

ERECTILE DYSFUNCTION? NOT JUST “YOUR” PROBLEM; READ ON - CONSIDERATIONS FOR MEN AND THEIR PARTNER

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Despite the difficulty you may be experiencing in gaining the return of an erection, it is important that you continue concern for that of your 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 set-back. 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 situation are dealing with much frustration. I wish I had the answer, but I'm only a continuing patient since 1992 and androgen deprivation patient myself since 1996, so probably as inadequately addressing this situation as well as I should in my own wonderful marriage continuing since 1954. Here are a few things brought to my attention and are so important and will most certainly help any couple: 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 are much more easily resolved.” And in regards 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?) of 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. Keep in mind, if you are feeling a person hurt because you are unable to have sexual intercourse, this is NOT the importance in your marriage or partnership you may be giving those feelings wherein you then try to protect YOUR feelings by avoiding any discussion with your spouse or partner. By avoiding your spouse or partner you are rather being selfish in thinking only about yourself. That spouse or partner has feelings as well and likely hurting for YOU while hurting inside as well because of your neglect, avoidance, even shunning any discussion. If you care, if you love that spouse or partner, SHOW IT. You will be surprised what a simple hug and kiss will do for that spouse or partner; it will show that you still do care. As you read on, intercourse is not a prerequisite to being intimate and showing love and concern.

For men and their wives/partners experiencing difficulty with intimacy as the result of treatment, an excellent book is "INTIMACY WITH IMPOTENCE – THE COUPLE’S GUIDE TO BETTER SEX AFTER PROSTATE DISEASE" by Ralph (a PC survivor himself) and Barbara Alterowitz, both certified sexuality counselors (AASECT). This book can be purchased at www.renewintimacy.org.”

From Barbara B., wife of a PC survivor, posting on the intimacy support list pcai@prostatepointers.org:

“From a woman's perspective.....

I met my husband two years ago, when he was four years post-prostatectomy. Having been a sexuality instructor for decades, I thought (and told him), "no problem!" In retrospect, I was arrogant! I figured there are countless ways that a loving and intimate couple can express their sexuality and-- yes-- achieve orgasm, other than through vaginal intercourse. To me, in my naivete, the ED was a nonissue. What I did NOT realize was that regardless of my "vast knowledge" about sexuality and my openness to experiment, that ED was not HIS underlying issue. Rather, it was that he had experienced deep losses-- of his erectile ability, his ability to ejaculate, the depth and ability to have a "real"orgasm-- all major components of what it is to feel like a man. Until I could accept that he needed time to grieve (something even he was not aware of) and that until I could acknowledge his need to grieve and be there for him with empathy, it would never happen, and we would never be able to get on with our sexual lives together. In fact, this important issue spilled over, out of the bedroom, into every facet of our relationship. Couples therapy helped. So did sex therapy (which was quite holistic and which focused on far more than sex itself). And so did individual therapy. We were bound and determined to make it work, and we eventually got on the same page about it. Along the way, we discovered ways to deal with anger management (yup - another therapist - this one a behaviorist) and with stress (the mindfulness CDs that are out there are quite helpful). We have made and continue to make this journey together. Milestones along the way: discovering and appreciating that non-genital touch can feel good and be sexual as well as sensual, improvements over time in responses from Viagra and other ED meds, spontaneous erections from time to time, more initiation of love making from my partner (rather than me being whiny and demanding and going to that dark place that my therapist calls my "lizard brain"), penis-in-vagina intercourse with both of us having an orgasm (we are waiting for a second time on this but are becoming increasingly convinced that it will happen), discovery that using the Hitachi Magic Wand can produce wonders when it comes to an orgasm - for both of us, . . . and the list goes on. I am sharing what to us has been a sense of wonder, relief, and happiness that changes can happen, if you are patient with yourself and with your partner and if you stay open and honest with each other.”

And I hope the following opens the eyes of those of you men who believe an erection is an absolute for sexual pleasure for both you and your partner. This from Virginia E., in another posting to the pcai@prostatepointers.org support list:

“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". On page 79-80 she writes:

I tried to write about the role of sex in my life in "Fear of Fifty," but I realize now, in my sixties, that I didn't know the half of it. Until you get wise enough (or old enough) to understand sex as a whole-body experience, you know nothing. All my life I had heard about tantric sex and I thought it was utter bullshit...Most of our sexuality is so focused on the stiff prick that we have no idea what to do when that becomes occasionally problematic as it does with age. You can become a Viagra junkie or you can create other ways of making love. The deliciousness of skin, or oral sex, or sex without homage to the divine Lawrentian "phallos" can be a revelation....Whatever breaks our fixation on the genitals and turns us into entire bodies linked to entire minds enhances sex. The best Italian lover I ever had could practically make me come by stroking my neck. The married poet who shook with fear, then fucked me with a stiff cock, was no sort of lover at all. A lover makes love with words, with stroking, with laughter. ANXIETY RUINS SEX. [emphasis mine because I believe this is the heart of our problem.] Which may be why married people can have great sex--as can longtime lovers--or longtime friends. Music, stroking, scent, poetry--these things are far more important than a stiff prick. I realized only when my husband had to take heart medication and could not tolerate Viagra that we were able to discover things we never knew before. He could have whole-body orgasm while giving oral sex--his orgasm triggered by mine....When we were able to have genital sex after that, he said, 'It feels so localized compared to before.' Intercourse produces an orgasm in the pelvic area, but other kinds of sex produce it all over the body--and mind."

Another area of concern can arise when a man makes the decision to have a penile implant both because PDE5 inhibitors as well as penile injections are not providing the result expected, and in order to have an erection whenever necessary. For couples recognizing what this new capability brings to their relationship, this is not as much surprising as it is for men who come upon new partners who may not even be aware that such a procedure can be performed on men. Following is a woman's perspective, followed by a response by one of our regular contributors on the Prostate Cancer and Intimacy (PCAI) Us TOO Intl., Inc. online support list in this regard:

WOMAN'S PERSPECTIVE:

From my experience (as a woman), having sex with someone with an implant is not a noticeable difference...other than noticing a "third nut" at certain times.

There's just a little more in the sac..it's still a nice handful. Remember that women you have sex with will not have a reference point of your "before and after" as you will, so to me it is just like any other sexual discovery with someone new.

Everyone is built differently, feels different, and makes love differently. I'm more interested in the man, than the "machine".

And about when to tell someone...I think you have to go with your gut and take cues from the person you're with. There's no cut & dry method except for being *truthful & sincere*. Talk from your heart & not about previous conquests, how long & hard you can go or the various positions you can twist her up in without losing your hard-on & intimidate the hell out of 'em ;-). For perspective, if you were going out with someone for the first time and your date showed up with a prosthetic arm and never mentioned it, what might your reactions/feelings be? Not that you'd run screaming, but likely would feel taken aback or at least surprised. As humans we need time to process things that are "new" or out of the ordinary, and then be "ok" with it.

In my opinion, it takes a small-minded person to reject someone based solely on whether they have a prosthetic anything. So when you run across people like that, you can feel lucky you found out early so you are free to move on to someone who can appreciate you as the wonderful person you are.

It's really more about THEM -their pitfalls/insecurities- than you. Plus, in (name removed for privacy) example, the lady he gushed on and on about that decided she couldn't get past the notion of the implant...something else may have been going on there and it was a convenient scapegoat...knowing there is also insecurity around it makes for an easy target. You just don't hop into bed with someone knowing they have an implant and then use it as an excuse to dump them right after...seems like the easy/cowardly way out to me.

Sometimes, people just won't like you for lots of reasons, period. It's likely not about what's in your pants (implant or not).

In conclusion, if it looks like a dick, feels like a dick, it must be a dick! Hallelujah!

MAN'S (RESPONSE) PERSPECTIVE:

The funny thing is that I still hear from this woman. Mostly, I wish I didn't but I don't seem to be able to tell her to stop contacting me. The one and only time we were physical was a long time ago and I haven't seen her since shortly thereafter. She comes to me for networking favors for her son, to talk about all of her business dealings, how busy she is and has no time for a relationship at all now being all

over the U.S. Always via email or text. Probably better that I don't hear her voice. People I know that met her even commented on how her voice made them feel. Interesting and scary at the same time. The crazy thing is that I get to the point where I start to get her out of my head and I get a warm, friendly sounding email..... like this morning. Maybe there was other stuff going on like her needing to focus all her energy on an amazing business idea that she has raised a ton of investor cash to get rolling that should make her rich in the new few years, her kids being on opposite sides of the country with her daughter being a cadet at the military academy. Her comment was that she didn't need to know when I told her about my bionics and it made the relationship feel weird for her at the time. Had I not told her at all, she said she would not have noticed anything unusual that one time except that it went on longer than she has ever known it to, and that "was an awesome thing". For me, I was insecure at the time. I knew I was head over heel nuts for her on our third date. I hoped that if she was going to be turned off by me being "different" physically, she would say so then before I got more emotionally invested. Too bad it didn't happen that way.

All I know for sure is that the woman I am with now heard about my implant on our second date. She was intrigued even though she later told me she didn't need to know about it so soon at the time. She told me recently that she loves me for all of me, not just for my penis, but what I have sure adds to what we have together. Nice. I think it is a topic to add during the safe sex talk that should occur just before that first encounter, or during or after the first encounter. I think you are soooo right about not making a big deal of it. After all, it is just part of me now. If it is no longer a big deal to me, it should not be to a partner, just different. Like you (the woman's perspective above) said, we are all different. I sometimes think we should just not really say much about it until the topic comes up or has to come up so as not to scare anyone off.

Thanks for the female perspective on this touchy topic!!!!!!!!!!!!!!!

IMPORTANT TO NOTE: Men meeting a new partner and a physical relationship not yet established, would best hold back any mention of the penile implant, since at that point it is not important to what is likely a developing relationship. Should a physical relationship ensue, even then there need be no reason to mention the penile implant unless the partner brings up any question in that regard. Only then, or after a reasonable period of acceptance of intimacy by you and the partner should you consider bringing to light that the exceptionally great "coming together" has been improved by your penile implant. Then take the important time to explain what and why a penile implant was required and how important it has

become in your mental and physical attitude to a loving, caring, and physical relationship with this partner.

The following was written by someone who faced not 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, as she explains elsewhere). ” **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.”

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.”