to wake up in a dry bed makes it all worthwhile (I think!). Each man diagosed with prostate cancer must make his own decision regarding his primary therapy, but if I had it to do all over again, I would likely opt for watchful waiting or seed implants rather than a radical prostatectomy.

Here are some lessons learned from my perspective for whatever they are worth. **First**, whenever a PSA test and/or a digital rectal examination indicate an abnormality, don't wait - get the biopsy. **Second**, upon diagnosis, do your homework so you can make a fully informed decision regarding your primary therapy. **Third**, even "successful" surgery can have serious side effects. If I had it to do over again, I doubt that I would select surgery - the potential impairment in quality of life can be too great. And given that prostate cancer is generally slow growing, watchful waiting may be an option for many men. **Fourth**, men whose primary therapy for prostate cancer results in substantial incontinence should promptly opt for the artificial sphincter - it works like a charm.

Fifth, if you do rely on an artificial sphincter, make sure that **EVERYONE** involved in any subsequent medical treatment is fully aware of the fact! **Sixth**, the malleable penile prosthesis is painless, efficient, and appears to have no undesirable effects except for some slight loss of erotic sensation (but then, beggars can't be choosers! And as noted earlier, it facilitates my urination situation.)

I hope my experiences in coping with prostate cancer and incontinence will be helpful to men encountering circumstances similar to mine.

READERS RESPOND

Charles Paddock described his experience in dealing with prostate cancer in the November 2005 issue of the WRAMC Us TOO Newsletter. In summary, he reported that he had a recurrence after surgery, requiring follow-up radiation therapy. Although his PSA is now undetectable, he is living with the side effects of incontinence and erectile dysfunction, and is particularly affected by incontinence. He had not taken any of the coping alternatives available to men in his situation, but he invited readers to advise him of their experiences in coping with incontinence and erectile dysfunction.

Thirteen readers responded to Mr. Paddock's call for advice. Many noted their own favorable experience with the artificial sphincter and urged him to pursue that alternative. Others related their experiences in dealing with erectile dysfunction using the vacuum pump, self-injection, and the penile implant. He has considered the advice and plans to discuss the possibility of an artificial sphincter with his urologist early in 2006. He is grateful to the men who responded so promptly and generously to him.

CENTER FOR PROSTATE DISEASE RESEARCH

The website of the Center for Prostate Disease Research (CPDR) at www.cpdr.org offers the current issue of each WRAMC Us Too Newsletter, as well as back issues. The website also provides reports of basic and clinical research being conducted at the CPDR. Check it out!

THIS NEWSLETTER IS MADE POSSIBLE BY AN EDUCATIONAL GRANT FROM ASTRAZENECA, MAKER OF CASODEX AND ZOLADEX.

PSYCHOLOGICAL FACTORS IN HELPING MEN WITH PROSATE CANCER

Steven J. Tulin, Ph.D.
Clinical Psychologist, WRAMC

(A summary of a presentation to the WRAMC Us TOO on November 2, 2005.)

INTRODUCTION

First let me tell you how I got involved with the Center for Prostate Disease Research (CPDR) here at WRAMC. For several years I had been working with women who were being treated for breast cancer. This gave me insights into the concerns of persons dealing with a diagnosis of cancer and the subsequent therapy. When the CPDR began using a team approach for men and their families facing prostate cancer, it just made sense for me to get involved. I became part of the team that includes a urologist, a radiologist, a medical oncologist, a patient counselor, and other specialists, as required. The team works with individ-
ual patients to evaluate their situation and make treatment recommendations. This unique approach enables me to deal directly with the patient at the outset rather than waiting to work with them later in the process. A brief discussion makes the patient and his family aware of what I can offer and lets them know that I am a resource they can look to in the event they need help in coping with the disease. Feedback from patients indicates that they value this approach even if they do not always seek my assistance.

GETTING HELP

The fact is that only a small number of men who are experiencing distress from their diagnosis with prostate cancer ever receive help. Why is this the case?
Well, it's just not a "guy thing" to talk about feelings, admit emotional pain, or perhaps even be aware that it is present. Men have been programmed, so to speak, from an early age to repress these responses. Ask for help for an emotional problem? Forget about it! Psychologists have a fancy word for this--"alexathymia," or the inability to recognize and deal with our feelings. Alexathymia is to men's feelings what color blindness is to vision. In fact, it's probably worse because denial of their right to have and get relief from emotional pain can leave men in a precarious condition.

The situation is often exacerbated by the likely response from medical doctors who treat cancer. They have a lot on their plates. Their job is to diagnose and treat the disease effectively. They may not sense the emotional factors at work in the patient. This is where the clinical psychologist can help, especially within the team approach we use in the CPDR. But there is some good news. A recent

report said that Aetna Insurance will soon fund training for primary care providers to recognize depression in patients and to make referrals for treatment. Of course, insurance companies have a motive for doing this. They realize that in the long term what is good for the patient in dealing with emotional pain is also good for them. It's just good business!

DEPRESSION

Let's talk more specifically about depression. The terms "depressed" or "depression" are frequently used by the lay person, but what do they really mean? Many times a patient who was treated successfully for cancer continues to complain that he still does not "feel right." The doctor doesn't understand the complaint because from his perspective, the treatment was a success. Psychiatrists use nine criteria to diagnose depression. They are:

Depressed mood most of the day, every day
Diminished interest or pleasure in most activities
Significant weight loss or weight gain
Insomnia or hypersomnia
Psychomotor agitation or retardation
Fatigue
Feelings of worthlessness or guilt
Diminished ability to think or concentrate
Recurrent thoughts of death or suicide

If a patient is evaluated as positive for five of the criteria, he is considered to have "major depression." I think these criteria are useful, especially the first one, "depressed mood most of the day, every day."

There is another category called "minor depression." A person may have some of the classic symptoms, and often expresses them by saying he is "just not feeling like myself." He can slide into depression gradually before it really hits him hard. It frequently happens that someone in his life starts to comment - "You're pretty grumpy these days. You don't seem to be laughing any more. You're not eating. You don't care what I serve. You're not finishing meals and you're losing weight. You're just not acting like your old self!" Many men hearing comments such as these will quickly deny being depressed.

Now let's look at the issue of helping men over time as they cope with prostate cancer from the diagnosis through primary therapy and beyond. Depression has been called a recurrent disease. If someone has been depressed at some time in the past, chances are good he may have a recurrence of his depression in dealing with prostate cancer. In the old days, they didn't call it "depression." It was a "nervous breakdown." Remember that term? When I inquire about a patient's family (a tendency to depression some-times runs in families), I may hear that "No, but I remember that sometimes in the winter my grandmother wouldn't get out of bed for three months."

GETTING THE DIAGNOSIS

Now I want to talk about what likely happens when a man is diagnosed with prostate cancer. It's a shock when he gets the bad news. Even though he knew that his rising PSA warranted a biopsy, the confirmation that he indeed does have prostate cancer often is like a bad dream, followed by a sudden and profound change in mood—the psychiatrists call it

"adjustment disorder with depressed mood." That's a fancy term, but in the vernacular, it means that the diagnosis likely hits the guy like a ton of bricks.

By the time the newly diagnosed man arrives at our clinic, he may have shifted into a "take charge" mode. He has done some research, scoured the Internet, and perhaps consulted with a support group. It helps him cope with his situation. The big decision is what primary therapy to select to overcome the disease. Of course, at WRAMC we often deal with men with the "military mindset" - a damn the torpedoes, full speed ahead approach, if you will. Having decisions to make and tasks to complete helps to make the patient feel effective and motivated.

But there is another part to it. The good news is that people survive cancer. Modern medicine enables us to survive, but with the burden of having to live with the disease. In the good old days, you didn't have to cope with living with cancer - you weren't going to be around very long anyway. Your family and friends might have had to cope with your loss, but you didn't have to learn to cope with the disease. You were going to die - that was it! Learning to cope with it is something relatively new. Again, in the good old days, many patients were not even told they had cancer. Today, we have a different situation. Patients learn, and expect to learn, the details of the diagnosis and the various therapies available. So they must learn to cope. Persons with cancer who refer to themselves as "survivors" appear to be doing so.

Also, we know that prostate cancer often recurs after apparently successful primary therapy. We see these men regularly at the CPDR. Some observers think that disease recurrence must be very upsetting to the patient. They ask how can men cope with the disappointment of recurrence. Yet I have found many men are somewhat peaceful about it. I think they've had a longer time to adjust to the disease. And, of course, there are additional therapies available to these men.

ROLE OF THE SUPPORT GROUP

Many of you participate in support groups. Does participation in such groups help men to cope emotionally with their disease? Can feeling better emotionally help men medically? In the 1990s, a Doctor Spiegel studied the effect of support group involvement on women with metastatic breast cancer. Did such involvement help reduce stress and improve longevity? At the time, support groups were not as prevalent or as structured as they are today. Dr. Spiegel found that the women participating in support groups lived longer than similar women who did not participate. His study conclusions got wide attention in the popular media. Subsequent studies found that there was inconclusive scientific evidence to support Dr. Spiegel's original findings regarding survival, but well-being and quality of life do appear to be better. Dr. Spiegel agreed that a cancer patient could not simply wish the disease away. Nevertheless, he argued convincingly that persons diagnosed with a life-threatening disease often feel better and cope better when they participate in support groups. The quality of life is enhanced; it just seems to happen.

ROLE OF DIET

A recent newsletter mentioned Dr. Dean Ornish and his study of prostate cancer. I'm familiar with Dr. Ornish because we have a study here at Walter Reed for patients with severe heart disease. The patient has to be highly motivated to participate in it. I helped with that program. It required a vegan diet, regular exercise, group therapy, and yoga. Dr. Ornish believes that this regimen can actually reverse coronary heart disease. The Ornish study evaluated men with prostate cancer, and it had a control group. In general, it concluded that the PSAs of the men on this program went down and the PSAs of the men in the control group went up. I am skeptical, but we are seeing more and more evidence that a specific diet may inhibit cancer. Certainly, a healthy diet combined with exercise will enhance a feeling of well-being. In short, improving healthy behaviors helps you feel better, and gives a sense of "taking charge."

GETTING HELP

Individual psychotherapy and certain medications can help men cope with illness. As a psychologist, I am not permitted to prescribe medications. Psychologists generally do not do so, although we are seeing more of them becoming licensed to do so after appropriate training. But I have certainly worked with many individuals who are receiving medication for depression and anxiety. When I ask these patients how the medicine is working, they frequently say the results are like a miracle for them. My observation is that carefully prescribed medications for depression are effective. I've learned that medicines like Prozac and other antidepressants have helped millions of people with very significant depression.

When should a man diagnosed with prostate cancer (or anyone, for that matter) consider going for psychological services? I would say when you are simply just not enjoying life the way you used to. You may find yourself embarked on a slow decline into negative feelings; you find yourself losing interest in things that you previously enjoyed; you procrastinate before doing important tasks that aren't enjoyable; you notice that your personal situation worsens because you aren't doing things you must do or enjoy doing. All the while you are getting more depressed, and the cycle continues until you get effective help. Persons in the military health care system are fortunate that such services are available. I am here at WRAMC to help provide these services.

SIDE EFFECTS OF PROSTATE CANCER THERAPY

There are other factors that I want to mention. The side effects of treatment for cancer can affect the patient's mood. Hormone therapy is an example. You may have metastatic prostate cancer requiring the chemical suppression of testosterone. Hormone therapy can do that, but it may make the patient feel distressed, irritable, dissatisfied, and generally very unhappy. The good news is that medications for depression can help with this situation. You may ask, "Why give another medication when the effects of the first medication (hormone therapy) are so bad?" Well, we do so because we know that it makes men feel better. Frankly, most of the patients I

deal with who are on hormone therapy aren't particularly bothered by it. But for men on hormone therapy who do become depressed, I often see dramatic improvement after they use antidepressants for hormone-related depression. Furthermore, one of the medications for depression actually helps to relieve the hot flashes that often accompany hormone therapy.

Let's face it, there are other potential side affects associated with the various primary therapies for prostate cancer that are distressing in a very fundamental way. Many men must contend with impotence and incontinence. They must confront the issue, adjust to it, and go on from there. But it is a stressful situation that could lead to depression. Sleep disorders are another likely side effect of treatment for cancer. The patients is under stress and may have trouble sleeping, so he feels bad. It becomes part of the cycle. We can help you sleep much better than we used to, whether it's a temporary or a long-term condition. I am of the opinion that if your prostate cancer therapy has side effects that negatively affect your mood and mental health, then depression therapy can be helpful. Whether your distress is associated with hormone therapy, impotence, incontinence, or sleep disorder, there is just no need to suffer. It's worth it to try depression therapy. I have seen dramatic results. Patients often report their satisfaction, saying they have noticed great improvement, and wondering aloud why they waited so long to seek help.

Coping with life-threatening illness may alter your perspective on what is truly important to you and your family. Furthermore, adopting healthy behavior, such as beneficial diet and exercise, can give you the sense of taking charge of events, rather than the sense of victimization. I often hear the comment, "Not that I wanted to have this cancer, but now I appreciate some of the things that I have." Others say, "People think I'm crazy to say this, but in a way, I am glad this happened. I am better for it."

ADDRESSING THE PROBLEM

There is another aspect, as well—not acknowledging that coping with serious illness can be depressing. You may encounter persons who are coping with life-threatening situations or challenges openly and who realize that over the long term it helps to talk. Another central issue is alcohol consumption. Distressed and dismayed, a man may think that an extra drink is what he needs in order to cope. It easily can become habitual, and in the long run, it is counter-productive. Overall, it's helpful to adopt a problem-solving approach. Focus on your daily challenges in order to decrease that sense of lost control. When people appear in our clinic seemingly overwhelmed by their health situation, we try to break down the several issues of concern, one by one, as a way of addressing the problem.

In general, psychology does not provide a message of spirituality. Nevertheless, the psychologist will want to capitalize on the patient's "strong suits," so spirituality can be a very important consideration in

many cases. Psychologists have studied patient spirituality in relation to successful therapy. And, yes, it appears that people who have a strong spiritual connection often do better. On the other

hand, an existential approach is often indicated, i.e., an individual's health situation is neither “fair” or “unfair.” It is just the way it is. So we move on from there to treat the condition.

Hans Selye in the 1940s convincingly demonstrated the correlation between stress and illness. Nowadays, people have become very concerned about stress and its effect on them. Although proven that stress has a relationship to illness, it's not a one-to-one relationship. Many people cope very well with stress. Why should a series of stressful events make some people sick more often than others? Well, we're getting better and better at understanding it. You should never feel that you must remain in bed with a pillow over your head; you have to continue to live your life. Let's put things in perspective. By all means avoid stress, but understand there is only so much you can do. And help is available.

RECURRRING DEPRESSION

Mood disorder or depression is considered a recurring illness. Some may have only one episode of depression in a lifetime, but for others, it can come back. A man with a history of depression may find himself brought low again by a diagnosis of prostate cancer. That's quite a challenge for the man and for those of us who want to help him. Obviously, the relationships you have within your personal support system are really important. So dealing with depression is not a one-shot deal. Your initial treatment is very important; you want to keep your follow-up. You're in it for the long haul, and you have to keep a good relationship with your treatment team. It's a long-term relationship that you must work at.

MAINTAINING HOPE

One of the symptoms of depression is a loss of hope - you don't think anything can get better. Coping well with a challenging medical situation shows that you have hope. Perhaps there is a promising new treatment on the horizon that fosters hopefulness. On the other hand, some people may have false hope; they think they are going “to beat this” even when the medical reality is clearly otherwise. Other people are in denial. I only use that term when a person declines treatment that he or she truly needs. Some persons have relatively mild medical challenges while others face more serious ones. Both groups can have hopes of defeating their illnesses. There's nothing wrong with that, but your medical condition should not be preoccupying you all of the time. We're here tonight, we're talking about physical health and depression, we’ll think about it on the way home, but if it is your unrelenting focus, then that is too much. Reach out for help.

Now I will be glad to take your questions.

QUESTIONS AND ANSWERS

Q: We frequently hear the word “anxiety” used in reference to patients diagnosed with cancer. How is anxiety related to the term depression? Is it a separate category?

A: That's a very good question. There is a large overlap between the terms

depression and anxiety. Anxiety is largely what is experienced upon an initial diagnosis for cancer. It sometimes can prevail for an extended period, even turning into clinical depression. Anxiety is treated in the same manner as depression, i.e., by using positive behavioral therapy. Sometimes we may think that a person has unreasonable anxiety, for example, being overly anxious about driving over a long, high bridge. In any case, the way to treat anxiety is to talk the person through the basis for the anxiety. We use the words, "What's the evidence?" I often find that there is no evidence that the person need be anxious. An observer might say, "Well, the reality is that this person is very ill and has a reason to be anxious." My response would be, "Is the level of anxiety helping the patient to cope with the situation?" The answer to this question is usually, "No." When I talk to the person, I ask, "Is there a good reason for you to be feeling anxious? Is it helping you?" Here is a place for the person's support system to start functioning. In addition, there are medications for anxiety that are very helpful. Patients may develop great anxiety just prior to a major medical procedure, and they may be able to get through it without medication. On the other hand, if they face frequent, repetitive, anxiety-inducing treatment for their condition, they should not hesitate to ask their physicians for an appropriate medication. Under these circumstances, it is probably unlikely that they can be talked out of their anxiety, so medication may be the better answer.

Q: Can coping with anxiety influence the patient's ability to fight his disease?

A: Some practitioners have called a patient's ability to cope with serious illness as having "a positive attitude." As I've said, there is research that addresses this issue. One researcher uses the term "hardiness" to label a patient's ability to deal with his situation - a tough cookie who won't give up, so to speak. There is some anecdotal evidence that these "tough cookies" have better outcomes because their toughness helps them. These individuals simply want to take charge of matters. They do what they think they need to do, and if it doesn't go right, they find another way to gain control. They don't accept the approach that one should just lie down, take it, and suffer. I have one caveat here. Some people simply don't want to be that way. It's not in their nature. They can be encouraged somewhat, but not by the person who comes into their hospital room and demands, "You've gotta fight this. You've gotta fight this!!!" That patient may not be in a mood to do that right then, or it may not be his or her style. We have to respect that.

When I was working with HIV patients, we had a group where all the patients sat together. Naturally, some of them would have a more positive attitude than others. And I thought to myself—this is where the group is so important. All day long they would talk with this positive attitude. You could observe the beneficial effect on the entire group.

Q: Our WRAMC prostate cancer support group is very active, and one of the keys to its success is the ability of the members to laugh at themselves even as they share their experiences. A good-humored approach seems to have a very positive affect. Our facilitator often says, "We take the disease seriously, but not

ourselves seriously." Do you have any comment about that?

A: Yes, it seems to exemplify the "positive approach" phenomenon that I just described. I think that it is great. I expect there has been some research on the effect of humor in coping with serious illness. I do have an innate feeling that humor must respect the sensibilities of those in attendance in order to avoid giving offense.

Q: Regarding your comments about anxiety, I think the common initial reaction to diagnosis is denial. Nobody wants to accept it. What's your experience with people going from denial, then becoming pessimistic about the outcome despite their doctors' assurances?

A: Well, here's what I would do. I would ask, "What's the evidence that the doctors aren't telling you the truth, that the cancer will assuredly recur, and that your days are numbered? The doctors tell me that, based on the clinical data, they are reasonably certain of a favorable outcome. So what's the evidence that makes you feel differently?" It usually turns out there is no such evidence. Regarding denial, you are right. We have this self-protecting mechanism when we are totally in a sad mood. Some people think it is a bad dream. We have a fancy word for it—"depersonalization." They say to themselves, "This couldn't be true!" Some even insist that it's not true. That's how deep their denial is. It is rare to see a person so overwhelmed by anxiety that he cannot cope. If we do encounter such a person, we have great resources at our disposal to treat them. A patronizing attitude toward those in denial is probably one of the worst responses that a patient has to deal with. Sometimes people say, "I'm surprised he is not more upset about the diagnosis." Well, his denial is protecting him from the reality.

Q: Is depression likely to exacerbate a medical condition?

A: There have been some studies by researchers who feel that if you're depressed, you're going to make yourself medically ill. Perhaps there's some relationship. I haven't seen that. We do know that there is a correlation between stress and illness. The correlation doesn't always hold; for example, some people who have terribly stressful lives are totally healthy, and people who lead charmed lives have all sorts of medical illnesses. But if you look at the results of that old study in 1947, the more stressful events that you have—the worse the stressful events—the more medical illness. Really a fascinating thing! But I think what you're asking is, is it important to treat depression so people won't get medically ill as well as being depressed? I don't know the answer to that, but I think there may be a relationship. Certainly we do know—this is absolutely a fact—that when people are depressed they don't seem to adhere to their medical regimen. It could happen that depressed people, who are diabetic and have to have their blood sugar measured and insulin monitored, are going to say, "Oh, what the hell! I'm not going to fool around with this diet. Who cares?" Depressed people tend not to take the medications that they're supposed to take. They don't give a darn. They're depressed. "Oh, what's the difference, anyway? It's not going to

help." Then they'll get more depressed. We know that.

Q: I have a question about this issue—the correlation between actual truth and hope. Can you expand on that a bit?

A: Yes, the actual truth is some objective measure. Let's say someone you know is terminally ill. He may still have hope—and he tells you he does and, in fact, he does!—and he feels better because of it. And yet, it's not objective. It's not correlated with the medical facts of the situation. Then there is the opposite situation - people who are not optimistic who have a very good prognosis. So it's in the eye of the beholder. And, of course, I think the more positive attitude is the one to adopt.

GOOD NEWS - BAD NEWS

The good news is that President Bush recently signed the Fiscal Year (FY) 2006 Department of Defense (DoD) Appropriations Act authorizing $80 million dollars to the DoD Prostate Cancer Research Program (DoD PCRP) within the Congressionally Directed Medical Research Program. The bad news is that last year, and for several years past, the annual DoD Appropriation Acts have provided $85 million for the DoD PCRP.

LAST, BUT CERTAINLY NOT LEAST!

The WRAMC Us TOO Newsletter begins it fifteenth year of publication with this issue. It started as a 10-page newsletter produced on an office copier in 90 copies for distribution within the Walter Reed Army Medical Center (WRAMC). It is now mailed without charge to 2,150 readers nationwide. This is all made possible by the steadfast support of the staffs of the WRAMC Department of Urology and the Center for Prostate Research. In addition, we are indebted to the WRAMC mailroom staff that provides timely postal support; to New Dimensions Printing and Graphics, our printer, for its reliable support and frequent technical suggestions for improvement; and to TAP Pharmaceuticals and AstraZeneca for the financial wherewithal to get the job done over the years.

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

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

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♦ MEETING ANNOUNCEMENT ♦

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7 PM

JOEL AUDITORIUM (SECOND FLOOR)
WALTER REED ARMY MEDICAL CENTER

♦ SPEAKERS ♦

RALPH and BARBARA ALTEROWITZ

AUTHORS OF

"The Lovin' Ain't Over: The Couple's Guide to Better Sex after Prostate Disease"

♦ TOPIC ♦

"RETURN TO INTIMACY AFTER PROSTATE CANCER THERAPY"