

Sexual Medicine

Chapter 1

The Long-Term Sexual and Urological Side Effects of Surgical Removal of the Prostate for Cancer: A Personal Perspective from a Research Scientist

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Abstract

A primary concern for victims of prostate cancer is survival, but side-effects of prostate cancer surgery can reduce one's quality of life in many ways. As a researcher and scholar, my experience of those side-effects may be more detailed than reported in much of the scientific literature or as discussed with cancer patients and their families by medical staff. The side-effects can be long in duration, can have an impact on family relationships as well as the patient, and can be ameliorated only in part in some cases. In order to make fully informed decisions about prospective cancer treatments, patients should be made aware of the details of their possible side-effects rather than merely hearing of them in terms of vague generalities.

1. Introduction

Prostate cancer has been estimated to become the second most often newly diagnosed cancer in the United States in 2019, representing 20% of all new cases of male cancers, with nearly 32,000 deaths, second (for men) only to lung cancers [1]. Cancer rates increase with older age, with nearly an 8% chance of diagnosis at age 70 or older [1]. However, if the cancer has not spread to outside tissues, survival rates approach or exceed 99%, with appropriate treatment [1]. Nevertheless, one source reports that nearly 88 men die from prostate cancer

every day [2]. In early 2015, this author was diagnosed with prostate cancer with an estimated Gleason score of 9, suggesting he was facing a very aggressive form of cancer. Nothing abnormal had appeared with respect to the usual ways of detecting prostate cancer. The PSA was normal (2.6) and two different physicians were not sure if they could feel any unusual nodules within my prostate. A biopsy revealed a large mass of cancer, up to 55% of some parts of the prostate. Definitive treatments were recommended but my partner and I obtained a second opinion and selected a major medical treatment center as the better option than having surgery done locally. Discussions of potential side-effects were vague and hopeful, with the idea that everything would cure itself in a year, then two years, then four years, etc. While recognizing that predicting the consequences of surgery can be difficult, it seems to this author, as a patient and a scholarly researcher that better advice could have been obtained. Perhaps the lessons learned in my experience can be further researched and more detailed information provided to future prostate cancer patients. One source suggests that doctors compare free PSA and bound PSA to better evaluate the presence of cancer as opposed to benign prostate enlargement [3: 94].

2. Goals

The goal of this discussion is to provide a training vehicle for physicians, nurses, and future prostate cancer patients to enhance the quality of care for men afflicted with prostate cancer. What I hope is unique about this discussion is that it comes from a prostate cancer patient who has gone through all the phases of treatment from the point of view of a researcher who may attend to the details of the process more than an average patient might. I will discuss each phase of treatment from discovery to preparation to surgery and to long-term recovery. Prostate cancer has been one of the leading causes of death among men; at one point in the past two years, three of my friends died of prostate cancer within a few months of each other. Although I will focus on many of the negatives associated with prostate surgery, there are important positives. First, you may avoid dying of it, not to mention the worry of whether you will die of it or not. Second, you may be able to sleep through the night without having to use the bathroom. Third, when you are using the bathroom at work, you may realize how much more quickly you can get the job done than other men who have enlarged prostate issues. Fourth, you may find a great deal of empathy for your wife and what she has been living through as a woman. Future research should assess both positives and negatives of the outcomes of prostate surgery, even though this report may seem to focus more on the negatives.

3. Baseline Before Surgery

However, I think it's important to set a baseline for how a man lives prior to prostate surgery. If a man carefully observes media commercials, most of the commercials concerning constipation or bladder leakage refer to women as the clients, which may suggest that men

are relatively free of such complaints. My impression is that having a prostate makes stool elimination easier, *ceteris paribus*, and that it acts as another valve for controlling bladder leakage, the latter fact giving men a substantial advantage regarding leakage, though not so much for retaining too much urine. When it comes to sexuality, I think most men assume and experience orgasm and ejaculation together rather than as separate phenomena. That conjunction creates a sense that the orgasm will come when and only if one is releasing semen from one's system, as the processes are interdependent. The release of semen serves, among other things, to signal that sexual intercourse is coming to an end (most likely), as an erection will probably subside soon after. Consequently, ejaculation can become a *de facto* goal of sexual intercourse and a terminus for it, making foreplay something that does come before, often more for the woman than for the man, since common experience suggests that women may take more time to become fully aroused sexually. The prostate also serves to start the sexual process as its fullness motivates men to approach a woman to obtain fluid release and tension relief as well as an orgasm. Thus, the prostate serves to push for the start of the sexual process as well as to signal its end. While one may be concerned for women and their bladder/constipation issues, TV ads also focus on men with erectile dysfunction (ED) issues and one might, before surgery, be glad of having avoided such sexual difficulties. This baseline will serve as a comparison for my later discussion of side effects of prostate surgery.

4. Discovery

My brother had been diagnosed with prostate cancer after it had metastasized, at age 62. He was treated with hormone therapy which initially involved castration. After that surgery he had to be re-hospitalized because post-surgical swelling blocked his urine flow. However, he is still alive and well, over 25 years later. Knowing that prostate cancer is more likely if close relatives have had it, I was careful to have an annual check-up each year with particular attention to my PSA test and rectal examination. My brother had skipped one annual check-up and that may have contributed to the greater extent of his cancer prior to its discovery. In January 2015, my family physician thought he felt a nodule in my prostate so he referred me to a urologist, who checked me and thought he felt it, too. That led to a biopsy except he could no longer feel anything unusual prior to the biopsy, so he considered delaying it. In what seemed like a mental coin toss, he decided to do the biopsy anyway. I was found to have had a Gleason score of 9 with something like as much as 55% of the prostate having cancer cells. This was disappointing to me because I had faithfully had annual exams and PSA tests and it seemed to me that the cancer was rather far advanced for not having been detected when I had, say, a Gleason score of 4. I would have hoped that there might have been some way to test urine or semen for indications of prostate cancer. The urologist told me that he had seen patients with advanced prostate cancer who had PSAs of 0.5 and patients without cancer with PSAs of 100. It seems to me that more sensitive tests are needed; I've heard there are some, but I have not

heard of their being used often. Perhaps insurance agencies should consider supporting more sensitive tests in order to catch the cancers earlier. My experience with both MDs highlighted the importance of the physician's attitude. My GP, when learning of the biopsy results and the likelihood of surgery, just said "Well, you will never ejaculate again, that's for sure". True perhaps, but not exactly encouraging. The urologist would say things like "You'd better not shake my hand, you know where it's been." That sort of anal-gallows humor may have relieved his anxieties but it didn't do much to relieve mine. It would seem to me that especially if you know your patient is high risk for prostate cancer it would be wise to work more carefully to detect such cancers as early as possible (detecting it at a Gleason score of 9 doesn't strike me as "as early as possible"). Surely there must be many men who are dying of prostate cancer for lack of early enough detection. In hindsight I wonder if other symptoms were an indication of prostate cancer. For example, the strength of my ejaculations had declined with age, but was that age or cancer? How could one tell the difference? I was getting up at night to urinate, but was that prostate enlargement (like my father had experienced) or was it prostate cancer? I wonder what if men buy and take the supplements frequently advertised to deal with prostate enlargement but their more important underlying issue is actually cancer? Do the supplements have the unintended effect of masking and delaying detection of the cancer until it has reached a more dangerous stage?

5. Biopsy

The biopsy wasn't as painful as I had expected but I bled for at least four weeks afterwards, in my urine and from my rectum. The continuing loss of blood serves to remind you of how serious a biopsy is. In rare cases, a biopsy can lead to complications and death [3: 99]. I was taking antibiotics to prevent infection but infection has to be a risk when damaging rectal tissue (frequently exposed to feces) in order to get to the prostate. Even though I knew what the results might be, it was still a shock to hear "cancer" for the first time. It feels something like a potential death sentence. Your friends will be sympathetic but unless they've heard the same bad news, they may not be able to emotionally grasp your feelings about it. You wonder when you tell your pastor about it, if he or she is thinking about what needs to be done to plan for your funeral. You realize that if you have any prayer life, it's time to kick it into high gear. What you may not realize is what the implications are going to be for your sexual partner(s). That is one area that I felt was totally absent from the discussion at all points of the cancer diagnosis and treatment process. One couple I met during a trip were returning from a two-week vacation in Hawaii before he was to have prostate surgery at the University of Kansas Medical Center; knowing what I know now, that was a great idea! Probably a great idea even if you couldn't afford it! Another issue that I felt was not adequately discussed was the relative urgency of starting treatment. I found out about the cancer in March and went to my cancer treatment center (CTC) in April and had surgery done in mid-June. Perhaps that was quick enough, but

in hindsight, perhaps I should have sought surgery in April. The cancer had reached the margin (prostate skin) on one side and led to loss of the nerves on that side. I'll always wonder if I had done the surgery two months earlier if perhaps the nerves could have been spared on both sides. This brings up the issue of genetic testing. After the surgery, genetic testing was done on the cancer and it was found to have 20% of the normal odds of metastasizing after five years (1.2% instead of 6%), so I may have had a slower growing version of prostate cancer. I don't know why the genetic testing isn't done on the biopsy material to help patients determine the genetic characteristics of the cancer so those results could inform their choice and timing of appropriate treatments rather than occurring after the start of treatment. One source remarked that "Someday, the hope is that all treatment will start with a genetic test, followed by custom treatments" [2: 15]. Earlier DNA testing might have suggested that my cancer was relatively benign even though the Gleason score had suggested that it was very aggressive.

6. Treatment Options

The urologist prepared a nice chart that he drew from scratch showing six major forms of treatment of prostate cancer. It was pretty overwhelming actually. My main recollection was that if you did the non-surgical treatments first, surgery was less of a follow-up option while if you did the surgery first, then you could still resort to some of the other options. Given all of the options, I wondered why does anyone ever die from prostate cancer? At least if you do the surgery first, you still have second or third options for surviving or at least slowing down the cancer. Furthermore, watchful waiting is one option, to assume something else will kill you first. The urologist said that he had a patient who had the surgery done only to be killed in a traffic accident three months later. What the doctor didn't do that I would have hoped for is recommending which treatment was probably best or better for me, given my unique circumstances. It would have been nice to know which treatment had the higher rates of success with men of my age and circumstances. Would a patient's sexual orientation matter? Would a patient's partner status matter? How would different treatments affect my libido and sexual capabilities? Those men who have taken the hormone therapy route have reported to me that they lost all libido, all interest in sex, even if they retained capability. In my case, I retained the same libido as before surgery, but lost much of my capability, which can lead to arguments about which is worse – having capability but no interest or having interest but no capability? If you are in your sixties as opposed to your fifties and nerve sparing is not effective, one chart I found on my own did not present an optimistic result; as I recall, the chances of recovering erectile functioning were between 13 and 33%, lower than what I would have liked. In other words, given each treatment and the patient's unique circumstances (age, likelihood of nerve sparing success, sexual orientation, partner status, general health, vitamin D levels, diabetes or other complications) which treatment would offer the better chances of success for defeating the cancer and for reducing side effects in the near-term and the long-term? I think

I was told that after five years, most of the treatment outcomes were the same, which I find hard to believe. That might be true, for example, but what if “the same” means poor erectile functioning after five years? What about erectile functioning for the first two or three years? In other words, if both treatments cure the cancer equally, but one preserves sexual functioning for a couple of years and the other does not, then perhaps the former is a better choice, even if sexual functioning is absent both ways in the long term. Another factor in treatment options is what I would call “pre-treatment” options. For example, if you have diabetes, what must you do before surgery or other treatments to reduce your glucose levels to a point where they don’t interfere with the healing process for your particular treatment? Should you take more vitamin D to raise your blood levels of vitamin D as a way to facilitate more rapid healing? Are there other nutritional changes or supplements that would help if done or taken before treatment begins? For example, it was recommended that I take a low dose of Cialis after surgery to increase blood flow to the wounded area and help with healing; would it have been useful to take the same drug before surgery?

7. Selecting Treatment Providers

Because of the lack of recommendation from my local urologist, my wife consulted the internet for an alternative provider and found a major cancer treatment center (CTC). It turned out that my insurance provider only covered cancer treatment at the Chicago location, meaning that we would have to travel a considerable ways, both ways. There are many CTCs so it can be a difficult choice. Some may be far away from the patient’s home. Some CTCs help with travel costs, but if you have federal insurance (Tricare, Medicare) such payments may not be allowed, being deemed an “incentive” for treatment. That’s one law I might want to see changed. In our first year, even though insurance covered most of my cancer treatment and follow-up, the unreimbursed travel costs exceeded \$4,000. Questions to consider are how many days will it take to reach your CTC? Will an overnight stay be required en route? Which method will cost less and/or be less stressful – driving, flying, or taking the train? An important consideration is which method will be easiest on you after surgery when you are still healing and may be very tired? Ultimately, after trying to drive ourselves, we decided on AMTRAK because it took two days to drive but only one by train. Furthermore, the time for diagnosis, evaluation, surgery, and follow-up involved several weeks the first year. Such extensive sick leave may trigger FMLA (Federal Medical Leave Act) requirements, which involves more paperwork but ensures you know that your employer may be required to offer you unpaid leave for as much treatment time as you need. By the way, the costs of cancer treatment can be considerable; in my case, they ran upwards of \$150,000 the first year, though my insurance carrier negotiated payments down to about \$30,000 of which I had only to pay about \$100. My CTC said they offered no cost treatment to those who had no insurance or could not afford to pay for treatment. After your initial treatment, you may have to decide on follow-up

treatments; for example, if you have surgery, will you do chemotherapy or radiation afterwards to destroy any cancer missed in the surgery? We met one man who had the surgery at the same CTC about the same week who was found with a higher PSA four years later and had to return for several weeks of radiation. One wonders how many men can take off that much time from work and retain their job. We decided against chemo or radiation but that decision came with risks (either way).

8. Pre-Treatment Experience

We spent nearly a week in April getting evaluated. One key component was a nutritional evaluation. However, this led to a debate between my wife and the nutritional expert, with each of them thinking they knew more about nutrition than the other. I was thinking, here I am perhaps going to die of this and all you two can think about is protecting each other's positions on nutrition? The CTC eventually removed the nutritionist from our case and assigned someone else who seemed less provocative to my wife. The point is that the CTC is not just treating the patient; the patient's caregiver can get involved in the process in both constructive and not-so-constructive ways. I was told I needed to start taking insulin to treat my type II diabetes. That was a big change but my A1C was a high as 11 and the CTC didn't want to do surgery unless it was lowered considerably. I started taking high doses of vitamin D because that was supposed to help keep the cancer at bay. It was like a whirlwind, meeting so many different staff members, in the CTC's attempt to provide comprehensive, integrative care. What was missed in my view was discussing sexual effects of prostate surgery and how that might affect our couple relationship.

9. Adjuncts to Treatment

The CTC seemed to take the larger environment into account as an aspect of treatment. First, they offered free transportation to and from transportation hubs, train stations or airports, which reduced a lot of stress. Second, they provided lower cost accommodations during treatment, rates that were half or less of what a regular hotel would have cost. The CTC's hotels provided free laundry facilities on site, some 24/7 free snacks, as well as recreational facilities and a salon (at reduced prices for both patient and companion). Over the years, some of these things changed, with reductions in the free snacks and moving the salon from the hotel to the hospital itself. Third, although this varied over time (was that variation a scientific experiment or a budget issue?), each patient and companion were provided a subsidy for their meals (\$7 for each meal), which was designed to promote better nutrition. First, it meant that those with limited budgets didn't have to choose between eating or travel. Second, more nutritional foods were priced low while less nutritional foods (cakes, pies, sodas) were priced higher, lending the situation to an incentive to eat more quality food. The food was prepared by highly trained chefs, making it feel like you were at a resort rather than a cancer hospital. Fourth, free bus

service was provided every 20 minutes from the hotels to the hospital, which was especially important during inclement weather. Fifth, free transportation was also provided to local stores and shopping malls, as well as to nearby tourist sites, on weekends. Sixth, the abundance of other cancer patients, especially during meal times at the hospital cafeteria, lent itself to sharing one's experiences. Since those who might have died of cancer were not in attendance, this meant one was exposed to more hopeful outcomes, that being those patients who were still alive after up to several years. Seventh, the CEO and co-founder of the CTC would commonly eat with or greet people coming off the bus from the hotel. He would make jokes like "Who's running this place? Do you have any suggestions?" It made you feel like you had an ear with the chief executive officer of the CTC. I don't know what research has to say about these environmental differences, but they seemed to make me feel less anxious about my treatment experience. Future research might evaluate such matters.

There were only two negatives in terms of experience. First, space was arranged so that regular patients would see patients just coming out of surgery because the paths intersected; that seemed to change after they expanded the facilities, but beforehand, some of the surgery patients looked in pretty bad shape, which was not encouraging, though no doubt real. Second, the CTC did accept patients who had been rejected at other CTCs as being too far gone. One patient had advanced stage brain cancer and died within a week of arrival, which was discouraging to hear (our families met at the hotel in the lobby). It was great that our CTC was willing to try but sad to hear that the patient had died. One time we were going back to the hotel on the bus and a woman joined us; we discovered that her husband had just died of cancer that very hour. It was so sad and you had to realize that the same situation could be yours in time. However, we met far more people who had been in a stage 4 cancer situation who were still alive after several years, which was very encouraging.

10. The Surgical Experience

We discussed the surgery with the surgeon beforehand. I was aware of the risks of urinary incontinence and loss of sexual life, but I foolishly told him that "I didn't want to wear diapers for the rest of my life". Had I known how discreet and useful adult diapers are these days, I probably would have focused more on nerve sparing and sexual functioning. He was an experienced and great surgeon, with multiple research publications, splitting his time between the CTC and Northwestern University's Medical School. Eventually, the university forced him to drop work for the CTC which was a serious loss in my view. I later looked up his publications. One thing was clear from reading the research on cancer surgery – more experience by the surgeon tends to be correlated with better surgical outcomes. That might be due to attrition (worse surgeons drop out) but one has to wonder who gets the inexperienced surgeons and accepts what may be a higher risk? However, there were some things I wasn't told before the surgery that I think patients should be told. I wasn't told that they would not only

remove the prostate but also seminal vesicles, the vas deferens, and much surrounding tissue (lymph nodes), as well as part of the bladder, though that appears to be a standard protocol [2: 37]. At the same time, I wasn't told that some of the prostate gland is often saved in order to secure the urethra in place [3: 35], which means that some cancer might be missed. I was not told the end result would be permanent sterility, even though this is a recognized result [2: 37]. I don't think I would have changed my mind had I been told all, but it was a surprise to learn all that *after* surgery. I had expected some small ability to ejaculate because I had assumed the seminal vesicles would have been spared at least. It was not clear to me what happened if you did have sex and the testicles pushed sperm out into a cut off vas deferens (did the sperm just go into a body cavity or end up stuck in the far end of what was left of the vas deferens?).

11. Recovery from Surgery

I was amazed at the number of holes in my abdomen, like six to eight for various things. This meant continued loss of blood at some of those points. Between the tubes running in and out of me, the blood pressure measuring cuffs, airbags on my calves (to prevent clotting), and other things I felt pretty "wired-up". This presented challenges to moving around to find better reading or sleep positions. I was pleasantly surprised to receive a gift bag from the staff, mainly being a white robe. I had not brought a robe with me because I wasn't sure if one were needed. But they wanted me up and walking within a day of the surgery and a robe was needed to stay warm and decent looking. But the event was very pleasant and memorable. I have kept the robe as a supplemental blanket even though I don't wear robes at home much. It has become a symbol of having survived the experience and beaten the cancer, so its symbolic value is much higher than its actual cost. Some of the staff were outstanding. One nurse named Kim had a smile and attitude that might not launch a thousand ships but it just might save a thousand cancer patients. On the other hand, I had one nurse tech who seemed to think I was a side of beef when it came to checking me and giving injections. It's amazing how the same treatment can be of minor pain with one staff member but a much more painful process with another. Some of this may have been a risk from training their own medical techs at the CTC itself, which I presume was a combination of a recruiting method and a way to reduce staff costs.

I knew beforehand I would wake up with a catheter and a urine bag. It was still an experience to actually walk around with them in place. The robe was useful at hiding the bag when I ate in the cafeteria. After a couple of days or so, the bag was changed to one that was attached to the upper thigh, which was interesting as you could feel the warmth of the fresh urine as it was released. My urine was tinged red with blood for a week after the surgery, a fact easily noticed by the color of the contents of the bag. Finally the day came for catheter removal, which was not nearly as bad as I had anticipated. The nurse distracted me with some issue and it was out before I realized why she had done the distraction. "You tricked me" I

thought, though I was glad she did.

12. Follow-up

The first year, we went for two follow-up visits; then for two a year, and now it's once a year. The biggest change is in terms of diet. I used to eat whatever I wanted, whenever I wanted, and however much I wanted. Now that has all changed. I eat far more vegetables and fruit and far less cookies, soda, and ice cream. That is mainly to lower my A1C for my diabetes but it's also somewhat of an attempt to lower my chances of getting more cancer. An MRI found that my pancreas had issues, so I usually have an annual MRI to check for pancreatic cancer, but none has been found so far. My doctor was surprised I wasn't walking around in terrible pain all the time due to the state of my pancreas, which was usually associated with alcoholism (I don't drink alcohol, but maybe the gallons of ice cream and soda I consumed in my youth were like alcohol to my pancreas).

13. Long-term Side Effects

There are at least three main side effects from cancer treatment for prostate cancer.

13.1. Bowel Control

First, and more surprising to me, is the issue of regularity, avoiding constipation. When a man has a prostate, it's like a wall against which to push when you are trying to expel a bowel movement. Without that wall to push against, it's like trying to stand up when you don't have any ground against which to push. Recognizing this issue, the doctors require that you take a laxative or stool softener after surgery; they don't want a hard stool damaging the area of the surgery and delaying healing. However, I quickly learned to eat much more fiber than I had previously. I also found that taking magnesium tablets was a great help. One time I had to travel out of town without many bathroom stops and found myself with a huge bowel movement that I could not get out on my own. I went to our local hospital pretty embarrassed about it. After some x-rays and checking I was given a regular over-the-counter product that was guaranteed to produce a bowel movement so quickly it wasn't clear if I could make it from the bed to the toilet in time. Fortunately, I did make it in time, but the process felt like what a woman must feel like when giving birth. When I told the nurse that, she scoffed, like "no way". But when she saw how large the product of evacuation was (at least two inches in diameter and several inches long, with flat ends on both top and bottom), she exclaimed "That's the largest I've ever seen!" and perhaps scoffed a bit less. But that experience was a good reminder to eat fiber, use the bathroom at the earliest hint of needing to go, and to exercise a lot, to keep things moving along.

13.2. Urinary incontinence

A better known side effect of prostate surgery is urinary incontinence. One source suggests that urinary incontinence can last up to a year while stress incontinence can last for the rest of a man's life [3: 4]. At first, I leaked a lot and needed to use two or three diapers a day. I used large pads in bed in case I leaked out of my diapers while I was sleeping. Gradually, my condition improved. Soon I didn't need the nighttime pads. At first, coughing, sneezing, or bending over or lifting any sort of weight led to leaks. Sometimes I would feel some sort of momentary anxiety about something and then it was like my bladder said, "hey, we are going to leak, no matter what right now". It was almost like the anxiety prevented me from thinking to use my kegel muscle to try to stop the leak. That brings up a key point. Before prostate surgery, it's like a man has three valves to control urine flow out of the body. You have a muscle at the exit of the bladder, you have your prostate, and you have the kegel muscle. After surgery, your bladder may be injured and the prostate is gone. Thus, you've lost at least half or more of your control system at least temporarily. Your system now resembles that of a woman, who, if the TV ads are to be believed, have more issues with bladder control (although partly due to often having given birth). The staff wanted me to shift to pads rather than diapers but my wife has always wanted me to wear boxers rather than briefs and pads seem designed more for briefs (another example of how one's partner has an impact on recovery from cancer). Furthermore, diapers reduce the risk of getting wet gas on your underwear as well as controlling urine leaks. The final stage of this side effect for me was passing gas. It seems like the muscles used to expelling gas are tied into the muscles for releasing urine, so this "male privilege" of passing gas is the last stop on the road to total recovery. For example, I found out that if I did not pass gas all day, then my diaper would be totally dry. It's even more complicated in that you might be able to pass gas without leaking if you were sitting or lying down or the gas was very ready to go. On the other hand, if you were also carrying a heavy load, the gas was farther up your system so it took real effort to move it out, or if you were standing up, leakage might occur more easily. Now I think I know why ladies don't tend to pass gas as much outside of bathrooms as men may, because they are trying to reduce bladder leaks, which intact men don't have to worry about nearly as much. You might notice more ads for women about constipation, which may be related to women not having a prostate. Thus, in at least two ways, prostate surgery puts you into a situation in which you can sympathize with women more in these areas. Another issue here is that the catheter has to be aimed to one side or the other, which means that your penis is bent to that side and may not regain its normal, straight shape for months or years; this complicates leakage because if it is aimed to the side rather than to the lower front, the urine may bypass the absorbing material and leak out of the diaper. My point is that you have to take care to aim your penis properly if the diaper is to work properly.

Your intestines can interact with your bladder and bladder control. I found that if I drank

too much liquid before going to bed, my bladder would become full by early morning. That wasn't an issue unless my bowels were active and moving material or gas past their closest passage near the bladder, putting pressure on it. Then on rare occasions, it felt like someone was sticking a sharp nail into my bladder area and the pain was terrible, leaving me in this awful choice of "Do I get up in more pain and get to the bathroom to empty my bladder, which will cure the pain" or "Do I lie still and suffer a bit less pain and hope that it passes as soon as whatever is in my gut has moved along past the bladder?"

Adult diapers are not invincible. If you pass gas violently enough, you can blow up the absorbent material and make them less useful. If you wear them for too long, the material will degenerate and start falling into small, irritating pieces. Women have told me this can happen with menstrual protection materials as well. You can also find adult underwear that serves as a diaper but can be washed and reused when dry. Another issue is that most men are used to using urinals at work. If all you have to do is unzip and move your underwear out of the way, that is not too hard to do. However, add the diaper to the clothing and adding that one item can make it difficult to "get it out" especially if you have a very urgent need to go. It's possible the urgency may beat your getting through the clothing issue and leave you urinating all over yourself and your clothes. The best solution may be to plan on sitting down to urinate, at least if it's urgent, even though that, too, puts you into more of a woman's situation. Has your wife been telling you to sit rather than stand to urinate? Now, you have your own reasons to sit.

13.3. Sexuality

This is probably the most substantial area of interest for men after prostate surgery. One source indicates that on average about 50% of patients who experienced good erections before prostate surgery will continue to do so, which also means that about half will not [2]. Men whose erectile nerves could not be spared, who are older, or who are obese or in poorer health (e.g., diabetes) will have even lower success rates. I was told at the CTC that as many as 40% of couples never have sex again after the man has prostate surgery. It's almost a coin toss. But there are many questions. But one key question is "Will you recover your ability to have erections and/or experience orgasms?" I have also heard that depression is not uncommon among men after prostate surgery when they realize how much their sex life has been affected. The good news is that the nerves responsible for orgasm are not the same as the ones often severed in prostate surgery or damaged by other prostate treatments. The bad news is that the erectile nerves are often damaged by cancer treatments, sometimes more quickly than with others.

There are several general issues that I will discuss first and then in more detail. As a man, one is accustomed through decades of experience to associate having an orgasm with having an ejaculation; I suspect that many, if not most, men consider ejaculation the primary

tangible object of their sexual experience. With ejaculation a thing of the past, can a man adapt and retain orgasmic capability without ejaculation? Recovery time is another issue. We are used to the idea that if you have a headache, you take an aspirin and quickly the problem is solved. Recovering full erectile functioning after prostate surgery is an issue of more than a few minutes; it's months to years. A third issue is that sex has many sources of pleasure that perhaps most couples don't think much about; which of those are impacted by prostate surgery? A fourth issue is that sexuality, though it is often treated as an individual issue at CTCs, is really a couple (or multiple partner) issue. Fifth, although there are a number of "solutions" to erectile dysfunction (ED), they are not as simple to use as may be explained at your CTC. Sixth, you may find that there is a difference between a good looking erection and a useful one because, like a narrow child's balloon, something can look good, but have no practical value in terms of the tension needed to penetrate a vagina or rectum.

A further issue is that sexuality with a partner is a process issue, an experience that unfolds over time, often in a specific sequence. For example, one sequence that is possible may be that the man, largely motivated by his prostate's needs for pressure relief, spends a great deal of time in foreplay mainly to raise his wife's interest level in sex. At some point the process shifts to focusing on either her orgasm or perhaps that for both, but intercourse is probably a later step in the process, concluded often by the man's orgasm and ejaculation. There may be a sense of relaxation after sex for both and some pillow talk before going to sleep. The side effects of prostate surgery can disrupt such a sequential process. Not only may the wife need a lot of foreplay, now the husband may need as much or more in spite of being less motivated to become engaged in the sexual process. Not only may he need foreplay but he may need to take pills ahead of time, wait for them to take effect, and use other technical procedures (penis rings, vacuum devices, penile injections, etc.) as part of getting ready for intercourse. Even with all the best technical support, obtaining an erection firm enough for engaging in vaginal intercourse may not be possible at all times, if at all. If intercourse is not possible, what sequence do you do now? Maybe the husband should have an orgasm from foreplay first and then the wife (reverse of the sequence). Without ejaculation to signal an endpoint in the process, what will now serve as the endpoint signal? Before surgery, perhaps the whole process took 30 minutes. If one adds in the longer time that may be needed for the man now, perhaps it may take 50 minutes after waiting half an hour or more for pills to take effect. For some couples, that may just be too long to justify in light of their many other responsibilities, among them getting enough sleep. If time becomes a limitation, sex may become "alternative" in that one day perhaps the focus is on the woman's pleasure alone and another day on the man's. Some may feel that sex without vaginal intercourse as part of the process isn't really "authentic" sex and may feel that sex is no longer real or important. If the wife feels that the potential to get pregnant is part of the reason for sex and part of what makes it exciting, making love to a now sterile husband may seem like an exercise in futility. An irony of prostate

surgery is that women may be able to have ejaculations (Komisaruk, Whipple, Nasserzadeh, & Beyer-Flores, 2010, pp. 20-21; Rehman, Lazer, Benet, Schaefer, & Melman, 1999, p. 80) as well as transgender women (for whom the prostate is not removed; Komisaruk et al., 2010, p. 56), while men, after prostate and/or seminal vesicle removal will not be able. It is possible to have dreams about having a strong erection only to wake up and find that the reality does not correspond to the dream.

13.4. Sterility

Prostate surgery removes the connection between the testicles and your penis, rendering you sterile. Some might welcome this change, others not so much. Some men pride themselves on being able to cause a pregnancy well into their old age. Some women believe that their ability to control their own fertility includes having a husband who is able to make them pregnant if they wish to become pregnant. Some men may have prostate cancer at a young enough age that the surgery limits the number of children they might have, which could frustrate a wife who wanted more children. If the wife is fertile and wants more children, a man may need to save enough semen before surgery to allow for impregnation of his wife after his surgery. Alternatively, a wife might want to try to become pregnant before the surgery, as a last chance, even though having a new baby and dealing with a partner recovering from cancer surgery may not be things to try to do at the same time. Some women don't believe in men having vasectomies and may not be pleased that prostate surgery is a functional equivalent. They may feel cheated as in "I told my husband to never get a vasectomy and now he's basically done it without my permission" (since if the husband isn't told he will become sterile from the surgery, the wife hasn't been told either, of course).

13.5. Having "Dry" Orgasms

Many physical activities have a functional side and a pleasurable side. When you eat food, it satisfies your hunger (functional) but tasty food is also pleasurable to eat. Sometimes people will try to separate these two issues and throw up their food so they can get more pleasure by eating more, but generally satisfying your hunger and enjoying the taste of food go together as an integrated phenomenon. With sex, men have a physical release of semen (function) that is accompanied by intense pleasure so that the two things become strongly associated in the male mind. This association will no longer exist after prostate surgery. In my experience I had heard about so-called "dry" orgasms but if I had an ejaculation there was a refractory period afterwards during which I had to build up more semen in my system before I could ejaculate again or have an orgasm again. I tried on occasion to have a "dry" orgasm by having sex "too soon" and never achieved that type of orgasm. So I faced the prospect of only having "dry" orgasms with a bit of curiosity but a lot more anxiety, if not fear. What if I could not ever have an orgasm again? Not an entertaining prospect. I had questions. Could a man

have an orgasm if he did not have an erection? What if you can only achieve a partial erection? If you don't have erections is it a "use it or lose it" situation? What if my wife doesn't want to "help" in the recovery process? Through a lot of trial and error, I learned that when it's either a dry orgasm or nothing, your body will eventually figure out a dry orgasm is better. You may also discover that even having a partial erection seems to feel good to your penis, even if no orgasm is attained. My guess is that bringing more blood into the penis provides its cells with more oxygen and nutrition.

I think you have to change your mental goal from getting the semen out to attaining a pleasurable experience. Again, I think you come closer to being a woman in that respect as women don't seek an ejaculation but want to have a pleasurable experience regardless. But you have to keep trying, it may not "work" at first. Furthermore, you may find that the orgasmic experience itself will change. You might recall that a woman's experience can vary with sex; some nights are better than others, to be blunt; sometimes the earth moves and other times not so much. Now that female type of variation may become your male experience. When you were able to ejaculate, you could count on a "good" orgasm nearly every time. In fact, the sense that your pleasure was virtually guaranteed if you did ejaculate was a powerful motivation for having sex if it had been long enough since your last ejaculation. Who doesn't like to do things with a nearly 100% guarantee of success? Consider male/female differences here. The woman is thinking to herself, I might have an orgasm but if I do have one, it might be good or it might be great, who knows? The man is thinking to himself, I am going to have an orgasm and it will be great. Hence, there is less intrinsic motivation for the woman because the probabilities are lower *and* more uncertain. *Now*, that will also be true for you as a man. The bright side of this is that with your orgasm unchained from your ejaculation, you can have orgasms more frequently and sometimes they may feel stronger than they did before (but sometimes weaker). You will probably learn that the better your erection, the easier it is to have an orgasm and your orgasms will probably be stronger, but even with very little of an erection, it's still possible to have an orgasm of sorts. I learned that there was what I call a "shadow" orgasm, where your rate of breathing goes up and it seems like an orgasm may be coming but when it's over you're not really sure what happened; something happened but was it a regular orgasm? Are we having fun yet? Maybe. Gaining a full erection can take months to years so you have plenty of time to learn how to have a dry orgasm. On the other hand (no pun intended), your partner may need to adapt and shift from a focus on intercourse to a focus on manual or oral sex if they want to please you sexually. In other words, it may be months or years before regular sexual intercourse will be the primary way to attain sexual satisfaction. The mental shift is so important. Before surgery, you could focus on the sexual function (releasing semen) with the pretty firm sense that a good orgasm would accompany that process. Now your mental focus will have to shift to where you really want the orgasm by itself and almost "expect it into existence". In other words, a mental block or other distractions can more easily impede your chances of having an

orgasm. You might remember how your wife could be distracted by the baby crying or a noise outside; now you will find yourself in the same situation where your mental state becomes so very critical to the physical experience. Again, on the positive side, your refractory period will be shorter; I don't think it is quite as short as a woman's, but it will be a lot closer to hers. To me, it still seems like I have some refractory period even if I am not waiting for the prostate and seminal vesicles to "fill up" again. Another issue is that the foreplay needed to attain an orgasm will vary a lot more. You may have found that you could predict how much stimulation you needed to reach an ejaculation. Whatever that was, now it will vary a lot more. You might recall how sometimes your wife might climax in a couple of minutes but other times it might take half an hour of stimulation. That will probably become your situation, too, now. This has the potential to dramatically change your sexual experience. It used to be that your wife might not want sex but be willing to give you a "quickie". And thus, worst case, sex might take a couple of minutes for both of you. Now, since your penis can't do "double" duty to stimulate you and your wife at the same time, it may be necessary to take turns where each of you now needs up to 30 minutes of stimulation. This means that sex can change from a two-minute deal to an hour long deal. That may be great if you are into sensuality and have the time, but what if you are both dead tired and have lots to do and too little sleep? If you are under a lot of time and emotional stress, sex may simply become too difficult in terms of the demands on your time and efforts. It's a bit like now having a marriage of two women living with each other sexually. This change is so deep. It used to be that your wife could almost always count on you to be "hot" and highly motivated to please her because you were so desperate to relieve the pressures in your body, mainly your prostate and seminal vesicles. No longer. And she knew that she could get satisfaction from pleasing you, quickly, even if she didn't get any direct sexual pleasure. No longer. You will have less physical motivation for sex at the same time that she will need to supply more motivation to engage in the longer and more intricate foreplay that you now will need. She could depend on her man to initiate sex with a strong motivation, so that she didn't really need as much motivation on her own, she could count on her man to provide that for her pleasure and for his, too. But now he will have less motivation and you, as the woman, will need more. Do you see how this is a sort of "double whammy"? But I am getting into the "couple" issues that are often overlooked. Linked to the probability that you both are aging, both may be having medical issues (e.g. diabetes, heart disease, etc.), and this "double whammy" problem, some couples simply, though sadly, give up on ever having sex again.

14. Solutions for ED

14.1. Medications

After surgery, it is likely that you will be given Cialis or its equivalent to promote blood flow and healing to the area of the surgery. Of course, Viagra or similar medications

may be prescribed to help you regain erectile capability. There are many non-prescription pills, vigorously advertised on radio, TV, or the internet that promise to give you the best erections ever, often with outrageous prices (in some cases pills with the same ingredients are sold at local stores for a tenth of the radio or TV price). However, my experience with these medications has been disappointing, many are clearly not worth the money they cost. Viagra not only depends on using it but on the dose and the timing that will work for each man. If you use the wrong dose or the wrong timing, it may not work as expected for those reasons. You will need to coordinate the dose and the timing with your doctor. The use of products like Viagra intersects with your wife's cooperation. In other words, she has to approve of the timing. Suppose the timing is one hour from when you take the pill. What if she is interested after 30 minutes but falls asleep before the hour is reached? What if you take the pill and then remind her and she says she isn't interested in sex tonight, no matter what the timing? What if she gets into bed with you and says she's interested right now but you haven't taken the pill and will need to wait another hour, but she wants to fall asleep right away if you can't perform right away? Whatever the timing is for you and your medicine, it has to work for both of you, or it may not work at all. It may be because of these sorts of complexities that up to 40% of couples stop having sex altogether after prostate surgery. Some of the time for some men, Viagra or its equivalents may not work at all, regardless of timing, which can be very frustrating for such men at such times.

14.2. Vacuum devices

It is likely that you will be shown an erectile vacuum device. The penis can be inflated by a vacuum as the reduced air pressure draws blood into the penis. On the surface, this looks like a wonderful idea. I was forewarned when one couple who knew of my surgery told me that they had thrown their vacuum device away because they could never figure out how to make it work. I found out that it's pretty complicated. First, to have a vacuum, you need a seal, like a military gas mask won't work unless it is sealed properly. One reason men shave in the military is to help gas masks seal so the enemy's poison gas cannot sneak inside the mask due to beard hair preventing a seal. That's why Hitler wore his silly little mustache, as an after effect of being gassed in World War I. What this means is that you will need to shave your pubic area; not perfectly as with a blade razor but as well as you can do with an electric razor. You have to be careful not to cut yourself shaving; then you may become more worried about stopping the bleeding than about having sex. If you are not willing to shave that area, the vacuum device may never work. I was told you could help the seal by using Vaseline around the base of the device but then you – and your partner - have to be OK with “greasing” yourself up before sex with a lubricant suitable for not just one, but both of you. I found that shaving in the shower (without the water running) was the easiest way to remove hair without getting it all over the bed or the bathroom. Second, you may need to lubricate your penis before using

the vacuum device. If the penis is limp it can expand and make a U-turn if it gets caught dry against the side of the vacuum tube; obviously, that's not a good thing. Third, you don't want the vacuum to suck your testicles into the vacuum tube along with your penis, so you may need to tie off your testicles with a sock or an erection ring to prevent that from happening. Fourth, you have to put on an erection ring after the penis is expanded, but that is easier said than done. In my experience, enlarging your penis is a bit like stretching a rubber band; it may take a few tries to get the best result. You may find that once you have a partial erection, you can put on a ring and then use the vacuum device again for best results. Fifth, you need to be aware that the penis will eventually lose its size, so you may have to act fast, which may or may not be acceptable in terms of timing with your partner. Sixth, some partners complain that a penis made erect by this method is cold to the touch and they don't like that feeling. Seventh, even if the penis looks great, it may not have the tension needed for penetration even if you do everything as well as you can. However, even if this process isn't adequate for having sex in terms of intercourse, it may increase your chances of having an orgasm through other methods and it gets more blood flow into your penis, which is good for the cells in it and for keeping your penis from shrinking in size due to lack of use (use it or lose it). Normally a man's penis has erections naturally while the man sleeps but after surgery, this may no longer occur, even though the penis still needs such expansion on a regular basis for its own health. The point is that vacuum devices are a great invention but their use is more complicated than one might expect. The cost can vary greatly as well. Some devices sell for hundreds of dollars and others for under fifty dollars; they may work equally well regardless of the cost, so I would suggest trying some of the less expensive models first. They can break, so be prepared to send a broken one back for a replacement. By breaking, I mean that the tube won't break but the way the vacuum is produced, those parts can break, often easily. Use of a vacuum device may seem so artificial to you or your partner that it may interfere with having sex and be self-defeating in the long run.

14.3. Lubricants

My sense is that most women enjoy some degree of use of lubricants to enhance their sexual arousal and excitement. Men may also, but if intercourse has been the primary endpoint of sex, then they may not have felt a need for artificial lubrication. If the man cannot engage in intercourse, then he, too, may now need lubrication to get the most pleasure. All it will take is a visit to the internet or a store and you will find a plethora of choices, which can almost be overwhelming. Many of them are not cheap. The best I can say is that trial and error may be needed to find out what works best for you and your partner.

14.4. Electrical devices

I have seen advertisements for electrical or mechanical stimulators for treatment of ED

but I have never tried any of them.

14.5. Penile constriction rings

You can buy constriction rings of various shapes and sizes from the internet or sex shops. They won't last forever, they can develop cracks or break completely. They can be thick or thin, larger or smaller, of various shapes. Again, you have to do some trial and error to see what works for you. Even if you aren't using a vacuum device, rings can be helpful for maintaining an erection. The key seems to be timing. If you put a ring or rings on before your erection is good enough, it will backfire and prevent further enlargement. If you put on the rings too late, you may not get the best result either. You can probably put on the rings most easily if the penis is lubricated first. You don't want to "snap" them on because that can hurt and ruin the mood. They have to be removed after a few minutes (no more than 30 minutes) or the penis could be damaged.

14.6. Condoms

You might try condoms while using an erection device. One novel approach would be to remove the tip of the condom only and allow the sides of the condom to help increase tension in the penis. This may or may not work for any given man.

14.7. Heart Problems

If you have a weak heart, sex might be ok, but some of the ED solutions (pills or injections into the penis) may not work because they might cause tachycardia or too much stress on your heart.

14.8. Injections

One solution to ED is to inject medications into the penis or insert them into the end of the penis. While these methods can work, they are contraindicated if you have heart problems. They also require some training so you don't put the medicine into yourself in the wrong way and cause damage. They are often unacceptable for many men [3].

15. Dysfunctional Belief (of either person) Problems

Aside from the technical issues discussed above, mutual participation in some form is usually required. But mental blocks can stop the process dead in its tracks, if so allowed. If your partner or you think that sex isn't the same or any good if:

Erections have to be perfect

Sex must take less than ten minutes

Sex has to involve intercourse

Sex is useless if pregnancy isn't a possibility

Sex has no meaning if ejaculation cannot occur

Erections have to last for ten to twenty minutes to be helpful

Sex is too much bother if the man needs lubrication

Sex is too artificial if pills, pumps, or other devices are needed

Sex is too expensive if it takes expensive pills or other devices

Sex isn't worth it if my partner isn't totally desperate to get prostate relief

If my husband can't guarantee having an orgasm, why bother?

Sex is too much bother if my husband needs my hands or mouth for stimulation

Sex is too much bother if it's going to take more than ten minutes to please both of us

If the man can't ejaculate, sex is pointless or not real

Just enjoying being naked together and enjoying sexual sensuality is not enough

If sex doesn't help me get what I want because my husband is so desperate to relieve his prostate, then why bother?

Sex is no fun if I can't feel the ejaculation inside of my body

Sex is no fun if I can't enjoy the vicarious pleasure of my husband's relief when he empties his prostate

It only takes one of those mental blocks to end your sex life together. If sex seems to end for good, one or both partners may easily become depressed. A man might decide that if he's never having sex ever again, why bother with hugging or kissing his wife much? If he stops that, she may withdraw even further emotionally or sexually. A death spiral of sex or even the whole relationship can result. One of the things I think is neglected in prostate cancer treatment follow-up is discussion of such partner concerns. I wonder about the same thing for other forms of cancer (e.g., breast cancer) treatment.

16. Sexual Changes

Prostate surgery can change the way both partners experience sex and gain satisfaction from it. I have tried to list some of those changes in the tables below, for men and for women.

The extent of the changes depend on nerve-sparing success to some degree. If more extensive erectile nerve damage will exacerbate the problem then I have marked it with an asterisk (*).

Figure 1: Sources of sexual satisfaction for men

Source	Before surgery	After surgery	Gain/loss
Feeling yourself develop an erection (feels good)	No problem	May not feel anything even when you have one (*)	Loss
Being able to visually admire your good erection	Most of the time	Only some of the time, if ever (*)	Loss
Sense your wife is proud of your strong erection	Most of the time	Some of the time at best (*)	Loss
Anticipation of engaging in intercourse	Almost always present	Depends on ability to get and maintain an adequate erection (*)	Loss
Being stimulated to a quick erection by mere sight of partner	Possible	Less likely (*)	Loss
Feeling your body get ready to collect fluids as you are nearing ejaculation	No problem, feels good	No fluids, no such feeling	Loss
Ejaculating	No problem, provides much relief, can feel semen leaving the tip of your penis	Nothing	Loss
Completing a definitive biological activity	Almost always that you completed a definitive biological act	May not feel that way without production of semen	Loss
Orgasm	Coincides with ejaculation, high probability of success	Less probable, sometimes no results regardless of stimulation (*)	Loss
Not dependent on wife's level of foreplay as long as intercourse is permitted	Not much of a risk	Lack of foreplay may doom results; even with adequate foreplay, may not get results	Loss
Wife is usually pleased that you had a good time	Probably will please you	She may not be pleased since you may not have a good response even if she tried to help you	Loss
Maximum possibility of orgasms (frequency) and maximum possible intensity	Regulated by semen build up	May occur more often and with (sometimes) greater intensity	Gain
Chance of not having any orgasm or a weaker orgasm	Less likely	More likely	Loss
Possible like or dislike of smell, taste, or stickiness of semen	Present unless man uses a condom	Not present	Gain/Loss
Less chance of a wet spot on sheets	Very likely	Less likely	Gain
Enjoyment of spontaneous sex	Likely	Less likely (may need to plan for Viagra, use of pump, rings, etc.)	Loss
Chance of a dry orgasm	Less likely	More likely	Gain

Sense of purpose in being able to help make a baby	Probable	Not possible	Loss
May feel you “owe” wife due to physical relief intercourse with her provides	Probable	Less of a debt in this sense; maybe more of a debt if she is eager to invest enough time and energy in the foreplay you now need	Mixed, risk of changing relationship either way
Your wife didn’t have to be precise in dealing with your erect penis, stimulating one part of it would probably stimulate the rest of it	Almost any touch will “work”	If the penis is not erect, touching just one part may not “work”	Loss

Figure 2: Sources of sexual satisfaction for women

Source	Before surgery	After surgery	Gain/Loss
Orgasm, self	husband is highly motivated to try to please wife (or she won’t help him empty his full prostate)	husband may not be as motivated to try to please wife, having no prostate to be emptied	Loss
Orgasm, self	Husband’s strong erection may help	His penis may no longer be able to help (*)	Loss
Testosterone supplement in semen from husband to improve libido	Available to motivate wife for future sex	Not available	Loss
Ability to become pregnant, if desired, which can afford a woman a great sense of life purpose, even if she doesn’t get pregnant	Usually possible	Not at all possible	Loss
Having had an obvious transfer of DNA, body fluids	Very apparent	Takes some imagination, maybe some transfer from wife to husband	Loss
Ability to congratulate self on ability to please husband	Almost always	Possible, not probable	Loss
Ability to see the obvious results of your arousal of husband	It’s visually obvious that you’re making a difference when he gets a strong erection	He may no longer get a strong erection through your efforts (*)	Loss
Effort required to please husband	Minimal except for being available at inconvenient times, places	Much more effort and planning, foreplay for him, and coordination required	Loss
Chances of being able to please husband	Nearly 100%	Far less	Loss
Able to enjoy actual intercourse	Nearly 100%	May not be possible at all (*)	Loss
Husband’s ability to empathize with female issues with sex	Not easy	Much easier due to increased similarity	Gain
Vicarious pleasure of a combination of having power over your husband because he is so desperate to relieve his prostate and getting him to “owe” you so much for doing it and for simply being able to make him so happy because of the prostate relief	His pleasure so tied to ejaculation, he may not appreciate your sexual help as much	He may have stronger, longer orgasms some of the time (*), but in general you no longer afford him the great relief that he used to get from having sex with you	More loss than gain
A sense of being desperately needed by your husband	Usually present	Not as clear anymore	Loss
Husband’s great need for you can give you a great deal of negotiating power	Present	Much lower need, much lower negotiating power	Loss

Being able to feel the semen squirt against your vagina or wherever	Present	Not present	Loss
Husband's arousal (needed to be orgasmic)	Took care of itself once he saw wife or had minimal foreplay	May require far more assertive (cougar-like) response by wife	Loss or gain, depending on perspective
Semen control (wet spot on sheets)	Need to decide how to deal with semen from intercourse (wet spot) or oral or manual sex	No semen, no issue	Gain or loss depending on attitude
Control of sex	A wife can often easily arouse husband with a glance, light touch, scanty clothes, whatever. This means she has a lot of control and power over the process, especially in terms of initiation if she wants.	The same things may not work and a loss of control may be experienced, which may lead to confusion, apprehension, a sense of greater risk in suggesting, etc. A greater chance of being turned down or rejected.	Loss
Having G-spot stimulated by man's penis	Possible	Less likely (*)	Loss
If sex diminishes after surgery, husband may feel less value in hugging, kissing	Not likely	Possible	Loss
If husband loses interest in preliminaries, wife may feel less loved or that she was only loved before on account of sex	Not likely	Possible	Loss
If husband needed sex more than wife, this may have led to conflict over sex	More conflict	Less conflict	Gain
If there was conflict over sex before and now there is less, restarting a sex life may seem to be a threat to the relationship (i.e., conflict will start up all over again)	Less conflict after surgery	More conflict if we start having sex again	Loss

16.1. Relationship side effects

Sex can mean different things to men and women. Sexual pleasure can come from many different aspects of the sexual process. Prostate surgery can affect these matters, which are organized in Figures 1 and 2. Sexual orientation may change some of these perceptions, which might be a basis for a different discussion in a different report.

There are at least three things to notice from the above Figures. First, there are a few positives, a few gains. A man may enjoy not being held captive as much to his sexual needs. Second, the losses will probably exceed the gains, especially if there is more nerve damage. Third, even if you have no erectile nerve damage, there will still be losses to the sex life of both partners. Fourth, if you do have nerve damage, there will be even more losses. Viagra and vacuum devices and penis rings can help restore erectile capability, but there is a learning curve to using all of them and even in the best of situations, they may not restore enough of an erection to permit intercourse. Fifth, the side-effects have a direct impact on the wife or other partner as well, which then can influence how the couple, as a couple, deals with sexuality.

Since it only takes one partner to decide to stop having sex altogether, it is quite possible for the couple to become celibate after surgery, even if one partner does not want that outcome. My sense is that couple issues are very seldom considered after prostate treatments. For example, before surgery, my sense is that for many couples, sex means that the man actively engages in foreplay with the woman, with a goal of arousing her sexually, more than her arousing him – he’s probably already aroused just seeing her. This doesn’t require but does allow the woman to be more passive in the process, if she wishes; ultimately, he may be quite fulfilled if she eventually allows him to have intercourse. But, what if surgery means that he can’t engage in intercourse any more? That may change the entire dynamic of sex. It may be that the woman has to become more active, less passive if the man is to be satisfied sexually. She may have to think of his penis as more of a longer clitoris that will need stimulation more like hers does. And the techniques may need to be more precise. That is, with an erect penis, touching one part will through tension affect other parts, but if the penis is limp, then whatever is touched, well, that’s about it. Thus, pleasing the man will become more difficult, more time consuming, and more frustrating. For instance, suppose a dog barks outside. Possibly such distractions would break the path of arousal for the woman in the past, but now such distractions may just as well break the path of arousal for the man now. In general, the costs/risks of sex increase, for both parties to the endeavor, while the rewards may decrease, creating a tipping point in between at which sex may seem to just not be worth the effort. Therefore, I would recommend that couples work on a pre-surgery contract, which will be illustrated later in the Appendix.

16.3. How Long?

One might think that you can endure the aforementioned side effects for a few months as long as you know they will be solved in time. What I found distressing in the process was that the doctors cannot predict with certainty how long it will take, if ever. If the problems persist at six months, then they will say, wait another six months. If the problems don’t go away for a year, then they tell you to wait for two years. If they don’t go away for two years, then they say wait for the third year. If the problems exist after three years, well maybe in five years, they will be gone. Sure, if we wait long enough, you will die and then it won’t matter at all! I felt they were revising their recovery forecasts mainly because of my slower recovery, which may be an attempt to maintain hope but can lead to the patient feeling “toyed with” in terms of his future.

17. Conclusions

I have tried to describe in detail some of the kinds of issues you need to know about before surgery, so they will not take you by surprise and so that you can make a more informed decision about what is the right cancer treatment for you. It’s one thing to talk about the consequences of cancer treatments; it’s another to experience them for yourself. It’s quite likely

that some of your medical caretakers have not experienced cancer treatments, which may be more theoretical than practical for them and weaken their understanding of and empathy for your specific circumstances. Besides surgery, there are treatments involving chemotherapy or radiation. I was told by the CTC staff that the research suggests that after five years, side-effects are pretty similar, regardless of treatment. However, it would appear that in the short run, chemotherapy and radiation have fewer sexual side-effects. However, it is not clear that chemotherapy and radiation are better at killing the cancer; one serious factor is that you can turn to other treatments if surgery does not work, but you may not be able to turn to all other treatments if chemotherapy or radiation do not work. One other treatment is castration, but I am told that such a treatment tends to radically reduce your sexual desire in general, even if you retain your capabilities. Since castration only partially eliminates testosterone, which fuels prostate cancer, you have to take other medications to counteract any remaining testosterone, which may reduce muscle density and bone mass, as well as killing your sexual desire. There are also castration-resistant forms of prostate cancer, in which case such “hormone” therapy may not work well.

One better approach would be to detect prostate cancer earlier; earlier detection may mean fewer side effects, if only because younger men are more likely to recover from most of the side effects compared to older men. If the Gleason score is 4 or less, heavy use of vitamin D or other supplements might deter or eliminate prostate cancer. My suggestion is that if prostate cancer seems to run in your family, you need to focus on earlier detection because there may be a genetic component. Likewise, avoid sugars and fats that seem to increase the chances of prostate cancer developing; see a professional nutritionist for advice on these issues.

There are many new treatment options, some only in clinical trials, for treating even advanced prostate cancer [3]. Try to find information on them if you find yourself with advanced prostate cancer. You may wish to consult with cancer treatment centers that specialize in dealing with cancer. Also, remember that laboratory tests can be wrong. I’ve known of men who were cured of prostate cancer but had false positive readings from lab reports that were later determined to have been in error; don’t panic if you get a bad lab report, just verify it first.

Within this report there are many explicit and implicit opportunities for research with cancer patients both before, during, and after their cancer treatments. It is my hope that this report will instigate many different aspects of cancer treatment research beyond the standard “Did it work” or “Did the treatment get all of the cancer” approaches to evaluating the outcomes of treatment. I think there is a great need for more research on any cancer that impacts the sexual life of couples, whether heterosexual or same-sex. Such research should take into account patterns of sexual values and activities before cancer treatments as well as those occurring after cancer treatment.

Appendix: Couples contracts

I think that recovery from prostate surgery might be enhanced by having couples discuss and sign on to contracts about how they will help each other recover from the surgery. Below are some ideas for such contracts. Future research might test the usefulness of such contracts or ways in which they might be improved to increase their helpfulness.

Husband	Wife/Partner
Even if I feel I have lost much of my sex life, I will still try to sexually please my wife on a regular basis	Even if my husband becomes much harder to please sexually, I will do my best, with great patience, to please him sexually
I will try to continue to hug and kiss my wife and be romantic even if the chances of that seem dim for leading to sexual activity	I won't wait for my husband to initiate hugging or kissing, I will do it myself
I will try to help my wife understand how my needs and requirements have changed after surgery	I won't depend on my husband for initiating sex, I will initiate it if he doesn't, even if he seems shy about it
If I have become more like a woman in many ways, I will try to use that learning to help me better understand some of what it means to be a woman	When my husband shares his new needs and requirements about sex, I won't belittle or dismiss what he says or is trying to tell me
If my wife tries to initiate sex, I will not refuse her for long and I will appreciate how much she is trying to be responsive to me	When my husband tries to be romantic, I won't tell him all he wants is sex nor will I act like he should not be interested in me sexually any more
I will try to not allow my sense of loss from the side effects of prostate surgery to keep me from enjoying as good of a sex life as possible with my wife	I will try to overcome any fears that starting up a sex life again will lead to more conflict over sex like maybe we used to have before surgery
I will try to understand the ways in which my surgery represents loss or difficulties for my wife and encourage mutual sharing between us about such issues or problems	If my husband shows a flicker of interest in sex, I will try to fan the flames of desire so we have the best chance of having a good sex life

18. References

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