

INTIMACY - OFTEN CHALLENGED BY SURGERY, RADIATION, CRYOTHERAPY, OR ADT

Charles (Chuck) Maack (ECaP) – Prostate Cancer Survivor, Volunteer Mentor since 1996 to men diagnosed with Prostate Cancer and to their Caregivers locally and on-line worldwide, Advocate, Activist.

Disclaimer: Please recognize that I am not a Medical Doctor. Rather, I do consider myself a medical detective. I have been an avid student researching and studying prostate cancer as a survivor and continuing patient since 1992. I have dedicated my retirement years to continued deep research and study to serve as an advocate for prostate cancer awareness, and, from an activist patient’s viewpoint, as a mentor to voluntarily help patients, caregivers, and others interested develop an understanding of this insidious men’s disease, its treatment options, and the treatment of the side effects that often accompany treatment. There is absolutely no charge for my mentoring – I provide this free service as one who has been there and hoping to make their journey one with better understanding and knowledge than was available to me when I was diagnosed so many years ago. **IMPORTANTLY**, readers of medical information I may provide are provided this “disclaimer” to make certain they understand that the comments or recommendations I make are not intended to be the procedure to blindly follow; rather, they are to be reviewed as MY OPINION, then used for further personal research, study, and subsequent discussion with the medical professional/physician providing their prostate cancer care.

Intimacy is an important relationship between couples that can be challenged as an effect following surgery, radiation, cryotherapy, or when a man’s prostate cancer has escalated to the necessity of androgen deprivation therapy (ADT) to survive.

It is extremely important that both patient and wife/partner receive appropriate counseling so that both understand what occurs following surgery, radiation, or with the administration of androgen deprivation therapy when an LHRH agonist must be included in androgen

deprivation treatment. Trauma to neurovascular bundles from surgery or radiation often takes many months to recover. And for men requiring the necessity of androgen deprivation therapy – the shutting down of testosterone production to remove the fuel that stimulates prostate cancer cell growth – this treatment has a dramatic effect on blocking mind/sexual stimulation a man has little ability to control. Thus, the importance that both parties recognize this may occur and work together in discussing the emotions they each are experiencing to work together to overcome and resolve the cause of those emotions. Intimacy can still be experienced despite the loss of erectile capability. Both must better communicate, and in that communicating keep in mind that wrong inflections or tone can be misinterpreted and bring about stress and misunderstanding.

Despite the difficulty experienced in gaining the return of an erection, it is important that men continue concern for that of their partner. There is no excuse for any man to clam up and come near to shunning his partner because of possibly feeling inadequate because of this hopefully temporary setback. Love and intimacy are more than sexual intercourse. Though sexual intercourse is a comforting and exciting coming together of those who love and care for each other, it is not the entirety of intimacy. Intimacy has so many other acts that express love, care, concern, and need for the other as well as needs of the other. We read recommendations of seeking counseling but that, too, is easier said than accomplished. The questions posed are first, who in the community (pastor, physician, counselor) is experienced in this type of counseling and could adequately address what is occurring sufficiently to understand and want to do something about it? And secondly, likely more important, are you willing to participate in such counseling? When the first question cannot be answered because such professionals are not available, it then becomes paramount that we work with our partner to resolve the intimacy issue in other ways. Obviously, those of you caught up in this uncomfortable and for many almost unbearable experience are dealing with much frustration. I wish I had the answer, but I am merely a prostate cancer survivor since 1992 and androgen deprivation patient myself since 1996; probably as inadequately

addressing this situation as well as I should in my own wonderful marriage continuing since 1954. This is my small contribution in that effort.

Both men and women need to recognize these very troublesome side effects that come from treatment or the medications required to sustain life so that together they can research and study how to go about continuing being able to love and be loved and enjoy the intimacy that can come from a caring and loving relationship. A loving relationship does not have to hedge around being able to have sexual intercourse. True love is the result of comfortable “intimacy” between two persons; the ability to show concern and care for the feelings of the other, to continue the “look,” the caress, the hug, the kiss, the holding hands, and to be willing to open-up exchanges of emotional feelings in order to recognize and understand the needs of the other.

In an email, I had remarked “From past experience in reading many such issues between couples, this is a subject that has so many variables that it is difficult to come up with a simple conclusive recommendation. The key word is "communication." With communication and regular discourse between couples, the effects of androgen deprivation therapy and erectile dysfunction are much more easily resolved.”

In reply to that remark, a woman provided likely the best perspective of what the partner/caregiver is experiencing emotionally while trying to comfort and show understanding:

“Sometimes I think that talking is the most evil form of communication there is. We take such comfort in it, yet we can undo everything we've said in one gesture or in one look, or even in one misinterpretation. Show me. Take me outside and let's watch the sunset together. Put your arm around me and pull me to your side for a long hug that tells me I'm treasured. When you wake up in the morning and meet my eyes, smile when you see me there. Surprise me with a picnic you've made for two, or arrange dinner for four with my friends at a cheerful place that won't mind if we linger until closing time. Send me happy-to-be-with-you messages. Join me in the shower and let me wash your back after you've washed mine. Touch me, even if it's just a gentle hand on my shoulder, or on my leg beneath the table. Work your way to

"bolder" but ease off at the first sign of resistance. I will do the same, always respecting the signals you give, whether you utter them or not. Show me. Discover me. Rediscover us. Show me what you are saying is true. Then I'll listen to what you need to say."

What a powerful rendering regarding what many (most?) we men fail to recognize; fail to act on! I was so impressed and told her so as did several others. In my reply I added "I still believe communication is vital, but you alluded well that words used in communication and gestures that accompany those words must be considered carefully so that a remark is not perceived as hurtful." I would encourage all men reading this paper to re-read what this woman provided for our recognition; then take that advice and act on it.

The following are suggestions provided me by a couple with the intent I provide others towards hopeful enjoyment of intimacy despite erectile issues:

"This is for those who may be still wondering what to do after reading the excellent messages that have been posted about ED medications, vacuum devices, injections, and implants. If those methods leave you unsure which way to go, this might help. My wife and I have found that a different approach to intimacy works for us, and I am writing to offer our learning as an alternative to the foregoing techniques. After my seeds were implanted in Feb of 2007, my sexual abilities were significantly reduced and continued to plummet as time went on. We regard this as a 'couple problem', so my wife and I attended a few sexual intimacy seminars, read some material, and had several great discussions about this. Perhaps the best resource we found was "Intimacy with Impotence", The Couple's Guide to Better Sex after Prostate Disease by Ralph and Barbara Alterowitz. (***My note:** direct email access to order provided at end of this article*). We read a few paragraphs out loud then stop to talk about it. A few days later pick it up and read some more then stop and talk again. Continuing in this manner over several weeks, we became better informed about several alternatives and about our own intimacy needs and desires. High on each of our own priority lists is being a good sexual partner to each other. To achieve this requires knowing what the other person really wants. Even

after over forty years of marriage, I found that my wife's real desires turned out to be quite different from what I had thought. Her preferences boil down to holding each other, having her hair brushed, and (*My note: suffice it to say graphically sexual, thus omitted*). We snuggle frequently. About once a week I brush her hair for as long as my arms hold up. She gives me a wonderful genital massage every day using a variety of techniques. We usually spend from ten minutes to an hour doing this just after we wake up and pray together. Sometimes she takes me over the top while enjoying watching me react to this. Once every six weeks or so we take some ED meds and try traditional intercourse. Sometimes that works sometimes not. If not, it is no big deal. We have come to realize that the key factors impacting my ability to have an orgasm are (A) my not worrying about it, (B) taking time to enjoy the passion, and (C) maintaining an erotic atmosphere. It has been fun to explore creative ways to keep the passion high. All this results in both a personal relationship and a sexual satisfaction that exceeds the levels we had before the PC. In addition, our approach doesn't entail medical risks, pain, inconvenience, or expense. This path has worked well for us, and it is our hope that at least one other couple out there might find our sharing of this useful."

This from Virginia E., in a posting to an online prostate cancer support list in 2011:

"Another woman who writes joyfully about sex--in case you haven't read her books--is Erica Jong. I never met her, but I can identify with her. I am her age and went to college in New York at the same time she did and I guess you could say we were shaped by some of the same influences in our generation. We both grew tired of B.S. and wanted to get to the truth regardless of what other people thought. I'm reading her most recent book (although another is due to come out in June) "Seducing the Demon". (*My note: Since this book and the reader's remarks were in graphic detail, rather than included here recommend procuring the book available online*).

Virginia provided another important recognition in another post: "I think men equate libido with physical signs they are accustomed to, and when they don't immediately feel and see these signs, they feel

depressed, and nothing kills the energy that fuels libido like depression. I think it's even possible that before the spark ignites, the unconscious immediately switches it off as a defense against feeling that disappointment of the missing physical response. The unconscious is reasoning "better to feel nothing than risk failure." Of course, the only way to counteract this is to break through the unconscious and to redefine failure. This means exploring a new reality, seeking new methods of stimulation to replace those that can no longer be relied on in the interest of preserving life and health. My explanation is not the only one - in many cases loss of libido is real and is due to real lack of hormones and nerve connections. But in other cases, it is primarily mental, as in my experiences. Either way, it is possible to find a way to find a path to satisfaction, with courage and perseverance and patience."

The following was written by someone who faced not only prostate cancer but just one of the many other conditions that come with getting older. (In her case, her husband almost died of an aneurysm):

"The benefits which come from the need to adjust our sexual attitudes and approach as we grow older or experience injuries can really enhance our sexual lives if we can address them head-on and truthfully rather than fleeing from them or avoiding them. Prostate cancer is one of the most devastating conditions but it isn't the only one that interferes with sex as we have known it. In other words, prostate cancer survivors aren't as alone as it seems at first. After curing or controlling the disease, life goes on--and our sexual lives can go on--if we let them, if we are willing to fight."

To conclude, consider obtaining the excellent book, "Intimacy With Impotence – The Couple's Guide to Better Sex After Prostate Disease" authored by Ralph and Barbara Alterowitz, certified sexual therapists. This book can be purchased at www.renewintimacy.org." You may also want to add "A Woman's Guide to Thriving after Prostate Cancer" by Cindie Hubiak to help in this recovery process, available online.

Would that the foregoing provides helpful considerations for a continuing healthy, caring, and loving relationship.