

PCNG

PROSTATE CANCER NETWORKING GROUP

of
Greater Cincinnati

PCNG (<http://www.pcngcincinnati.org>) is a chapter of USToo

Founder: Bob Kanter - Conveners Emeriti: Adrian Boie, Lou Stadler - Facilitators: 8/03: Stan Moczydlowski; 9/03: Steven Plymire; 10/03: Tom Young; 11/03: Steve Steiner; 1/04: Jerry Glenn; 2/04: Jack Ramsay; 5/04: Dick Fencil
Newsletter (328 copies this issue) - Editors: Kees DeJong & Fran Stanton

779-0144 Adrian Boie: 1989, PSA 13, GS 9; RP, EBRT, IHT, HT
751-6888 Kees DeJong: 1996, PSA 24, GS 9; IHT, EBRT+Brachy, IHT
253-6768 John Hoffmann: 1997, PSA 5, GS 6; RP, EBRT

TELEPHONE CONTACTS:

528-2769 Gordon Huntley: 1999, PSA 4, GS 9; RP and Orchiectomy
733-5745 Bill Riggs: 1995, PSA 33, GS 6; RP, EBRT, HT

761-9645 Lou Stadler: 1987, PSA NA, GS 7; EBRT, HT
542-4908 Fran Stanton: 1999, PSA 157, GS 8; HT, EBRT+Brachy, HT
984-3343 Tom Young: 2002, PSA 7.8, GS 6; RP

19/20xx: year of diagnosis - PSA: Prostate Specific Antigen - GS: Gleason Score - RP: Radical Prostatectomy - EBRT: External Beam Radiation Therapy - Brachy: Brachytherapy ('seeds') - HT: Hormonal Therapy - IHT: Intermittent Hormonal Therapy

Next Large Group Meeting Will Be Held On Wednesday, June 30th

at The Wellness Community, 4918 Cooper Road *Women Are Very Welcome!*

6:30 pm: hospitality and networking - 7:00 pm: new members & sharing; 7:45 pm: additional networking

8:00 pm – Incontinence and Impotence: What to do? *Neil Frankl, RN*

Neil Frankl is the Clinical Nurse-Coordinator of the Division of Urology, University Hospital, Cincinnati

Next Small Discussion Group Meetings will be held on

Wednesday, July 14th from 7.00-9.00 pm at the Wellness Community

One Discussion Group for men, and a separate Discussion Group for their Spouses, Partners, or Family Members

We start this issue with a brief review of what types of treatment are available for impotence.....

Summary of impotence treatments

Impotence can be treated and often cured. The American Medical Association estimates that doctors can effectively treat 95% of impotence cases with one of the following impotence treatments:

- **Drug therapy:** Drugs work to increase blood flow to the penis. Viagra® is one of the major impotence treatments today. Other drugs with similar phosphodiesterase inhibitors (PDE5) are Levitra® and Cialis®. Some drugs even work on the mental or nerve-transmitting part of impotence, which helps the brain communicate to the penis.
- **Penile implants:** A surgeon places a small, saline-filled medical device that recreates the erectile function. The device transfers fluid to the penis when an erection is desired. The device is totally concealed. This procedure has one of the highest patient satisfaction rates of all impotence treatments.
- **Vacuum erection device:** The man puts a plastic tube over his penis and creates a vacuum by pumping the air out. The vacuum draws blood to his penis. This makes it erect. He then places an elastic band around the base of his penis to maintain blood in the penis and keep it firm.
- **Injection therapy:** The man injects medication into the side of his penis. The medication makes the blood vessels widen. As blood vessels widen or "dilate," blood flow increases to create an erection.
- **Urethral suppository:** The man inserts a soft pellet of medication into his urethra. His penis absorbs the medication. Blood flow increases, creating an erection (similar to injection therapy but without the needle).
- **Sexual Counseling:** Whether ED has a physical cause or not, a man may benefit from therapy that teaches him how to reduce his anxiety about sex.

“.....and continue with the role that sexual counseling could play in dealing with ED

Restoration Of Intimacy

Adapted from a paper by Peter J. Fagan, Ph.D
Director of the Sexual Behavior Consultation Unit
The Johns Hopkins School of Medicine Hospital

Erectile dysfunction (ED) most often has a physical cause and today, thanks to Viagra, Levitra, Cialis, and other non-oral treatments, the physiological aspects of ED can be treated successfully. However, without also addressing specific issues of intimacy between a couple, a critical component of a man's emotional and sexual life, these treatments will take that man only so far. Sex involves two people whose feelings must also be recognized. Many men often shy away from talking about their sex life in general, and ED in particular, for a variety of reasons, including embarrassment, frustration, even fear. When a sex life has problems, emotional estrangement can quickly occur. Dealing with the problem, in all its complexity, is the only way to assure that the problem is solved to the mutual satisfaction of both partners.

Without an emotional connection to your sexual partner, you won't develop the deep, satisfying awareness that defines great sex. For those of you who took your sex lives for granted prior to your cancer, this is a golden opportunity. Not only do you have available the means to restore your sexual function, but by talking to your partner about your sex life together you can also bring new emotional perspective to your relationship, creating a stronger, more resilient bond that will enhance your sexual experiences as well as those of your partner.

Facing the many psychological reverberations that ED causes in men and their partners after a prostate cancer procedure is a very important part of treating the condition successfully, which is why sexual counseling can play a critical role.

Q. What are the best ways to initiate change in one's sexual relationship?

A. Talking with your partner is the biggest step you can make since it's never easy to admit that your sexual relationship needs help. Modifying it takes work and time, but knowing those areas that are giving you and your partner trouble will make it easier. You always need to keep the lines of communication open. It's paramount that you speak frankly with your partner about your condition. Be honest about your feelings, sexual needs, and desires. If you both come to agree that counseling is the right course, your partner needs to be part of the process.

Q. When does someone need counseling?

A. When it starts to hurt too much emotionally, whether it is the man or his partner. The earlier a couple seeks counseling, and I like to see couples, the better the results will be. Most of the patients I see have had their local treatment 9 to 18 months before. In that pe-

riod, the first nine months especially, the couple was being patient but then when the erections did not return as before, they began to get worried and wanted answers. If you find that you cannot satisfactorily resolve your problems, I urge you and your partner to seek additional help. Hopefully, you will find that sexual counseling can be an effective way to strengthen and deepen a relationship while regaining lost pleasure.

Q. What type of medical professional should a couple seek?

A. If there is a department of sexual health connected with the psychiatry or urology department at a major teaching hospital, call and ask for a referral. If not, check your county medical society or state psychological association. You want a mental health professional that is experienced in sexual dysfunction and related disorders, and has treated post-surgical and post radiation prostate patients or has had some experience with patients with a chronic illness.

Q. How long do you recommend that a couple stay in counseling?

A. For the uncomplicated post-treatment couple, with the strengths and weaknesses of most couples, I would estimate about two to three months of weekly sessions. I describe the therapy as an ongoing retreat, a period that will allow them to work closely together. It's a privileged time where they can step back, reassess, and see what they can do to make things better.

Q. What is the general emotional state of the male undergoing counseling?

A. The Hopkins prostate cancer patient already understands that the surgeon has three major goals, in the following order: stop the cancer, prevent incontinence, and spare sexual function. Patients are aware of this. The couple that has had minimal sexual activity will not be too traumatized at the loss of erection. However, if sex played a significant part of their relationship, it will be a much greater loss and require more counseling.

Q. What are your goals as a therapist?

A. What I hope will happen is the creation of as much intimacy and sexual expression as possible between the couple. Even if it is not possible to achieve sexual intercourse, it is still possible for sensual pleasuring to take place and I make this clear to the couple. If the man had previously thought that sexual intercourse was the end point in a sexual relationship, I invite him and his partner to now write new sexual scripts for themselves. This works to diminish sexual estrangement between the couple.

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Q. Is it difficult for a man to review his sexual history with a therapist?

A. Most couples have difficulty talking to each other about their sexual life. Granted, they can talk about sex in general, for example, sex in the news, but when it comes down to the man and his partner, it's often a challenge to talk about their sexual wishes and concerns. Therefore, it really comes down to the level of comfort that's established by the therapist with the couple. "I'd like to get an understanding of how sex has been for both of you," is a typical non-threatening question asked of the couple in the first session. With each one answering in turn, an easy dialogue is created that should carry over for the rest of the meetings.

One of the things I ask couples soon after we've met for a few sessions is why they have intercourse. "Pretend I'm from Mars," I'll say. "Why do you humans do this sex thing?" Oftentimes, through this ensuing dialogue, the couple comes to realize that it's more than an erection, more than orgasm, that sexually attracts them to each other. I will ask the man and his partner to look inward and bring out into the open issues that may have been waiting beneath the surface. To make their bond stronger, to create a trusting atmosphere that will foster growth, to progress to a mutually-fulfilling relationship, the couple has to find out how each one really feels about sex. This can encompass everything from the meaning of sex in their relationship, and their reactions to utilizing ED therapies, to their degree of personal sexual satisfaction, identifying sexual problems, and anxieties related to intimate matters.

Q. If sex was a big part of a relationship, will the relationship be permanently broken if erections don't return?

A. Sex is frequently made to carry more of an emotional burden than it should. A therapist has to first see how the couple is handling the death threat imposed by the cancer. This means that the couple has to come to terms with what the cancer has done to their lives. Even though the prognosis is often good following a radical prostatectomy or radiation treatment, 99.9 percent of the couples are still jarred by a cancer diagnosis. A woman has been forced to picture herself as a widow, while the man has had to come face to face with his mortality. A couple that comes in for counseling may be totally focused on their sexual life and don't typically say they're suffering from the angst of dealing with mortality. It must be recognized in order for true healing to take place. They then need to be able to find joy in their lives together again. They need to be grateful for the days, for the time that they have together, taking the baseline

that is there in terms of intimacy, the emotional as well as sexual, and build on it to make it even better.

Q. How do you counsel the man who is devastated by his inability to get an erection?

A. If the man is really depressed about his inability to achieve an erection, then he will need special care. Treatment for this depression includes medication, counseling, or a combination of both. These treatments not only improve behavior and mood, they also reduce suffering and enhance quality of life. Family and friends are usually the first to notice the changes in behavior and mood, and should encourage the man to seek the evaluation of a doctor or mental health professional when symptoms are severe or last for two weeks or longer. Some symptoms to look for include a persistent sad or 'empty' mood, loss of interest or pleasure in ordinary activities, fatigue or loss of usual energy, sleeping problems, including insomnia, early waking or oversleeping, loss of appetite or overeating, difficulty concentrating, remembering, or making decisions, and feelings of guilt, worthlessness or helplessness.

Q. Does the difficulty or inability in achieving an erection bring about a sexual reawakening in some men?

A. Yes, it does. Some men have been so intercourse-oriented that they never really understood the power of romance and what intimacy really meant for their partner. Without being able to have an erection or to sustain one as before, they soon come to realize that something as simple as a hug or gentle back rub or massage helps firm the intimate bond between the couple.

Q. Is it difficult to convince a resistant man to create new sexual scripts?

A. ED is really a couple's issue. It's a question of the couple being educated about various options and then, being respectful of their esthetics and values, having them understand that they are being given permission to broaden the sexual scripts, to have more variety than there might have been. The couple has to come to realize that it's this sensual pleasuring of each other that can preserve, restore, and enhance the intimacy between them.

Q. What have been the typical responses from patients after completing a full counseling session?

A. Uniformly, they are grateful for having done it because communication and intimacy have improved. How things actually work out sexually, depends on the pre-cancer sex baseline, how often and how satisfying sex used to be, and secondly, the effects of the treatment on their sexual performance. Even if there is not a return to baseline, I think most couples feel the counseling is extremely beneficial because it helps cement their intimacy and lets them come to terms with their new physical reality.

PCNG Newsletter, June 2004

ADDRESS SERVICE REQUESTED

PROSTATE CANCER NETWORKING GROUP
OF GREATER CINCINNATI

c/o The Wellness Community
4918 Cooper Road
Blue Ash, OH 45242



speakers:

- **Impotence and Incompetence**

features:

- **The Role Counseling Can Play**

*In every struggle the only ones who can truly grasp
your fear, your pain, your grief, your stamina that may
sometimes fail are those who share the battlefield with you.
It is no different when the enemy is prostate cancer,
and the fight is for your integrity as a man as well as your life.*
Robert Young, www.phoenix5.org

please, visit our web site

www.pcngcincinnati.org

--enter PCNG in your Google Bar – we are numero uno!--

you will find many links to information sites
from patients, the government and
various other organizations, and
there are also links to mailing lists, books,
print magazines and web magazines

According to the Am. Cancer Society - <http://www.cancer.org> - 230,110 new cases of prostate cancer will occur in the USA in 2004 (8,620 in Ohio); 29,500 men will die (1,290 in Ohio); 1 man in 6 will get prostate cancer during his lifetime, but only 1 man in 32 will die of this disease. ----- 2,475 clinical trials on cancer are listed at <http://www.clinicaltrials.gov>, with 179 trials on prostate cancer of which 17 trials are in Cincinnati, one described in the March '04 issue of our Newsletter. ----- 45,741 citations (of which 33,508 are abstracts) on prostate cancer can be found at <http://www.ncbi.nlm.nih.gov/> - PubMed (6/21/2004).
