# ERECTILE DYSFUNCTION (ED) – REASONS &POSSIBLE REMEDIES Compiled by Charles (Chuck) Maack – Prostate Cancer Activist/Mentor

**DISCLAIMER:** Please recognize that I am not a Medical Doctor. 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 research and study in order to serve as an advocate for prostate cancer awareness, and, from a activist patient's viewpoint, to voluntarily help patients, caregivers, and others interested develop an understanding of prostate cancer, 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 your journey one with better understanding and knowledge than was available to me when I was diagnosed so many years ago. Readers of this paper must 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 your prostate cancer care.

Herein is a presentation regarding Erectile Dysfunction I highly recommend you first watch/listen by Dr. Michael Gillman of Australia, who, though not a surgeon, is a community physician in Australia whose practice is entirely men's health issues. He is certainly a well-informed physician who obviously spends a great deal of time in research, study, and compiling all information relevant to his presentations. In this video he very comprehensively explains Erectile Dysfunction, why occurring, and what to do about it, and should be read by all patients to be treated for prostate cancer as well as their treating physicians. I completely enjoyed watching, listening, and learning from this well compiled video presentation regarding Erectile Dysfunction, and I am certain you will as well. Please note in view of the presentation including graphic displays, that the presentation be viewed privately, and despite graphic displays, the humor in some cannot help but bring a smile to your face. Please open and learn: <a href="https://www.youtube.com/watch?v=pWyMzYp1UXg">https://www.youtube.com/watch?v=pWyMzYp1UXg</a>

The following is a lengthy compilation of important information regarding erectile dysfunction that encompasses much of what you learned in the foregoing video.

For those truly interested in this subject, it is my opinion that taking the time to read this entire paper will provide you a more thorough understanding of erectile dysfunction, possible remedies, and an importance regarding intimacy you may never had realized.

I was reviewing a "Special Report" from the American Prostate Society published way back in the summer of 1996 regarding male impotence. It appears very little has changed over these subsequent years other than Phosphodiesterase Type 5 (PDE-5) inhibitors coming to the fore. I want to share some of the interesting aspects of that report. As far back as the mid-1980s health care professionals had treated impotence as "all in the mind." Even the men experiencing this problem came to believe that "if I can get my head straightened out" all would return to normal. Shame and embarrassment were so strong that men wouldn't even discuss this most intimate problem with a doctor. It was a no-win situation made worse by the man's partner justifiably wondering why she was no longer sexually attractive. Does this sound familiar? The report said back then and holds true today that any man who thinks time and hope will take care of his problem is deluding his self. This is one problem that won't go away; time just aggravates his situation. I found it interesting that the first step in ending male sexual incapability is to stop thinking of it as "impotence." "Impotence" means a lack of power and strength, and power and strength have nothing to do with making love. Any man who thinks of himself as "impotent" is not just wrong; he is putting himself down. The more accurate term is "erectile dysfunction," what the condition really is: an inability to attain and maintain an erection sufficient to complete sexual intercourse more than half the time sex is desired. This means rigidity as well as duration. Back in 1996 experts believed more than 30 million men in the U.S. were suffering from erectile dysfunction to some degree. This has unlikely changed. Back then, and I would venture to say even now, one man in two experiences this problem to some degree between the ages of 40 and 70. It is an equal opportunity affliction affecting men of every race, religion, and station in life. Even then it was considered that when those numbers are expanded to include women as partners in sexual relationships, we begin to understand the enormous impact of erectile dysfunction in the United States. The trigger for penile erection is sexual stimulation reaching the brain. The brain responds to the stimulation by signaling the heart to pump more blood into the penile arteries. These arteries promptly dilate to twice normal size. Blood-flow jumps sixteen times normal. As blood-flow increases in the arteries, it partly blocks the veins and traps the arterial blood. The two channels of the penis called "corpora cavernosa" become so full of blood that the penis lengthens and can double its cubic size. All of this can take place in a normal man within 60

seconds! This marvelously elaborate system happens, or it doesn't, depending on the flow of blood. If any part of the process breaks down, getting or keeping an erection becomes impossible. The system can break down from many causes: mental/emotional problems, a new partner, stress, anxiety, fear of sexual failure, disease involving the blood vessels, hypertension, diabetes, elevated cholesterol, some medications for high blood pressure, diffuse arterial disease (blockages in the small penile arteries), venous leak (though blood flows properly into the corpora cavernosa, the veins are not compressed to hold the blood where it is needed). Age plays a role since as men get older, the corpora cavernosa can lose their elasticity. When this happens, the chambers do not enlarge to accept an increase in blood sufficient to squeeze the veins and hold the blood in place. Other causes of erectile dysfunction include being over-weight, low testosterone, damage to the nerves, muscles, or bones in the groin area, and use of tobacco can have an effect. Alcohol's impact on the libido and sexual capability is well put in the saying "As whiskey make desire go up, ability goes down." The methods to counter some of these problems are nearly the same today as they were back in the 1990s. PDE-5 inhibitors were not yet available. Trazadone and Ginseng where sometimes considered as aphrodisiacs that might dilate the penile arteries to an indefinite, varying extent. And then, as now, the use of Muse (not very popular), Vacuum Erection Devices (VEDs), penile injections, and penile implants were the few methods to hopefully counter erectile dysfunction. That is a sad commentary that other than PDE-5 inhibitors, nothing has changed. Men experiencing this affliction should be aware that they are not alone. Rather, they in company with likely several million other men just here in the United States. And when this occurs and cannot be remedied, I invite your attention to "SOME CONSIDERATIONS FOR **YOU AND YOUR PARTNER** beginning on page 22, below.

A recent report (February 2015) <a href="http://tinyurl.com/n47lfzu">http://tinyurl.com/n47lfzu</a> using patient results from 2008 and 2009 came to this conclusion regarding erectile dysfunction as well as incontinence following surgical removal of the prostate gland and should serve as your forewarning that either may not return as rapidly as you might expect:

#### Results

• The study showed that before radical prostatectomy, urinary incontinence of various severity grades was reported in 18.8, postoperatively in 63.0% (p < 0.001) and erectile dysfunction of various degrees was reported in 39.6 at baseline compared to 80.1% 12 months postoperatively (p < 0.001).

Important in the foregoing information is for you to recognize that the more you put into return of erectile function (as well as continence), the more likely it will occur earlier than later.

Men with deficiency in Vitamin D levels can experience Erectile Dysfunction issues. From: <a href="http://onlinelibrary.wiley.com/doi/10.1111/jsm.12661/abstract">http://onlinelibrary.wiley.com/doi/10.1111/jsm.12661/abstract</a>

"Our study shows that a significant proportion of ED patients have a vitamin D deficiency and that this condition is more frequent in patients with the arteriogenic etiology. Low levels of vitamin D might increase the ED risk by promoting endothelial dysfunction. Men with ED should be analyzed for vitamin D levels and particularly to A-ED (arteriogenic ED), and for patients with a low level, Vitamin D supplementation is suggested,"

Men experiencing ED should include having their 25-hydroxy Vitamin D level checked. A level of at least 50ng/ml should be attained, and for men having been treated for prostate cancer, a preferred level should be within the range of 60ng/ml to 75ng/ml. If deficient, total daily intake of Vitamin D3 as supplement should likely be between 6000 IU to 7000 IU, and once the desired level is attained, likely 5000 IU total daily will maintain that level, though men should continue to periodically have their 25-hydroxy Vitamin D level checked to make sure.

An important paper titled "Persistent Erectile Dysfunction Following Radical Prostatectomy: The Association between Nerve-Sparing Status and the Prevalence and Chronology of Venous Leak" describes reasoning for difficulty regarding erectile function. It is certainly worth a read to have some idea why you may be experiencing this difficulty. Go to: <a href="www.pubmed.gov">www.pubmed.gov</a> then enter 19686421 in the search box).

In line with the information in that paper, even prior to and then again following surgical removal of the prostate or complications following radiation therapy, it is important to begin penile rehabilitation.

Keep in mind that it is unlikely that men will be able to achieve erection with a PDE5 inhibitor if both neurovascular bundles were removed. The use of penile injections, however, can still bring about a good erection. The information in the following indicates that with neurovascular damage PDE5 inhibitors would not serve to bring erectile function. That being the case, in the absence of neurovascular bundles, the same would apply.

#### http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1473007/

This next paper supports the information in the foregoing paper by commenting "PDE 5 inhibitors will not be helpful for men who experience impotence due to a prostate cancer treatment that has damaged the neurovascular bundles that are attached to the NANC. Without the presence of nitrous oxide, the chemical cycle never begins." And again, this would include the absence of neurovascular bundles. (NANC neuron: nonadrenergic, noncholinergic neuron).

#### http://tinyurl.com/49gh3rc

Importantly, penile injections can still provide reasonable erections for intercourse or, alternatively, penile implants as well.

A consideration for men experiencing erectile dysfunction from either surgical removal of, or radiation to, the prostate gland:

There are prostate cancer survivors who have learned that in addition to, for example the PDE5 inhibitor Viagra - or even in lieu of a PDE5 inhibitor – a combination of L-Arginine, Acetyl L Carnitine and Propionyl L Carnitine at 2000mg daily each, may be effective for return to hopeful reasonable erectile function as well as occur more rapidly.

Further explained here:

Carnitines—Better Than Testosterone for Impotence: <a href="http://tinyurl.com/ngkqqfj">http://tinyurl.com/ngkqqfj</a>

Using an L-Arginine Supplement for Impotence Treatment: <a href="http://tinyurl.com/nkofraq">http://tinyurl.com/nkofraq</a>

I refer you to the foregoing to provide you alternative considerations to only a PDE5 inhibitor that should be discussed with the physician treating you for erectile dysfunction.

For patients on hormone deprivation drugs, there is a loss of brain to penis stimulation to even experience a "desire" for sexual intercourse, and that being the case, if one's neurovascular bundles had been removed, the thought of making use of a penile injection, or even using one's penile implant, may be nil.

According to likely the foremost authority on penile rehabilitation, Dr. John Mulhall of Memorial Sloan-Kettering Cancer Center (MSKCC), and contrary to the opinions of some, the Vacuum Erection Devise (VED) will not provide appropriate penile rehabilitation. The VED, though suitable to exercise and help maintain length of the penis, draws venous blood into the penis but does not have the effect of oxygenation and arterial blood for penile rehabilitation. PDE5 inhibitors (sildenafil/Viagra, vardenafil/Levitra, or tadalafil/Cialis) provide this function, and this function can be enhanced by penile injections. Both PDE5 inhibitors and penile injections serve to provide increased arterial oxygenation, erection muscle protection, endothelium protection, neuroregeneration, increased prostaglandin secretion, collagen chemical blockage, and preservation of erectile tissue. PDE5 inhibitors are also helpful for vascular health, and the foregoing penile rehab should be practiced for those on androgen deprivation therapy to prevent penile atrophy. The use of PDE5 inhibitors help the arteries relax for access of external nitric oxide. L-arginine, an amino acid, can enhance the action of nitric oxide to relax the muscles surrounding blood vessels supplying the penis, so could also be considered for penile rehab. This dilates blood vessels to increase arterial blood flow and can help maintain an erection. Radiation stops the artery wall from making this necessary nitric oxide. Medical Oncologist Charles Myers personally prefers the prescribing of vardenafil/Levitra at a higher dose to be taken every Monday, Wednesday, and Friday as opposed to a low dose taken daily. He remarks that his patients have improvement over subsequent months of usage. The longer one avoids the use of PDE5 inhibitors and/or penile injections to provide this necessary arterial blood flow into, and oxygenation of, penile tissues, the more difficult it will be to later regain erectile function. Since health insurers often refuse to cover increased use of PDE5 inhibitors, considering such use to be for sexual satisfaction, Dr. Myers remarked that with his providing a letter to insurers

explaining that the increased use is not for sexual satisfaction but rather for penile rehabilitation following radiation or surgery, insurers have complied.

EXTREMELY IMPORTANT TO BE AWARE AT THIS POINT: If you are a patient also prescribed and taking nitrates, you SHOULD NOT take a PDE5 inhibitor. This could cause extreme opening of blood vessels, seriously reduce your blood pressure, and could even be fatal for some men. For information in this regard, please open and review the following paper – though this paper describes the use of Viagra with nitrates, the same would apply to any PDE5 inhibitor: <a href="http://tinyurl.com/pv6jh31">http://tinyurl.com/pv6jh31</a>.

Apparently this does not hold true if only administering a penile injection with no PDE5 inhibitor involved. In this paper the comment indicates that men taking nitrates and unable to experience an erection may find that a penile injection may enhance an erection. See the last paragraph on the first page of this paper: <a href="http://tinyurl.com/ozkx143">http://tinyurl.com/ozkx143</a>. If you are a patient prescribed a nitrate, I would encourage clearing the use of penile injections with the physician prescribing the nitrate as well as the physician prescribing the penile injection medication.

A point Dr. Mulhall emphasized is that we men are given all the wrong expectations, and not even told what is most likely going to occur when we are treated with surgical removal of the gland or radiation. He remarked that physicians should be forthcoming with a full explanation of what a man can anticipate regarding erectile dysfunction following whatever treatment he is receiving. Rarely are we provided such information, and more often we are told that "there are several things we can do to help get an erection." The trauma experienced by neurovascular bundles requires appropriate treatment post surgical removal of, or radiation to, the prostate gland, and even then can take several months to a few years to reasonable erectile function (read that again, so you recognize that recovery for many could take many months, so don't despair). And such return depends on pre-treatment function, age, delay in post treatment rehab, and other factors. Younger men may have earlier return of erectile function, whereas the older we get, the longer it may take. Key, again, is beginning penile rehab is early as possible; that can mean beginning daily or very frequent use of PDE5 inhibitors some weeks prior to treatment, then continuing following surgical removal (RP/RaLRP) or radiation (RT). In checking my "Saving Your Sex Life"

book by Dr. Mulhall, I concluded that as long as a PDE5 inhibitor appears to be resulting in an erection within a couple weeks following RP or RT, you won't have to begin penile injection therapy. However, if you are not getting natural or suitable erections with a PDE5 inhibitor by four weeks post-surgery, that would be the time to begin penile injections (best start with bimix rather than moving directly to trimix) and you should be aiming for three erections per week (please keep in mind that this treatment is for penile rehab and not for sexual intercourse in less than six weeks following RP or RT). If your choice is Cialis, then 5mg is preferred. If taking Viagra and getting a 100mg pill, it should be broken into four pieces with around 25mg to 50mg taken daily. If taking Levitra (which comes as a 20mg small pill), try to split in at least two and if possible, four, and take as low dose with 5 or 10mg daily. Dr. Mulhall appears to be more supportive of Viagra or Levitra, and I think this is more because Cialis is a stronger inhibitor and remains in the blood much longer than the other two inhibitors. It appears if taken daily, it could result in a longer-lasting erection that could become of some concern if it isn't "receding" in a reasonable time. And I note that if one is taking one of these PDE5 inhibitors, that they skip taking on the day they use penile injection; with more particular attention in doing so if taking Cialis (likely for the same reason you must not mix nitrates with PDE5 inhibitors). He does recommend to take these inhibitors at night. Anyone taking PDE5 inhibitors should check the side effects that one might experience from the medication. Another note is that patients whose treatment has been radiation should take a low dose inhibitor for at least 12 months. Dr. Mulhall makes note that there is no evidence this is absolutely necessary, but he prefers this be done for more appropriate penile rehabilitation. Recognizing that PDE5 inhibitors can become expensive, and that those with health insurance that covers some oral medication find their insurer will only cover a small number of inhibitors per month, patients may want to consider ordering their Viagra or Levitra from www.alldaychemist.com at a much reduced cost. Also, a prescription is not required and you can order as needed. Patients must recognize that this manufacturer is in India, but if one does some research, we find that a great majority of the drugs provided for sale here in the U.S. at much higher expense are actually manufactured overseas, with India being one of the primary suppliers. In monitoring the many prostate cancer support lists, many men have reported ordering/purchasing their Viagra and Levitra from this

source and noted no difference in effectiveness. Alldaychemist accepts Visa for immediate ordering/shipping or you can mail them a check, cashier's check, or money order, though this process will result in likely a month or so before receiving the product desired. If desiring to order from India either Cialis as generic tadalafil or Viagra as generic sildenafil:

# ORDERING EITHER CIALIS OR VIAGRA FROM PHARMACEUTICALS IN INDIA

If your physician is prescribing, or your choice is, Cialis/tadalafil, be aware that this is the most expensive of the PDE5 inhibitors. Viagra/sildenafil is much less expensive. Granted, Cialis is more potent and remains in the system a bit longer. Either tablet can be split to smaller dosage.

The importance of any PDE5 inhibitor is to get arteries in the penis oxygenated and open to blood flow and use of a PDE5 inhibitor helps the process.

Should you still have difficulty in attaining an erection, penile injections can be considered later, since the products Papaverine, Phentolamine, and Prostaglandin E1 also serve this purpose of oxygenation and blood flow.

You may have also been recommended a vacuum erection device (VED), however, though this device can help as an "exercise" in regaining length and girth, it does not provide the oxygenation or arterial blood flow that is necessary for penile rehab.

The following is provided as an education and where to purchase – and please read all the way to the end before visiting whichever pharmaceutical to order either generic Cialis or Viagra:

# From AllDayChemist:

• "AllDayChemist.com is a professionally managed generic drugs distributor, supplying generic drugs and formulations to patients around the world. We offer great-value generics, without ever compromising on quality. The brands we offer are manufactured in facilities that have been approved by any / all of the following regulatory authorities:

- 1. Food and Drug Administration (FDA), US
- 2. Medicines Control Agency (MCA), UK
- 3. Therapeutic Goods Administration (TGA), Australia
- 4. Medicines Control Council (MCC), South Africa
- 5. National Institute of Pharmacy (NIP), Hungary
- 6. Pharmaceutical Inspection Convention (PIC), Germany
- 7. World Health Organization (WHO)

The operations are always supervised by a team of qualified personnel including pharmacists. This helps us ensure that the drugs we source are not just inexpensive, but also conform to world-class standards of manufacturing and quality control. Dispensing is also done under the supervision of a pharmacist which ensures that the orders are packed and supplied as per the requirements in terms of both quality and quantity. Most medications on this website will require a prescription from a licensed Doctor." (My note: Viagra or Levitra does not)

Many medications available from AllDayChemist are manufactured by Cipla. You might review the following: <a href="http://en.wikipedia.org/wiki/Cipla">http://en.wikipedia.org/wiki/Cipla</a>. I wouldn't recommend patients to just any source in India. And I would almost bet that generics available from pharmacies here in the U.S. originate in India or other foreign sources since most all medications are out-sourced for manufacturing by less-expensive sources than here in the U.S.

From: <a href="http://tinyurl.com/mdmmzg3">http://tinyurl.com/mdmmzg3</a>

"India is the biggest overseas source of medicines to the United States and is home to over 150 FDA-approved plants, including facilities run by global players. Pharmaceutical exports from India to the United States rose nearly 32 percent last year to \$4.23 billion.

As U.S. demand for generics grows, especially under President Barack Obama's healthcare program, the FDA is under pressure to clear product applications while ensuring quality.

New U.S. legislation requires the agency to inspect global plants on the same schedule as domestic facilities, and to clear its backlog of drug applications within five years. Indian firms account for more than one-third of U.S. drug approval filings. In March, India allowed the FDA, guardian of the world's most important pharmaceuticals market, to add seven inspectors, which will bring its staff in India to 19. India produces nearly 40 percent of generic drugs and over-the-counter products and 10 percent of finished dosages in the United States.

Many in India note that drug makers globally, including in the United States and Europe, have also run afoul of increasingly stringent FDA inspection." Though alldaychemist also has tadalafil/Cialis, they remark that they cannot ship this PDE5 inhibitor for consumption in the U.S., so I only recommend tadalafil/Cialis from mysecuretabs because many patients have advised they purchase this product from this source, its effectiveness is as good as the tablets they earlier purchased in the U.S., and is the least expensive. You will note that the more you purchase, the lower cost per tablet; but in any case, waaaay less than the \$30.00 or so per tablet in the U.S. I have not looked into the pharmaceutical sources in India that provide this product to mysecuretabs. See: <a href="https://mysecuretabs.net/cialis20mg.html">https://mysecuretabs.net/cialis20mg.html</a>. Price varies by number ordered. As an example July 2015, generic of Cialis -

tadalafil 20mg cost for 90+10 free tablets (100) is \$146.70 (\$1.47@) with free shipping. Note also that CIPLA is the manufacturer.

For Viagra/sildenafil go online to <a href="www.alldaychemist.com">www.alldaychemist.com</a> or you can click on the below that takes you directly to Viagra in its generic form Sildenafil as Suhagra 100mg tablet manufactured by CIPLA, one of the largest manufacturers of medical products in the world, and likely the place where Pfizer or others "outsource" for Viagra production:



Suhagra - 100mg

# **Know More**

As an example at the time of this writing in July 2015, best to order at the 80 + 80 free quantity (160 tablets) for \$112.13. Add \$25.00 cost of shipping and handling and your total cost would be \$137.13, thus your total cost would be just over 86 cents each. Payment may be made with Visa card.

I am aware of many men who purchase their Viagra as sildenafl from this source and absolutely none have ever remarked that they did not work as good as those they were paying much more for in the U.S. Thus, the decision is yours. No matter what dosage or what number of the product you order, the shipping and handling charge is a flat \$25.00, so always add that to what you have figured your cost is for the tablet dosage and number you order. Then divide by the number of tablets being ordered and you will see your cost per tablet.

Dr. Mulhall explained that it means nothing following RP to hear your physician remark that "all went well" and "I spared the nerve bundles (either both or one side)" or "the nerve bundles looked good." If the nerve bundles experienced damage, and they most likely will from the trauma of surgery or radiation, they can go into a sort of coma for up to 12 months, and it can take another 12 months of recovery.

It is absolutely important to take the time to open the following URL, then click and view video presentations made by Dr. Mulhall at Memorial Sloan Kettering Cancer Center in NYC regarding sexual dysfunction that covers erectile dysfunction, penile rehabilitation, testosterone replacement therapy, and addresses most all sexual concerns addressed by men following surgery or radiation for prostate cancer. If in the presence of others, best to put on earphones then see and hear from one the most experienced physicians in this extensive problem experienced by men.

# http://www.mskcc.org/multimedia/penile-rehabilitation-after-treatment

PC patient and contributor to these support lists, John Mullineaux, provided these remarks: "I am not a doctor. Last year, I was fortunate to hear a presentation by the Director of Men's Sexual Health of a regional medical center (My Note: Dr. Mulhall) in our area. He explained the mechanism of erections and why it is a use

it or lose it proposition. Here is what I heard: The outer layer of the two corpora cavernosa is a form of smooth muscle cells. These cells can stretch and expand in both length and width during sexual arousal. They get "exercise" and additional blood supply from our nightly erections. There is an artery that runs down the center of each cavernosa. This supplies the blood flow necessary for an erection. The veins that return that blood run on outside of the smooth muscle tissue with very tiny vessels that enter the cavernosa between the smooth muscle cells. When a man becomes aroused, those nerves that the doc's try and spare send a signal to the arteries to open up. If they do, the penis starts to lengthen and thicken. However, that is only part of the process. As those smooth muscle cells start to expand, they constrict the veins. It is that venous constriction that generates the penile blood pressure necessary for an erection. After a prostatectomy, if those nerves are traumatized, nightly erections do not occur. Deprived of their exercise and additional blood supply, the theory says those smooth muscle cells begin to develop a plaque like substance that prevents them from stretching and expanding in the future. If this happens to enough of those cells, impotence in the result. Even with injections, the resulting erection will be smaller because some of those cells will not stretch. The speaker's recommendation was men should take daily viagra a month preceding surgery and start injection therapy (but not sexual intercourse) as soon as the catheter is out. The injections only have to produce the lengthening and thickening initially. As healing progresses, the dosage can be increased to produce full erections. He was not convinced of a VED's ability to preserve potency."

Another presentation by Dr. Michael Gillman of Australia that I believe very comprehensively explains Erectile Dysfunction, why occurring, and what to do about it, should be read by anyone taking the time to read this paper. I completely enjoyed watching, listening, and learning from this yet additional expert regarding Erectile Dysfunction, and I am certain you will as well. Please note that though including graphic displays, the humor in some cannot help but bring a smile to your face. Please open and learn:

https://www.youtube.com/watch?v=pWyMzYp1UXg

I have said in the past and I'll say again that it would behoove both prostate cancer support organizations as well as individuals to consider making an approximate \$150.00 donation to the Prostate Cancer Research Institute (PCRI), and in return for that donation you will receive a set of DVDs that provide each presentation of the several prostate cancer issues reported at the most recent annual PCRI

Conference on Prostate Cancer, including presentations regarding erectile dysfunction. If interested, go to <a href="www.pcri.org">www.pcri.org</a>. At the very least, one should purchase and thoroughly read the important paperback book by Dr. Mulhall, "Saving Your Sex Life: A Guide For Men With Prostate Cancer." Just go on the internet and type in the subject to find where you can order for under \$15.00 per copy.

To read more about Dr. Mulhall including contact information, please visit:

http://www.mskcc.org/prg/prg/bios/777.cfm

#### **ACUPUNCTURE:**

For anyone interested in acupuncture as a form of therapy towards return of erectile function, please read information in the following while keeping in mind that most health insurers do not cover this form of treatment and it could become expensive. Take note of the specific placement of needles explained in this paper that you may want to print out to take to an acupuncturist.

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### **ERECTILE DYSFUNCTION SPECIALISTS**

(Please keep in mind that this listing is of specialists regarding erectile dysfunction but not necessarily a list of those who provide penile implants – unless so noted. If interested in a penile implant, best to telephone or email to make that determination as well as ask how regularly the physician provides this procedure – you want one who has the experience of regularly providing penile implants)

### **NEW YORK CITY**

John P. Mulhall, M.D., Memorial Sloan Kettering, NYC, NY. To learn more about this specialist including contact information for an appointment, please visit: <a href="http://www.mskcc.org/prg/prg/bios/777.cfm">http://www.mskcc.org/prg/prg/bios/777.cfm</a>

J. Francois Eid, M.D., 435 East 63rd Street, New York, NY 10065, telephone 212-535-6690

http://www.urologicalcare.com/ (over 3000 implants)

#### **BOSTON**

Dr. Ricardo Munarriz, Boston Medical Center, Center for Sexual Medicine, Shapiro Center, 3<sup>rd</sup> floor, Suite 3B, 725 Albany Street, Boston, MA 02118. Telephone 617-638-8476. Website: <a href="http://tinyurl.com/8o2yukx">http://tinyurl.com/8o2yukx</a>

#### LONGWOOD, FLORIDA

Elias "Jake" Jacobo,. M.D., Urology Consultants, 515 West S.R. 434 Suite 302, Longwood, Florida 32750, Tel: Local 407-332-0777 or 1-800-776-8643, Email <a href="mailto:jakeddoc@aol.com">jakeddoc@aol.com</a> It appears he takes appointments at several locations. See: <a href="http://www.vitals.com/doctors/Dr\_Elias\_Jacobo/office-locations">http://www.vitals.com/doctors/Dr\_Elias\_Jacobo/office-locations</a>

#### **GLENVIEW ILLINOIS**

Jeffrey Albaugh, PhD, APRN, CUCNS, Advanced Practice Urology Clinical Nurse Specialist Sexual Health Program, NorthShore University Medical Group Urology, Glenbrook Hospital South Medical Building, 2100 Pringsten Road, Suite 128, Glenview, IL 60026, telephone: 847-657-5730, Email: jalbaugh@northshore.org Background:

http://www.northshore.org/urology/conditions/sexual-health-and-rehabilitation/Mr. Albaugh is not a surgeon, but highly regarded by many as one with expertise in the treating of general erectile dysfunction. He would likely know of a local physician he regards having sufficient experience/expertise if penile implant is your concern.

# ST. LOUIS, MISSOURI

Dr. Stephen B. Brandes, Center for Advanced Medicine Urologic Surgery Center 4921 Parkview Place, C, 11, St. Louis, MO 63110 Phone 314-362-8200 Dr. Brandes is a specialist in everything "surgical" in Urology to include penile implants. Fully explained here:

http://wuphysicians.wustl.edu/physician2.aspx?PhysNum=2240

### CHICAGO, ILLINOIS

Laurence A. Levine, M.D., Urology Specialists, S.C., 1725 W. Harrison St., Suite 352, Chicago, Illinois 60612, Tel: 1-312-563-5000, Email: drlevine@hotmail.com.

#### MADISON, WISCONSIN

David R. Paolone, M.D., Assistant Professor of Urology, One South Park Street, Madison, WI 53715, Tel: 608-287-2900, email: <a href="mailto:david.paolone@uwmf.wisc.edu">david.paolone@uwmf.wisc.edu</a> Dr. Paolone is highly regarded for his expertise with surgical penile implant.

### **HOUSTON, TEXAS**

Mohit Khera, M.D., M.B.A., M.P.H. Baylor College of Medicine, <u>The Scott Department of Urology</u> 6620 Main St., Suite 1325, Houston, Texas 77030, Phone: 713-798-4001, eMail contact: <a href="http://tinyurl.com/b8g6213">http://tinyurl.com/b8g6213</a>

Robert J. Cornell, M.D., 1315 St. Joseph Parkway, Suite 1700, Houston, TX 77002, Telephone: 713-652-5011, Website: <a href="www.urosurgeryhouston.com">www.urosurgeryhouston.com</a>, Email: <a href="drcornell@urosurgeryhouston.com">drcornell@urosurgeryhouston.com</a>.

Run Wang, M.D., Director of Sexual Medicine, Department of Urology, University of Texas MD Anderson Cancer Center, and Associate Professor of Surgery (Urology), University of Texas Medical School at Houston. Address 6431 Fannin, MSB 4.020, Houston, TX 77030, Telephone 713-500-7337, Email: <a href="mailto:Run.Wang@uth.tmc.edu">Run.Wang@uth.tmc.edu</a>, Info: http: <a href="mailto:www.uth.tmc.edu/urology/faculty/wangcv.html">www.uth.tmc.edu/urology/faculty/wangcv.html</a>

## SAN DIEGO, CALIFORNIA

Irwin Goldstein, MD, with Sexual Therapist Rose Hartzell, <a href="PhD">PhD</a>, San Diego Sexual Medicine, 5555 Reservoir Drive, Suite 300, San Diego, CA 92120, phone: (619) 265-8865, email: <a href="mailto:information@sdsm.info">information@sdsm.info</a> website: <a href="http://www.sandiegosexualmedicine.com/">http://www.sandiegosexualmedicine.com/</a>

#### **AUSTRALIA**

Michael Gillman, MD, Contact information: <a href="http://www.drmichaelgillman.com/contact/">http://www.drmichaelgillman.com/contact/</a>

OTHER ERECTILE DYSFUNCTION SPECIALISTS (Please note: I have no idea of their expertise). When opening the following, click on "ED Specialists" in the menu on the right, then when that opens, click on "PCAI list of ED Specialists."

http://pcai.pbwiki.com/PCAImaa%20List%20of%20ED%20Specialists
++++++++++++++++++++++++++++++++++++++
MUSE is occasionally recommended by physicians, but reports I continually read are that not only does it not work very well, but has caused discomfort and even pain to some patients.
Injections certainly work well and do not hurt. Many men reject the idea because they think sticking a needle into their penis would hurt. The needles are very thin and your urologist should provide you a prescription for the mix along with instruction on the appropriate place to inject. The only downside is going through the motions to bring on the erection while the partner is all primed for intercourse. The "upside" (pun intended) is that very good erections result.
++++++++++++++++++++++++++++++++++++++
INJECTIONS (PAPAVERINE/BIMIX/TRIMIX)
The following websites describe penile injection therapy for erectile dysfunction:
http://www.urologicalcare.com/other-ed-treatments/penile-injection-therapy/
http://www.urologicalcare.com/other-ed-treatments/diagrams/
Patient Guide to Penile Injections:

 $\frac{http://www.ucsfhealth.org/adult/medical\_services/urology/male\_sexual/injections.}{html}$ 

A prostate cancer survivor who has involved himself in research and study of penile injections and the use of Bimix and

Trimix is Michael Holland. He often posts on the pcai@prostatepointers support list in this regard and can be contacted directly for advice and concerns regarding

this procedure and appropriate use of the products to be injected. His email address is <a href="mailto:michaelmaumfh@hotmail.com">michaelmaumfh@hotmail.com</a>. If interested in subscribing to the PCAI (Prostate Cancer and Intimacy) support list, here is info:

Prostate Cancer and Intimacy

PCAI is a mailing list for frank and open discussion of the sexual issues surrounding PCa. To subscribe, go to:

http://www.prostatepointers.org/mailman/listinfo/pcai

\*\*\*NEW\*\*\* The PCAI Wiki

A collaborative treasure trove of knowledge and help from longtime PCAI subscribers. Please first subscribe to PCAI and then get the wiki URL from the PCAI welcome message.

#### WITH PENILE INJECTIONS, VERY IMPORTANT TO BE AWARE:

There can be occasions, though rare, where the erection does not subside for what could be a few hours. According to this paper: <a href="http://tinyurl.com/ps2fvz3">http://tinyurl.com/ps2fvz3</a> if your erection does not subside after two hours, take four (4) 30mg tablets of pseudoephedrine HCl (Sudafed®); if the erection continues to three hours you should call your treating Urologist or a hospital emergency room for instructions. If you have an erection that lasts 4 hours and you haven't talked to a doctor or nurse, this is a medical emergency and you should head for a hospital Emergency Room. You should treat it with the same urgency as a heart attack. Erections lasting longer than 4 hours can cause permanent damage. Further discussion on this subject can be reviewed here: <a href="http://www.theprostateadvocate.com/pdf/PRIAPISM.pdf">http://www.theprostateadvocate.com/pdf/PRIAPISM.pdf</a>

# VACUUM ERECTION DEVICE (VED)

I have observed several exchanges regarding purchasing a Vacuum Erection Device (VED) to help erectile dysfunction issues. Men considering this method of "treatment" should recognize that the VED does NOT aid in penile rehabilitation. It serves no purpose in arterial blood flow and oxygenating the penis, an effect necessary for penile rehabilitation following surgery or radiation. It does serve to

exercise and maintain length/girth thus preventing atrophy by drawing venous blood into the penis that is then hopefully retained in the penis by rubber rings to enable intercourse, but more often than not eventually just does not even serve that purpose very well. Penile injections are much more effective. However, for those interested in purchasing a VED:

Osbon VED info:

http://www.timmmedical.com/patients/

Another source is Encore Deluxe VED at <a href="http://tinyurl.com/q7e7st">http://tinyurl.com/q7e7st</a>

You can also find other brands on the internet by entering Vacuum Erection Device in the search box.

As an added bit of info, since "penile shrinking" has also been on support lists recently supposedly occurring because of surgery, Dr. Mulhall says that is rubbish. When the prostate gland is removed, the bladder is stretched down and reconnected to the urethra. The urethra is not a free floating organ. The "shrinkage" is the result of not following the same directions described above for penile rehabilitation. Doubt the validity of the foregoing? Contact Dr. Mulhall.

For more understanding of Penile Injection for an Erection,

Recommend visiting <a href="https://pcai.pbwiki.com/">https://pcai.pbwiki.com/</a> then clicking on the folder index "Injections," where Michael Holland has provided the results of his research and experience.

If not subscribed to <a href="mailto:peai@prostatepointers.org">peai@prostatepointers.org</a>, you may
Have to subscribe before being able to then also subscribe
To the peai.pbwiki site. PCAI is a mailing list for frank and open discussion of the sexual issues surrounding PCa. To subscribe, go to:

http://www.prostatepointers.org/mailman/listinfo/pcai.

#### Information regarding PDE5-inhibiting drugs:

There are now five oral ED drugs: sildenafil as Viagra, vardenafil as Levitra, or tadalafil as Cialis – the most common names we are used to – as well as vardenafil HCI as Staxyn, and avanafil as Stendra.

For all practical purposes, these drugs are the first line of oral treatment for males with erectile dysfunction. In certain circumstances in which the males are young, no comorbidities are recognized, and laboratory tests are normal one should look for the etiology of their erectile dysfunction before instituting treatment since the disease process may be more serious than the symptoms, i.e., the ED itself. In some cases, treatment of the primary disease may in fact resolve the sexual dysfunction. However, most men have a cause for their ED as noted by the history and physical examination and the laboratory tests and PDE-5 inhibitors are the first line of choice.

#### Viagra (Sildenafil)

Discovered by Pfizer, Sildenafil is a potent and selective inhibitor of cGMP-specific phosphodiesterase type 5 (PDE5), which is responsible for degradation of cGMP in the corpus cavernosum in the penis. This means that, when sildenafil is present in the organism, normal <u>sexual</u> stimulation leads to increased levels of cGMP in the corpus cavernosum, which leads to better erections. Without <u>sexual</u> <u>stimulation</u> and no activation of the NO/cGMP system, sildenafil should not cause an erection.

Viagra (Sildenafil) is a member of a family of drugs called PDE5 inhibitors. Viagra was the first PDE5 inhibitor on the market. FDA approved Viagra on March 27, 1998. <u>Viagra®</u> contains sildenafil citrate packaged as a <u>pill</u>.

Particular caution should be used when prescribing PDE5 inhibitors for <u>erectile dysfunction</u> for patients receiving <u>protease inhibitors</u>, including <u>Reyataz</u>. Coadministration of a protease inhibitor with a PDE5 inhibitor is expected to substantially increase the PDE5 inhibitor concentration and may result in an increase in PDE5 inhibitor-associated adverse events, including <u>hypotension</u>, visual changes, and <u>priapism</u>.

PDE5-inhibiting drugs are very effective. PDE5 inhibitor drugs appear to work in men regardless of why they have erectile dysfunction — including vascular <u>disease</u>, nerve problems, and even <u>psychological</u> causes. PDE5 inhibiting drugs can cause a number of minor <u>side-effects</u>, including <u>headache</u>, lightheadedness, <u>dizziness</u>, flushing, and change in <u>vision</u>. A few men choose not to use one of these drugs because they are bothered by these side-effects.

Studies in vitro have shown that sildenafil is selective for PDE5. Its effect is more potent on PDE5 than on other known phosphodiesterases (10-fold for PDE6, >80-fold for PDE1, >700-fold for PDE2, PDE3, PDE4, PDE7, PDE8, PDE9, PDE10, and PDE11). The approximately 4,000-fold selectivity for PDE5 versus PDE3 is important because PDE3 is involved in control of cardiac contractility. Sildenafil is only about 10-fold as potent for PDE5 compared to PDE6, an enzyme found in the retina that is involved in the phototransduction pathway of the retina. This lower selectivity is thought to be the basis for abnormalities related to color vision observed with higher doses or plasma levels.

#### Levitra or Staxyn (vardenafil)

Levitra (vardenafil to be swallowed with water) was the second oral PDE-5 inhibitor for erectile dysfunction to be Food and Drug Administration (FDA) approved in 2003. Studies done on Levitra have excluded patients that failed Viagra, and, therefore, the efficacies are somewhat shifted toward the positive. In general, the feeling is that Levitra is more potent and efficient than Viagra as demonstrated by hard-to-treat groups of patients.

Staxyn (vardenafil to melt in the mouth, then swallowed without water) — otherwise performs the same as Levitra except Levitra is swallowed whole with water. Staxyn was approved by the FDA in 2010. These two brand names should not be interchanged in use — use one form or the other).

#### Cialis (tadalafil)

<u>Cialis</u> has an estimated effective duration of 36 hours; however, there are studies showing high efficacy up to 100 hours. It is not affected by any food whatsoever, and in fact can be taken with pure <u>fat</u>. Viagra, on the other hand, is impeded by any type of food, and Levitra absorption is impeded by a high-fat <u>diet</u> in which more than 62% of the fat and the <u>food energy</u> are from fat.

#### Stendra (avanafil)

Stendra is the newest of PDE5 inhibitors to boost blood flow to the penis to help achieve and sustain an erection. An advantage is that it can be taken 30 minutes before sexual activity and can become effective in as little as 15 minutes. Stendra also clears the body more rapidly than the other inhibitors. This inhibitor was approved by the FDA in 2012. Read more here:

http://abcnews.go.com/blogs/health/2012/04/27/fda-approves-new-drug-for-erectile-dysfunction/

More good advice from PC survivor/advocate John Mullineaux for those experiencing a problem with their health insurer covering PDE-5 inhibitors:

"My insurance is with CIGNA. My script had been denied as it was considered a "lifestyle" drug.

I wrote the highest level female executive I could find. I told her I thought CIGNA had a problem with "gender parity". I further said I knew CIGNA covered hormone replacement therapy for menopausal females and I didn't see how that was less of a "lifestyle" issue than surgically induced impotence.

It seemed to work as they agreed to cover 8 pills a month."

# Viagra pre & post Surgery/Radiation?

(May 1, 2009) -- Rehabilitation and treatment before and after surgery for prostate cancer can give men a better chance of maintaining erectile function, said <u>Baylor College of Medicine</u> researchers this week at the <u>American Urological Association Annual Meeting</u> in Chicago.

"We have shown that treating these men, along with their female partners, before and after surgery significantly improves erectile function."

Two weeks before surgery, patients in Khera's study took Viagra daily. They also received a treatment called medicated urethral system for erection (MUSE) three times a week. See: http://www.bcm.edu/news/item.cfm?newsID=1403

Noted Sexual Therapy physician John Mulhall of Memorial Sloan Kettering Cancer Center in NYC remarks: "I would encourage patients to be proactive before surgery or radiation and ask their doctors about rehabilitation and erectile tissue preservation. Before your treatment, set up a plan for how you are going to do rehab. We now start treating patients before surgery and before radiation." See: <a href="http://tinyurl.com/yhv8u9u">http://tinyurl.com/yhv8u9u</a>

For those of you for whom he foregoing PDE-5 inhibitors fail to work, or if squeamish about injecting medications in the penis, TriMix-gel (TM) is product of TriMix Laboratories LLC As noted in <a href="http://tinyurl.com/ylxl3de">http://tinyurl.com/ylxl3de</a> ingredients in TriMix-gel(TM) are FDA approved but TriMix-gel(TM) is a custom compound made in a pharmacy and therefore has not been approved by the FDA for treatment of ED. There is a contact number in the above URL where you can discuss this medication.

Here are ailments identified by Johns Hopkins health alerts that may be contributing to the problem:

Two Studies Link Erectile Dysfunction with Cardiovascular Disease <a href="http://tinyurl.com/2clr5k">http://tinyurl.com/2clr5k</a>

# WHEN ALL ELSE FAILS, AN ERECTILE IMPLANT MAY BE CONSIDERED:

# **Erectile dysfunction (ED) implants:**

Two types of erectile dysfunction penile implants are Titan and Excel. Here is a paper in that regard:

#### http://www.garber-online.com/pdf/PenileImplantReview2005.pdf

You can find more information by searching "Penile Implants" on the internet, and American Medical Systems (AMS), a leading provider of world-class devices and therapies for both male and female pelvic health, announced the launch of a new consumer friendly website at <a href="www.EDcure.org">www.EDcure.org</a> designed to help men and their partners learn how penile prosthetic implants can restore sexual function to men suffering with erectile dysfunction (ED).

# Obviously it is important that you determine a physician with much experience and expertise in the penile implant procedure.

Comprehensive information regarding penile implants:

<u>http://tinyurl.com/8jxes3</u> (If not subscribed, when this opens you can subscribe for free.

A Urologist with experience and special expertise in the installation of penile implants for those willing to travel to get the best in treatment is David R. Paolone, M.D., Assistant Professor of Urology, One South Park Street, Madison, WI 53715, Tel: 608-287-2900, email: <a href="mailto:david.paolone@uwmf.wisc.edu">david.paolone@uwmf.wisc.edu</a>

The following is a lengthy, but worth reading, article regarding the importance of finding a physician with much expertise in surgically installing a penile implant that will provide an erection suitable for intercourse. I have included this because of the importance that is described:

NEW YORK, NY, USA (Press Release) - March 9, 2009 - After years of testing, Dr. J. Francois Eid, director and founder of Advanced Urological Care in New York City, has refined an innovative "No-Touch" surgical technique that has caused penile implant infection rates to plummet to near zero. Infection rates for the infrequent penile implanter are over TWELVE TIMES as high as Dr. Eid's rate, which is less than 1%. Unlike many infections, which require treatment, healing time, etc., an infected penile prosthesis must be completely removed and replaced. Penile shortening, fibrosis and loss of sensation commonly occur after an infection. Subsequent attempts at re-implantation are extremely difficult with and increased risk of urethral and penile perforation that often requires additional surgery in the future.

For this reason, post-operative infection of a penile prosthesis implant remains one of the most dreaded potential complications of this procedure.

Dr. J. Francois Eid, also a Clinical Associate Professor of Urology at The Weill-Cornell Medical College, has performed more internal penile prosthesis surgeries than anyone in the world. His worldwide reputation for excellence in the treatment of erectile dysfunction (ED) is built on innovations in patient care such as his No-Touch Technique.

Specialized Experience Leads to Breakthrough in Penile Prosthesis Implantation

Doctors that perform fewer than 3 penile implants per year account for 70% of all implants currently inserted in patients in the United States. Dr. Eid attributes his ability to conceptualize, develop, and implement the No-Touch Technique to his extensive experience performing penile implantations, over 300 per year. Despite stringent precautions, many experienced urologist infection rates are 5%, and some institutions are as high as 50%. Dr. Eid's No-Touch success rate speaks for itself, with infection rates near zero.

#### Dr. Eid's No-Touch Technique

Dr. Eid believes the best way to eliminate infection is through prevention of exposure to bacteria and normal skin flora. Because skin organisms (e.g. staphylococcus epidermis, staphylococcus aureus, candida albicans) cause most infections, Dr. Eid reasons that eliminating direct AND indirect contact (for example, through surgical equipment or gloves) between the prosthesis and the skin will most effectively reduce infection rates. In addition, pre-operative antibiotics and antibiotic coating of the implanted device (the routinely used strategy for eliminating skin bacteria), is ineffective against fungi, such as candida albicans, which account for 10% of post-operative infections. Furthermore, during the surgery, adjustment or even removal and repositioning of the cylinders, pump and/or reservoir is often necessary. When performed without the No-Touch Technique, this results in additional direct contact of the device with skin, thus increasing exposure to skin bacteria and increasing post-operative infection rates.

Experience with Replacements of Infected Penile Prosthesis further supports No-Touch Technique

Salvage procedures, where an infected implant is removed and a new device immediately inserted, have been successful in the past even though the new

implant is inserted in an infected tissue bed. Dr. Eid believes that "it is the decrease of total bacterial count and exposure to skin, rather than the complete elimination of bacteria from the procedure, that accounts for the success of penile prosthesis implantation." It is crucial to understand this reality because it gives the implanting physician the tools to further reduce and eliminate infections.

## About J. Francois Eid, M.D, and UrologicalCare.com

Dr. Eid is the director and founder of Advanced Urological Care in New York City. He is also a Clinical Associate Professor of Urology at Cornell University. Dr. Eid is one of the foremost specialists in urological prosthetic reconstruction and performs over 300 internal penile implants per year with zero, or minimal complications. Dr. Eid leads workshops on penile prosthesis surgeries worldwide. More information about Dr. Eid and his expertise with erectile dysfunction treatment, penile prosthesis implantations urinary dysfunction treatment, and ejaculation dysfunction treatment can be found on his website, <a href="http://www.UrologicalCare.com">http://www.UrologicalCare.com</a>, or by telephone 212-535-6690.

Please read on to that portion beginning on page 25 regarding a woman's and a man's perspective in bringing attention to a new partner that the man has a penile implant.

### SOME CONSIDERATIONS FOR YOU AND YOUR PARTNER:

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 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 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.

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 <a href="https://www.renewintimacy.org">www.renewintimacy.org</a>."

The following was provided me by a couple with the intent to provide others suggestions 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, distributed by US TOO. 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 alternates 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, it requires knowing what the other person <u>really</u> 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 playing with my genitals. 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 gets me slippery and 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, she finishes me off and we end up tired but happy.

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."

Here is another from Barbara B., wife of a PC survivor, posting on the intimacy support list <a href="mailto:pcai@prostatepointers.org">pcai@prostatepointers.org</a>:

"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 non-issue. 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 <a href="mailto:peai@prostatepointers.org">prostatepointers.org</a> 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:

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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."

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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) PERSPECTIVIE:

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 could 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.

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Please review the following two papers; the first regards discussing being prescribed estrogen to possibly increase libido despite even being on androgen deprivation therapy (ADT) medications: <a href="http://tinyurl.com/bzadumb">http://tinyurl.com/bzadumb</a>. The second regards the use of a dildo that, surprising to me, can result in satisfaction to both partners (such use should be discussed between both partners in order to agree that both understand this could be a worthwhile answer to their concerns): <a href="http://tinyurl.com/bfzucm7">http://tinyurl.com/bfzucm7</a>.

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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."