Reclaiming Sex & Intimacy After Prostate Cancer

A Guide for Men and Their Partners

2nd Edition

Jeffrey Albaugh, PhD, APRN, CUCNS

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Dedication

This book is dedicated to the amazing patients I have cared for and their partners who have taught me so much about courageously fighting to improve quality of life after prostate cancer.

Foreword

Erectile dysfunction (ED) was once considered to be entirely psychogenic in its origin and was frequently neglected by healthcare providers. More recently, there has been increased recognition of its many physiological causes, and its impact on the daily life of men and their partners is starting to get the attention it deserves. Intimate relationships in patients with cancer have been greatly improved due to this increased recognition and advancement in therapies.

Jeffrey Albaugh, PhD, APRN, CUCNS, is a pioneer in the field of sexual medicine whom I have had the pleasure of knowing and working with for over 15 years. Dr. Albaugh emphasizes that treating a man with prostate cancer requires an assessment of his sexual history. As a result of Dr. Albaugh's persistence and dedication, ED is no longer considered a foregone conclusion for patients with prostate cancer. His mission is to secure the quality of life and sexual health for the patient and his significant other after traditional cancer treatments are completed.

Assessing a man's sexual health is particularly important in the treatment of prostate cancer. Almost all treatments for prostate cancer can result in some degree of ED. Physicians understandably emphasize the importance of curing the cancer and have historically neglected to recognize the impact of ED and/or sexual dysfunction that occurs after the cancer was treated. Similarly, patients are often so focused on treating their cancer, that they never discuss the sexual repercussions before undergoing treatment. Dr. Albaugh has changed the landscape by teaching doctors and patients that sexual health after prostate cancer is something that should be discussed at the same time as the cancer treatment plan. In the past, it wasn't uncommon to hear otherwise healthy patients express regret about their cancer therapy due to the sexual dysfunction that continued to plague them long after their body otherwise healed.

Dr. Albaugh has developed a unique model that should be considered the gold standard for all men recently diagnosed with prostate cancer. I am fortunate to work alongside Dr. Albaugh so that before any prostate cancer treatment is performed, all patients and their partners undergo a sexual health assessment. During these visits Jeff assesses sexual health goals and sets forth a plan to preserve sexual function. Just like the treatment of the cancer needs to be evaluated on a case-by-case basis based on the nature of the disease and the patient's history, the same is true for sexual health. Jeff treats each patient situation individually and helps lay the groundwork for a plan of rehabilitation before any treatment begins. This support has dramatically improved the quality of life of patients and their significant others.

All men and their partners should read this book prior to undergoing prostate cancer treatment. This second edition highlights the patient and partner experience of acknowledging that sexual health is a fundamental part of treating the whole patient. It presents real-life interviews that have been conducted over the past 6 years. These voices tell the stories and experiences of men and their partners with prostate cancer. These stories make discussing a traditionally private topic easier. It is through this honesty that we are able to initiate discussions about topics that are truly important to patients and help to improve their quality of life before, during, and after prostate cancer treatments. I am truly honored and proud to work with Jeff on a daily basis. It is through his caring ways that he continues to touch the lives of so many patients. This book will be an invaluable resource for all men with prostate cancer and their partners.

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Chapter 1
Introduction

Sometimes the road to healing can be a challenging journey. You probably never thought you would be reading this book. You may be overwhelmed from your prostate cancer diagnosis. You may fear you will never have sex again. You may feel guilty for worrying about sex after your prostate cancer diagnosis. Yet, the thoughts and emotions you are feeling are very normal, and there is hope. You *can* continue to have a fulfilling relationship with your partner. You *can* reclaim intimacy and closeness with your partner. The information in this book is to help you better understand the sexual changes after prostate cancer treatment.

The prostate is part of the sexual reproductive system and it sits right at the bladder neck with the urethra (the tube that carries urine out of your bladder through your penis) going through the middle of it. When the prostate is removed or radiated, the most common long-term problems are sexual side effects and urinary side effects. This book is dedicated to you and your partner or future partner. So, where and how do you begin this journey of reclamation? You begin by increasing your knowledge about sex and intimacy.

Sex, Intimacy, and Communication

There are many definitions of sex and several things may come to mind when you think about sex. Sex is often thought of as the act of sex or those characteristics of being male or female. Sex is typically thought of in terms of genitals and arousing stimulation. Genital stimulation can be manual (using the hands to stimulate genitals), oral (using the mouth to stimulate genitals), rubbing (rubbing parts of the

body or genitals against a partner's genitals), vibratory (using vibratory stimulation to stimulate genitals), or penetrative (penetrating the vagina or rectum for sexual pleasure). Needs in terms of erectile hardness vary greatly depending on which types of sex you want to have with a partner.

All medical treatments have positive and negative effects, and prostate cancer treatments are no different.

Intimacy is communication on all levels, moving toward deeper communication and understanding with a partner (Hatfield, 1982). Sex and intimacy often occur simultaneously, but they are two distinct concepts. It may be useful for you and your partner to assess and discuss your goals regarding both sex and intimacy. In terms of intimacy, you and your partner might find that after prostate cancer treatment you need deeper communication and understanding. This involves intimacy (even without sexual relations). Intimacy brings closeness. This is important because one of the challenges of dealing with a cancer diagnosis is the potential for isolation between a man and his partner. Affection and physical touch may also be reassuring and play an important role in a deeper connection with a partner.

Your thoughts and goals in terms of sex may vary greatly as you navigate through prostate cancer diagnosis, treatment, and recovery. Even though sex may not be one of the most important things on a man's mind when first diagnosed with prostate cancer, it is likely to become a weighty concern after treatment.

Treatment Concerns

Prostate cancer is the most commonly diagnosed non-skin cancer in men, but early-stage localized prostate cancer is generally very survivable with treatment. There are several treatments for prostate

cancer including surgery (prostate removal), radiation therapy (seed implants or external beam), hormonal therapy (negating or decreasing testosterone levels through androgen deprivation), and active surveillance (carefully monitoring prostate cancer progression). The most common treatment for early prostate cancer in younger, healthy men over the past several decades is surgery (prostatectomy [prostate removal]).

The concern for many men is that prostate cancer treatment is not without side effects, the most common being sexual dysfunction and urinary problems. All medical treatments have positive and negative effects, and prostate cancer treatments are no different. Even active surveillance can have some negative effects because leaving prostate cancer in the body can cause apprehension. For many men, quality of life after prostate cancer treatment is their greatest concern. Unfortunately, the negative effects of prostate cancer treatment can impact quality of life.

Throughout this book you will find quotes from men with prostate cancer and their partners from a study I conducted asking men who were treated for prostate cancer 1-5 years prior to participating in the study to share their lived experiences with sexual dysfunction after prostate cancer treatment. Your experience is unique. You may or may not identify with the perspectives presented. It is important to understand the perspectives of men and their partners. I am completely indebted to the study participants for their personal insights and have infused the new edition of this book with their words.

Here are a few words of wisdom from men and one of the partners:

"I think that we're afraid to talk about our mortality versus the loss of sexuality *and the thing that I've seen with new people coming in is that though some are afraid of dying, they also want to go back to when they were a teenager [in terms of intimacy]. Well that isn't going to happen. And that's what they're most afraid of. But on the other hand, I discovered that there were feelings that I was missing all my life and that it's just different and just as rewarding [intimacy/sex after prostate cancer treatment] … And I've seen men put off treatment or choose the treatment based upon the sexuality of it and not the mortality of it. And so I encourage people to put some of those fears aside and really deal with the cancer from an informed set of circumstances or information instead of being afraid that they're going to lose something. They may lose something, but on the other hand, they're going to retain far more if they're open-minded [about sex and intimacy]. I think they'll learn to compensate in an area with feelings and intimacy that can be almost as rewarding."*

Another man said: ***"You're not really performing at the levels you were or have the drive you had when you were younger because, let's face it, testosterone dissipates*** *(as you get older), all sorts of things knock those drives out. But on the other hand, I still like sex a lot and intimacy and like my partner really a lot so this is a nice time. I don't know if it's the last hurrah or what, but she's been very matter of fact about the difference between something that's going to kill you versus something you can work around. Which makes the whole sexual experience really great. Even if it's different … A lot less penis, a lot more hands and mouth and eyes and ears and nose…"*

Another man said: ***"I was diagnosed not quite 2 years ago.*** *And I waited a few months to have the surgery, and then I had the surgery. Now, that was 15 months ago. So, I've been dealing with it for almost 2 years and will probably have another year at least of it being much more the center of my life than I'd want it to be … I'm probably one of the luckier ones, in terms of my recovery. I regained continence very quickly … And I have been regaining erectile function. I still need medication to have intercourse, but it has been noticeably improving, especially over the last 6 months.*

But it's still very hard, I think, for – it's certainly been hard for me. I can't really speak for other people. It's been very hard for me to let go of what life was like before, you know, like how it used to be. And it's not.

A partner of one of the men said: ***"It got way more intimate [after prostate cancer treatment because of the changes].*** *I think we learned each other's bodies better because then all of a sudden it wasn't just about the intercourse thing. Because the intercourse could happen, but it was totally, completely different, and he had to make extraordinary efforts to have intercourse so then all of a sudden it became about touching, and feeling, and finding different ways to please each other. And it also was a lot of trust, and it was a lot of getting past a lot of issues. And I'm sure as a man he thought, 'Oh, no woman is ever gonna want to perform oral sex on me again because of leaking, and women are weirded out by the whole penis thing anyway so they don't want that near them.' And I was like, 'We're gonna get past it. We're gonna get past it. We're gonna do everything that we used to do. We just have to communicate better now.' So I think it's better. It is definitely better now. We know each other the way I think you should know your partner."*

This book is about information and being informed. In my study, men said the following about the need for information and education on the impact of prostate cancer treatment:

"I was not prepared for what was to follow. *No doctor informed me about what I should experience, what I am going to face with challenges. I think everybody – all the medical staff starting with nursing and support staff and the doctors themselves – they really need to inform the patient with what's going to happen after the surgery with complications and side effects and on the surgical end and the physical end, but also the effects from the surgery should be talked about from the get-go so that patients are not surprised, that they know what's going to be heading their way – give them the full information. I'm very, very emotionally upset about it because if I would have known I think I would have been in a better place through the first year and following that first year if I knew."*

Another man said: ***"I was fully informed by everybody.*** *All the doctors that were involved fully informed me that these were things that I was up against if they removed my prostate. There's a lot of things that are happening to a person in my situation. So definitely – you definitely must keep everybody informed about what's going on. It's extremely important. I think because she [the partner] had all the information, she read the books that I was given, so she knew exactly what I was going through."*

A partner said: ***"I think we didn't have enough information in the beginning.*** *We had it afterwards, so we didn't know what we were getting into. All we knew was that I wanted him to live and I just wanted the cancer out. And then after that, I mean, we*

didn't know. The group [prostate cancer support group] that he went to is wonderful. And I think if there's any kind of cancer or anything, that's what I would seek first. To have more information … I think that would kind of get him ready or it could make him not want to get the surgery, I don't know. But we did this with closed eyes and that hurt him a lot."

Erectile Dysfunction

Erectile dysfunction (ED) is the most common problem after removal of the prostate (surgery), radiation therapy, and androgen deprivation therapy. The National Institutes of Health (NIH) defines ED as the "inability to attain and/or maintain a penile erection sufficient for satisfactory sexual performance" (NIH Consensus Development Panel on Impotence, 1993) and this definition was subsequently accepted by the World Health Organization and the International Consultation on Urologic Disease (Jardin et al., 2000).

Men experiencing ED after prostate treatment have trouble getting and/or keeping erections hard enough for penetrative types of sexual activity. ED can be caused by any disease process that impacts nervous conduction and/or blood flow such as diabetes, high blood pressure, heart disease, high cholesterol, obesity, head/neck/back disorders, or stroke (to name a few). ED can also be caused by surgery or radiation that impacts nervous conduction or blood flow necessary for erections.

Prevalence of ED in men after prostatectomy has been explored in many studies and has been reported to be as high as 78%-87% over 2-15 years after treatment in large population-based cohort studies (Penson et al., 2008; Resnick et al., 2013). In a multicenter study, ED

in men who underwent radiation therapy post treatment was also prevalent (ranging from 61%-94% at 2-15 years after treatment) (Resnick et al., 2013). Erectile dysfunction usually has a negative impact on quality of life or life satisfaction (Potosky et al., 2004). Sexual function remains important to many men, who often continue to be interested in sex in the later decades of life (Frankel et al., 1998; Mulligan & Moss, 1991). In light of the high survival rates associated with prostate cancer, issues impacting quality of life, such as ED, need to be addressed and treated in those men who are upset by their inability to get and keep erections.

One man described the challenges of ED in the following way:

> ***"If you have a lack of sensation, you don't have any nocturnal erections.*** *You don't wake up with an erection and I miss that. I miss it a lot. I miss the sensations of how I used to feel down there, how my body used to feel ... I don't feel whole and I think about it every single day … It's the first thing I think about in the morning when I wake up and it's the last thing I think about at night. I miss it. I wish I could have it back."*

Normal Erections

Men get erections every single day. The penis is erect approximately 3 out of every 24 hours, primarily during deep rapid eye movement (REM) sleep at night. A man experiences approximately 4-6 erections every night. When a man thinks sexual thoughts or his penis is stimulated or both, that information is synthesized in the frontal lobe of the brain. The message travels down the spine to the peripheral nerves. The peripheral nerves wrap around the prostate and go to the penis. In the penis, nerve impulses activate chemicals which tell the

blood vessels to dilate. The penis becomes engorged with blood, making it erect.

Every night a man's penis gets a workout with the smooth muscles around the blood vessels expanding and contracting to let more blood in the penis when it is erect and allowing less blood in the penis when it is flaccid. This is like pushups for the penis! Muscles around the penis literally get a workout from relaxation and contraction around the blood vessels. The increased blood flow associated with nighttime erections helps keep penis tissue healthy and normal. After prostate removal or radiation of the prostate, the nerves for erections are traumatized and do not conduct properly. Sometimes it is necessary to remove these nerves during surgery. This happens when the cancer has grown close to where the nerves lie on the back of the prostate. If the nerves are removed, they cannot conduct impulses. Not only can conduction be compromised from dissection of these nerves away from the prostate or radiation of the nerves, but the chemicals in the penis that tell the muscles to dilate may also be diminished. The cavernosal nerve is a source of synthesis for nitric oxide, which is one of the most important chemicals in the penis that helps blood vessels dilate (Carrier et al., 1995). This lack of nerve conduction can lead to less blood flow to the penis in terms of penile engorgement and can change the structure of the penis and lead to diminished muscle function.

Discovery and Learning

It is important to understand some things about research. Research is about discovery and learning new information about people and the treatments they are undergoing. There is a great deal of research presented in this book and references that correspond with that research. The research presented here provides some information

about penile rehabilitation. The goal of penile rehabilitation is to preserve maximum erectile function and length, and increase blood flow, which is important to proper function of the smooth muscles of the penis.

Not all research is equally relevant. The best information gleaned from research comes from the highest levels of scientific study. These studies are typically placebo controlled (treatment is compared to a similar looking but fake treatment), randomized (participants are randomly assigned to the treatment or placebo portions of the study), and blinded (participants do not know if they are receiving the treatment or not). Outcomes of studies are stronger if the researchers can compare a newer treatment to something that looks the same, but is not the real treatment (a placebo). Even when researchers conduct a randomized, blinded, placebo-controlled trial, the design may have flaws; therefore, it is important to examine the study carefully to understand the value of the information discovered. Randomized, blinded, placebo-controlled studies are expensive, and they are not always feasible. Sometimes scientists compare different types of treatments to each other, which can also be helpful. It is not always possible to have a comparative or placebo treatment because it would not be ethical for a scientist to withhold a treatment proven to be effective from patients in a control group. One example of a treatment that can't be studied in a placebo-controlled blinded study is the vacuum device. It would be impossible to use a placebo device because the real device would be readily apparent and have working suction.

Another important factor to think about when reviewing the strength of a study is the size of the sample (number of participants). Larger numbers of participants and a wide variety of participants from

various places (rather than one institution) also strengthen the findings of a study. Penile rehabilitation research with medications and vacuum devices is newer and more research needs to be done. Some of the studies did not use comparative groups and are relatively small in sample size. Although it is valuable and important to do studies of all sizes in all settings, it is always important to keep the findings in context.

Physician or institution-reported outcomes are not always actual research and are subject to that particular provider's/institution's definitions and views of ED. The best information is *patient-reported*, which means it was gathered from men with prostate cancer themselves and their partners through a formal research study.

Many references are provided in this book to give you resources to learn more about the studies. In fact, you may even find some newer research about ED treatment and penile rehabilitation that has emerged since this book was published. There is still much research to be done in the area of sexual dysfunction after prostate cancer treatment. However, new research shows that medical treatments for ED may have promise in terms of preserving maximal penile erection function after prostate cancer treatment. It is my hope this book will provide the knowledge and inspiration needed for you to reclaim sex and intimacy after prostate cancer.

Chapter 2

Prostatectomy, Radiation Therapy, and Androgen-Deprivation Therapy

One question asked frequently in terms of prostate cancer is whether it is necessary to treat every prostate cancer. Some prostate cancers are aggressive and will grow quickly, while others are indolent (slow to develop) and grow very slowly. Slow-growing prostate cancers may not require treatment, but rather *active surveillance* to monitor progression carefully. Active surveillance has been used for many years around the world, but in the past decade acceptance by the medical community in the United States is improving. Active surveillance is now widely viewed as an appropriate option for low-risk prostate cancer. As diagnostic and monitoring techniques, such as genetic testing and enhanced imaging are available, determining lower-risk prostate cancer becomes better differentiated. This newer testing should increase the opportunity for more men to have access to the option of active surveillance treatment. A man can live a full, productive life with prostate cancer and it may not lead to major problems. However, not every man is comfortable with watching, rather than treating, his prostate cancer. The risk with not treating prostate cancer is that it may spread outside the prostate, making it more difficult to treat. Yet, as experts determine better ways to monitor prostate cancer, some men may feel more comfortable actively monitoring prostate cancer rather than treating it.

Surgery

Removal of the prostate (prostatectomy) is typically done as a primary therapy with a goal of getting rid of the cancer completely. Despite

the availability of treatments of similar effectiveness with fewer side effects, removal of the prostate continues to be the treatment option for prostate cancer against which all other treatment options are measured (Zippe et al., 2001). The reason is surgery has been done longer than any other treatment, and, therefore, we know more about it than any other treatment. This does not mean surgery is the best choice for you, but it means we know a lot about this option because it has been performed for many years.

In an effort to preserve erectile function after prostatectomy, nerve-sparing techniques have been developed to save the nerves involved in erectile function (Walsh & Mostwin, 1984). Nerves run along the back side of the prostate and must be dissected off it in order to remove the prostate. Despite advanced techniques in nerve sparing, erectile dysfunction (ED) remains a problem for the majority of men following radical prostatectomy (Penson et al., 2005; Resnick et al., 2013). Researchers continue to seek better techniques to improve erectile function after radical prostatectomy and to minimize damage to the nerves responsible for erections.

The most predominant technique of recent years to minimize surgical complications of prostate removal is robotic radical prostatectomy. Robotic-assisted prostatectomy employs minimally invasive surgical techniques using a laparoscope (a long tube that provides magnified visualization and access through which to perform procedures) and approximately five to six small ports of entry to remove the prostate rather than the traditional open method of prostatectomy (El-Hakim & Tweari, 2004). The surgeon sits at a command console and uses hand controls that allow each of his movements to be translated into movements with the robotic instruments within the body while simultaneously filtering tremors, scaling movement to size, and

providing full range of motion through the instruments within the body. Cameras in the laparoscope provide a three-dimensional magnified image for the surgeon. While robotic prostatectomy may reduce blood loss, length of hospitalization, and other surgical complications, recent studies have shown that it does not reduce the incidence of treatment-related side effects such as ED.

Despite the newer techniques of robotic prostatectomy, ED continues to be the most common negative long-term outcome after robotic radical prostatectomy. Rates are comparable for robotic and open radical prostatectomy in a nationwide random sample of Medicare-aged men with 89% of men after open prostatectomy and 87.5% of men after robot-assisted radical prostatectomy reporting sexual function as a moderate or big problem at a median of 14 months post surgery (Barry, Gallagher, Skinner, & Fowler, 2012). The majority of men report problems with erection immediately following the procedure and some do not regain the function they had preoperatively. Regardless of the type of prostate removal you have undergone, it takes an average of 2 years for nerves to recover after surgery. The nerves may recover sooner, but the average is 2 years, so don't get discouraged if your erection is returning slowly.

Radiation

Radiation therapy is another common treatment for prostate cancer. Although radiation is directed toward the prostate with external beam radiation, or from within the prostate with brachytherapy (seed implants), the nerves for erections which run along the posterior side of the prostate can be traumatized and damaged from radiation exposure. The quest continues to improve delivery of radiation to the prostate in the most precise manner to minimize exposure to the nerves responsible for erections, but, currently, ED is the most

common long-term side effect from radiation therapy. The full impact of radiation on the penis is usually not completely determined until about 12 or more months after treatment. The negative effects on erections worsen over time as changes continue to take place within the body after radiation therapy. Diminished erectile function occurs slowly over time after radiation therapy is complete.

Androgen Deprivation

Androgen deprivation therapy may be used in combination with other treatments or alone. The goal of androgen deprivation therapy is to suppress testosterone levels and thereby decrease prostate cancer growth. The main sexual side effects of this treatment are decreased sex drive and ED. A decreased sex drive may also diminish motivation for dealing with the added burden of ED treatments needed for sexual relations.

Men in our study said the following about prostate cancer treatment:

> *"**Uh, we're alive, ok?** I was Gleason 7. My statistical life expectancy would be about 12 years, you know, that's average. Could be less, could be more. If I did not get treatment. My mentality was – and still is – I got it out, out of my body. I don't want to be messing with the cancer the rest of my life. I realized that there was a risk of both incontinence and impotence."*
>
> *Another man said: **"I think back.** Maybe I shouldn't have done it. And go with the shorter quality of life rather than a long life – a longer life with the situation."*
>
> *One partner said: **"Because he would always say,** 'Maybe I shouldn't have done that (the radical prostatectomy surgery)."*

And I'm like, 'You did it, so let's live on and not live in the past.' It got better, yeah. He felt like he was just – didn't want to live because it was – he didn't feel like a man. He felt like, oh, God, this is a mess."

Another man who had undergone surgery said: ***"I guess we had an excellent surgeon*** *and urologists who prepared us for a lot of it ... especially in my situation because after they removed the prostate, even though they spared the nerves, they informed me that the cancer was a very aggressive form of cancer. And after they took out the prostate, I also went through radiation treatment and hormone treatment at the same time. But I think because I had the triple whammy surgery and the hormone and the radiation, it knocked me back a lot. All the doctors were very encouraging. But a lot of times I wasn't feeling 100%. Because of the effects of especially the radiation. And now that's over. It's been the last month and a half to 2 months that I'm starting to feel more and more normal. I think possibly eventually, I may be able to get a natural erection. That's what I'm hoping for."*

Chapter 3
Orgasms: Sex without Erections

This may seem like a very strange topic and even may appear to be an oxymoron, but it is not. If you have not discovered it yet, most men *can* have a climax/orgasm without an erection. Orgasms are likely to be different in feeling and in quality following prostate cancer treatment.

Erections are wired separately through the nervous system from the ability to climax. The majority of men still experience a climax/orgasm sensation after prostate cancer treatment, especially with nerve-sparing techniques. You will likely not ejaculate during climax after prostate cancer treatment because the prostate and nearby glands play a crucial role in ejaculation. Some men say the orgasm is similar to the ones they had prior to surgery (even without the fluid ejaculate). Other men say the orgasms are not as intense and feel less enjoyable, but they still climax. A small percentage of men are unable to climax following prostate cancer treatment. Surprisingly, a small percentage of men report that orgasms are better after prostate removal or treatment. The large majority of men continue to enjoy orgasms after prostate cancer treatment. Some men report a degree of pain with orgasms in the first month or two after surgery, but this typically does not persist and most men eventually will enjoy orgasms after prostate cancer treatment. If you continue to have pain with climax, it is important to let your healthcare provider know because this problem may be resolved with medications.

Participants in my study said the following about orgasm/climax after prostate cancer treatment:

One of the men in my study who had more intense climax said: ***"I do not have any recall of having an orgasm like I have now.*** *And honest to God there has to be – I mean sometimes I go into mini convulsions because the orgasm lasts and it's so strong and lasts for probably 2 minutes."*

*Another man described the change in climax this way: "…****As far as the, I want to say simulated ejaculation feeling,*** *it's different, but it's enjoyable."*

*Another man said: "****The thing that surprised me was no longer having any fluids coming out*** *and no longer that ejaculate hit that was so intense for me (with orgasm). As I begin to discover that there was feelings that had probably been there the whole time but I never knew that they were there. So, learning to recognize and appreciate and enjoy some of the other feelings and things that were coming on (with orgasm). I won't say it more than made up for it… But here's the thing, there is dead in the bed or dead in the ground."*

A partner shared the following about the change in orgasm: ***"He had a little problem getting used to the idea*** *that there was no ejaculation fluid. It's like, okay, there's not but he still could come to climax. It's different but it's good, that's what he says."*

The majority of women climax from clitoral stimulation, so the good news is that if you are partnered with a female, she can climax with or without your erection. Women typically take four times longer than men to reach climax, so foreplay must focus on stimulation that is most pleasing to a female partner. After prostate cancer treatment with surgery or radiation, men can also orgasm without an erection. Both men and women can have pleasure and orgasm, even without erections. If reproduction is not the goal of sex, the goals of sex become about connectedness, pleasure, and orgasms. Each of these goals is achievable with or without an erection. Intimacy and sex are supposed to be fun and enjoyable.

Some couples choose to enjoy non-penetrative sex such as manual or oral stimulation. Mutual masturbation can be enjoyable or you can stimulate each other through a variety of other ways. The important thing is to discover what each of you enjoys and explore all options for stimulation, cuddling, and climaxing together. Some couples may even choose not to be sexual together and, if both agree that this is acceptable, this is a perfectly valid choice. Men and women can climax from many types of stimulation, so determine what you and your partner are most comfortable with and explore those options.

Sometimes when men or women have trouble climaxing, vibratory stimulation can make a difference. Vibration of the genitals may lead to better erections and/or ability to climax. A medical vibrator for the penis, called Viberect®, is available (see Figures 1-3 & 2-3). The limited published studies using vibration for improved ability to climax have been mostly done with patients with spinal injuries (Castle et al., 2014; Chong et al., 2017). Some men having trouble reaching climax and/or erections may find vibration helpful. Other non-medical vibrators are available for both men and women. The

Figures 1-3 & 2-3.
Vibertect X3®

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Viberect is a powerful medical-grade vibrator with a variety of settings designed specifically for the penis. Although most women climax from clitoral stimulation and men from penile stimulation, vibratory stimulation may also be enjoyable in other areas of the body such as below the scrotum in men or around the rectum in men and women. Sample and explore the options together.

Some couples do not communicate about sex, and this can be a big problem when either of them worry about the other person's expectations, needs, or feelings, but don't clarify or talk about those issues. Some men and women stop being affectionate because they are afraid the other person might feel uncomfortable with anything that may lead to sex or intimacy. Physical affection can be very important in terms of intimacy and closeness, and there is no reason to stop kissing, holding hands, embracing, and touching each other. This physical affection can make your partner feel he or she is still attractive and can be very important in terms of self-esteem, image, and confidence. Talking about being affectionate and the fact affection is not necessarily an indication of the need for sex can relieve anxiety and stress. Sex is different after prostate cancer and communication can be key in helping with this important change. Don't let your affection for your partner suffer because of lack of communication or misconceptions.

Participants from my study shared the following information about intimacy after prostate cancer treatment:

"I was fortunate to find this woman [I am with] and it [intimacy] just enhances every single aspect, *whatever, if you're going to a social event, you're going on a vacation, you are just being intimate around the house, you're sharing thoughts and dreams. It [intimacy] just encompasses what life is all about. Some people don't care about it [intimacy], but for the men that do, it [sexual dysfunction] is devastating."*

Another man said: ***"I miss the holding of hands****. I miss hugging and things like that. That's not sex in the definition of this survey. But that's what is available to me in my current physical condition … and so, yes, it's important. Is intercourse important? I've had wonderful sexual experiences and not always intercourse. So I don't need to have an orgasm. If I can bring my partner to an orgasm and she enjoys it, that's a turn on to me."*

One partner shared: ***"I think the other part is just the intimacy and the closeness.*** *We've always been very close that way and touchy-feely, and all that. And as far as just the act of sex itself, my experience has been nothing but great. I mean I'm more worried for him. And I feel we have a great relationship, and we can talk to each other, you know, like, 'Okay, is this good? What can I do for you?' which was very important, but we were like that before. And I think that's what you need to be when you care for somebody."*

Another partner said: ***"Anything I could tell anybody going through this is like,*** *'If you guys are not intimate, and able to talk*

with each other now, you better get that straight before the surgery. Better get it straight because you're going to need each other, and you're going to need the intimacy more than you've ever had it. It's ongoing, but you know what? You've got to stay connected as a couple. You'll get through it, and just make sure you love somebody because it's going to be a journey, but it's worth it."

Orgasm and Urine Leakage

You may leak urine during sexual activity, particularly with orgasms. This is not uncommon, even if you never leak urine any other time. Leakage is not unusual and not problematic because urine is sterile and not harmful. If urinary leakage bothers you or your partner, consider wearing a condom to prevent transfer of urine. The UroStop™ constriction device is a tension loop tightened and worn during sex. It is designed to stop the leak of urine during sex. This is unnecessary from a hygienic point of view, but some men and women may prefer this approach. Sometimes it can be helpful to empty the bladder immediately before sex. This may decrease urine leakage with orgasm. Leakage of urine during sexual activity may decrease over time, but if this problem persists, consult your urology healthcare provider for advice.

Chapter 4
Penile Shrinkage

Some men have described shrinkage of their penis after radical prostatectomy. You may or may not have noticed shrinkage of the flaccid penis after prostate removal. Penile shrinkage has been documented in several studies (Kohler et al., 2007; Raina et al., 2006).

Penile shrinkage may be related to several factors. Unchallenged muscle tone within the penis after removal of the prostate may cause some shrinkage. The penis is primarily a muscle and those muscles can shrink. When your penis is full of blood, the smooth muscles around the penis are relaxed; when your penis goes back to the soft/flaccid state, the muscles are contracted around the blood vessels. So if the muscles that surround the blood vessels are no longer contracting and relaxing with nighttime erections, the muscles of the penis are no longer getting a workout, muscle mass can diminish, and the penis can shrink. The flaccid penis seems to disappear up into the body. This diminished flaccid penis size can be upsetting for some men.

The vacuum device may be of benefit for stretching the tissue of the penis and filling the penis with blood. Men who used the vacuum device daily for a minimum of 10 minutes had less penile shrinkage and reported better erections. Maintaining flaccid penile length may occur with regular daily use of the vacuum device (Kohler et al., 2007). This will be discussed in detail in Chapter 6. Some anecdotal reports from men have reported success in reducing or reversing

shrinkage through the use of a penile stretching/traction device, but there is currently no research to support the use of these devices.

One man described the shrinkage this way:

> ***"Well, I'm hopeful now as of today, more so than I was when I walked in here.*** *But I'm hopeful. Since surgery, self-examination (of the penis) was pretty damn discouraging. The shrinkage … I get fat down there and it's disappearing and it ain't working anyway. I never had problems before … It's been rough. I try to stay out of my mind. We all got these preconceived ideas about manhood as it relates to sex, performance-based ideas. I have to use a vacuum pump. I'm taking it day by day, man. I feel that stress if I constantly meditate on it, but I don't meditate on it. Like I said, I'm grateful that I can use the device even though I don't like the device. My doctor has given me Cialis to go along with that and that helps. And we can have intercourse with that device. I haven't attempted it [intercourse] without it because I don't feel like I'm hard enough to penetrate."*

Chapter 5

Overview of Treatment of Erectile Dysfunction and Penile Rehabilitation after Prostate Treatment

The goal of erectile dysfunction (ED) treatment after prostate treatment is an erection sufficient for sexual relations. Although you may come across some incredible claims about treatments with herbal remedies, in general these medications do not work as well as the U.S. Food and Drug Administration-approved treatments discussed in this book. Some herbal treatments such as red ginseng and L-arginine have had limited research showing a degree of efficacy. The problem is most herbs for ED generally do not work as well as other treatments discussed here and there is no evidence related to long-term usage. If a purported treatment is as safe and effective as the current approved treatments, it should undergo the same rigorous research testing as the current approved options. Some men have spent a lot of money on these herbal treatments, which are not recommended by most experts in the field of sexual dysfunction.

There are four well-established medical treatment options for ED and each option has also been utilized for penile rehabilitation in men after prostatectomy. Initial research for each treatment option shows promise for helping to preserve erectile function. The goal of penile rehabilitation after prostate cancer treatment is to maximize erectile function recovery through the use of available medications and

devices for treating ED. In terms of penile rehabilitation, the goal is to preserve pre-treatment erectile function by promoting blood flow and oxygenation to the penis during the period of neuropraxia (erectile nerve dysfunction).

The first options are noninvasive and involve venous occlusive devices to keep blood in the penis during intercourse. They include the venous constriction device Maintain® and vacuum constriction devices. The second option includes oral phosphodiesterase type 5 (PDE-5) inhibitors such as Viagra® (sildenefil), Levitra®, Staxyn® (vardenafil), Cialis® (tadalafil), and Stendra® (avanafil). The third option is the urethral suppository MUSE® (alprostadil). The fourth option is penile injection. The final option for treating ED (not for penile rehabilitation) is the surgical penile implant.

The Best Treatment for You

The ultimate question is how to determine which treatment is best for you and what treatment will provide the best erectile function recovery. There is currently insufficient research available to provide clear guidance; therefore, treatment selection is driven by your preference. Each treatment must be evaluated and understood so you can make an educated and informed decision. Each treatment has advantages and disadvantages. The pros and cons are presented in Table 1-5. Each treatment is described in detail in the following chapters.

Table 1-5.
Advantages and Disadvantages of ED Treatments

Treatment	Pros	Cons
Oral PDE-5 Inhibitors (pills)	Quick and easy to administer Discreet Suitable for travel	May have poor efficacy in the early stages after prostatectomy Side effects possible (headache, nasal congestion, flushing, stomach upset, muscle aches) Costly
Venous Constriction Devices (Maintain® and vacuum constriction device)	Noninvasive High efficacy rates Fairly quick and easy after "mastered" Suitable for travel May be incorporated into foreplay One-time cost	Cumbersome and awkward Messy Time consuming Penis may feel cool to touch and appear pink/purple Penis is wobbly at the base Challenges and comfort of wearing tension rings during sex May have side effects of bruising, pain, or discomfort
Intraurethral Suppository (MUSE)	Simple to use Less invasive than injections	Doesn't work in majority of men Side effects may occur (pain, burning, hypotension, increased heart rate, dizziness, and lightheadedness) Some patients uncomfortable with putting medication in urethra Expensive
Penile Injections	High efficacy rates Reliable treatment No tension ring needed Erection usually lasts about 60 minutes	Invasiveness: Need to inject the penis each time for erections Side effects possible (pain, bruising, bleeding, priapism, and Peyronie's disease) Need to refrigerate some medications Comfort level with self-injecting and hassle of doing this procedure FDA-approved injections costly, but may be covered by insurance; trimix and bimix are much less expensive Some injectables must be refrigerated making travel challenging
Penile Implant	High efficacy rate High satisfaction rates No travel issues	Permanent: Your penis will never be the same again and even if the device is removed, you may not respond to other treatments any longer Side effects (pain, infection, mechanical failure, and erosion of the device through the skin) Surgically invasive procedure Surgery is expensive

Here is what some study participants said about treatment of ED:

*"**If you're in a relationship with any significant other,** I urge you to always communicate with them to set their expectations and seek their support. And then talk to your doctor to figure out which one of these solutions is best for you. Don't be afraid like I was – I was desperate – but don't be afraid to try everything you can. In my case, I've used Viagra and Cialis, as well…"*

*Another man said: **"The pills don't really do anything so we've concentrated on using the pump.** And the doctors talked about injections and I mean the whole needle thing is kind of, you know, I think it freaks anyone out, but as the doctor said, it hurts more in your head than it hurts in your pants. But we still haven't tried that, the injections. So, other than having to plan your evening, the pump is working out for us."*

*Another man said: **"Injections have been pretty good.** Cialis is good for monitoring, because I can see things improving. Without injections, I'm getting better and better, but it's not nearly enough for penetration. You know what I mean? It gets more feeling, thicker, and longer extending, but it's still, they're still soft [with using Cialis]."*

*A partner said: **"I would say it's been a very good experience, a positive experience,** but also [name of the man with prostate cancer] is the type of person where he follows everything to a tee … So he did everything – the pills, the pump. He tried Viagra and all that stuff, and we just found what works. And slowly but surely, everything pretty much came back to life, and we're fortunate that way."*

It is important to keep in mind that different men have different motivation levels in terms of sexual function and that motivational levels may also change over time. Your motivation for sex and intimacy is probably different than some other men. In one study, as many as half of patients (650 men) with ED after prostate cancer treatment reported indifference about ED, yet use of at least one erection treatment aid was an independent determinant of more favorable sexual health related quality of life (Miller et al., 2006). Therefore, treating ED may improve life satisfaction for some men.

Even though not everybody is concerned with sexual function, research continues to show that regular improved blood flow to the penis through medical treatments such as oral medication, vacuum device, intraurethral suppository, and/or penile injection may improve erectile function. Without regular blood flow to the penis, the penis may shrink and damage may occur to the penile tissue, further jeopardizing erectile function. Getting blood into the penis on a regular basis is important after prostate cancer treatment.

Chapter 6
Constriction Devices

Noninvasive options are used on the penis itself to provide erections sufficient for intercourse. Men have been putting tight bands and rings around their penis for many decades to help keep it hard during intercourse. There are many different tension loops and rings designed to help hold the blood in the penis advertised on the Internet and available in stores. The important safety feature that needs to be present on any ring or band is a mechanism to remove or release the tension after sex. Some of the hard rings without a release may actually get stuck on the penis, trapping the blood in the penis. No ring or band should be worn for longer than 30 minutes. It is essential to be able to release or stretch the band or ring to remove it from around the penis.

One such constriction device is Maintain® (see Figure 1-6) which consists of an adjustable elastic loop that is placed and tightened around the base of the penis. This adjustable band is used to maintain blood within the penis during sexual relations and should not be worn for more than 30 minutes at a time. The Maintain adjustable constriction loop and similar tension rings or loops are most helpful for men who get, but cannot keep, an erection since it will not make the penis much harder, but rather is designed to decrease blood flow back into the body by trapping the blood inside the erect penis. Advantages to the Maintain band are that it is completely noninvasive and simple to use. The Maintain constriction loop costs under $30 and is compact for travel. The disadvantages are that the tension band

Figure 1-6.
Maintain® Adjustable Constriction Loop

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must be worn during sexual relations to maintain the erection and it may be uncomfortable as the elastic can catch or pull on pubic hair.

The vacuum constriction device is the second most commonly used treatment for erectile dysfunction (ED). The vacuum constriction device (see Figures 2-6 to 4-6) consists of a pump attached to a plastic airtight cylinder and a tension/constriction ring to maintain the erection. To use the device, the penis is placed into the open end of the cylinder that already has a previously applied tension ring at the edge of the open end of the cylinder. The pump is on the opposite end and when the device is placed against the body with the penis inside, suction occurs from the negative pressure and blood is pulled

Figure 2-6.
Pos-T-Vac® Manual Vacuum Therapy System

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Figure 3-6.
Pos-T-Vac® Battery-Operated Vacuum Therapy System

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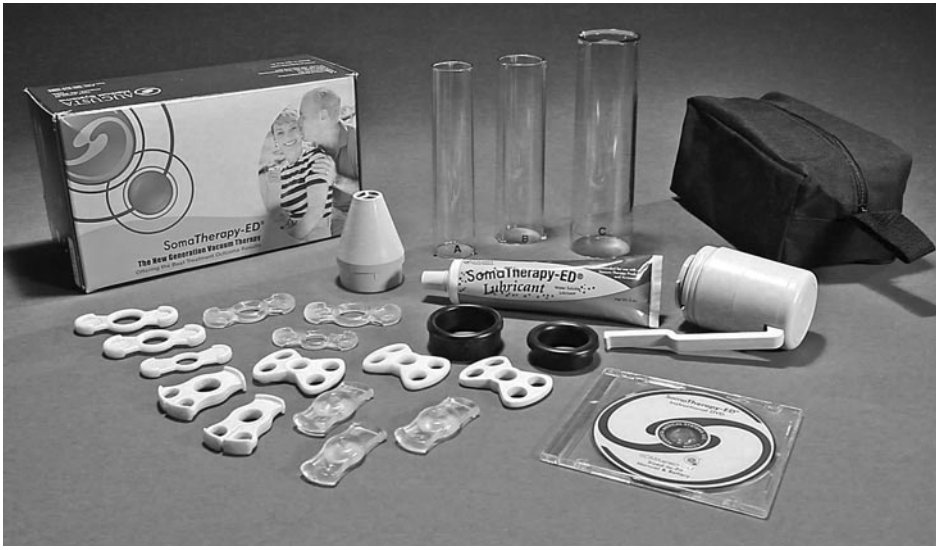
Figure 4-6.
SomaTherapy – ED®



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into the penis. The tension ring is applied to maintain the erection during sex. The vacuum device works for most men if they are trained properly on its use. Efficacy of the vacuum constriction device, in terms of creating an erection sufficient for intercourse, has been reported to be as high as 87%-92%, regardless of the reason for the ED (Turner et al., 1991; Witherington, 1989). Long-term results of the device ranges from 50%-64% after 2 years (Cookson & Nadig, 1993). Success with the vacuum device is dependent on proper training since it can be tricky to apply and use. There are some very important tips for using the device which are outlined at the end of this chapter.

Advantages of the vacuum device identified by patients in one study were that it was reliable, noninvasive, fairly quick and easy to use after practice, suitable for travel, and could add to the sexual experience if the couple is amiable to introducing the vacuum device into foreplay (Soderdahl, Thrasher, & Hansberry, 1997). In my clinical practice, with over 1,000 men using the vacuum device, I can assure you it works. If used carefully, side effects are minimal, and this is what men like about this treatment. In addition, a medical-grade device can be purchased for about $100-$350 and then used as much as desired without incurring ongoing costs (except to replace the rings or device as needed).

Disadvantages identified by patients include: bulky, messy with the water-soluble gel, time consuming, penis has a cool feeling to touch and was "hinged" or wobbly at the base, and that it detracted from the romance of the sexual experience (Soderdahl et al., 1997). In my practice, patients often express displeasure with the quality of an erection that feels unnatural and having to wear the tension ring during sex. The vacuum device is only used with great caution and careful consideration (if at all) for men with a history of priapism (persistent abnormal erection), sickle cell anemia, or certain bleeding disorders. In a comparison study with penile injections, both therapies were effective, but the dropout rates were much higher for penile injections versus vacuum devices (60% vs. 20%) (Turner et al., 1992). In men who failed to respond to intracavernosal injection therapy, 71% attained adequate rigid erections with the vacuum device (Gould, Switters, Broberick, & deVereWhite, 1992).

The vacuum device costs approximately $100-$550 and is not covered by most insurance providers. A medical-grade vacuum device such as the Pos-T-Vac® can be purchased without a

prescription from www.walgreens.com or www.amazon.com for about $100-$120. The vacuum device requires one-on-one training with an expert provider and men need to utilize the treatment daily in the beginning to master it. The vacuum device is in no way discreet, and this may be an important factor for men who are not in a committed, understanding relationship.

The vacuum constriction device can also be used in conjunction with oral agents (PDE-5 inhibitors), which have been shown to in-crease efficacy and satisfaction (Chen, Sofer, Kaver, Matzkin, & Greenstein, 2004). Remember, the stronger the erection when put into the vacuum device, the easier it will be to get the penis to fill with blood and become hard enough for penetration. Oral medications may create a fairly natural partial erection that can be put into the pump and brought to a complete erection. This is especially important for penile rehabilitation since the goal is to get as much oxygen-rich arterial blood into the penis as possible.

Here is what some men say about the vacuum device:

> ***"I have to use a vacuum pump.*** *That seems so mechanical, so to speak … And we can have intercourse with that device. I'm not trying to deny it, but I'm here, man. That's it. It's not an easy thing, but my partner, who's also a cancer survivor, she's been supportive with me. And hey man, I'm just taking it day by day."*
>
> *Another man said:* ***"I can't have an erection right now without the vacuum pump*** *… So having the pump will allow me to have something like an erection and that's the way I kind of do it now."*

*Another man said: **"I invested in the vacuum device, in early summer,** and I tried to use that on a somewhat regular basis, to try to restimulate that feeling of having an erection, and trying to figure out what size (tension ring) works for me, and this and that, but still very frustrated that I haven't made that connect to get my own erection on its own, and my wife and I have attempted intercourse … Once, rather successful, with using the vacuum device, not on its own."*

Penile Rehabilitation with the Vacuum Constriction Device

Some studies offer promising results for using the vacuum device for penile rehabilitation. Regular use of the vacuum device may improve return of spontaneous erections after prostate cancer treatment and may minimize penile shrinkage (Kohler et al., 2007; Raina et al., 2006). The combination of an oral agent and the vacuum device resulted in 30% of post-prostatectomy men reporting return of spontaneous erections and reports of improved satisfaction over therapy with either sildenafil or the vacuum device alone (Raina, Agarwal, Allamaneni, Lakin, & Zippe, 2005). A retrospective chart review found that using PDE-5 inhibitors along with the vacuum erection device provided the best results for penile rehabilitation after bilateral nerve-sparing robotic-assisted radical prostatectomy across all groups of men with preoperative Sexual Health Inventory for Men (SHIM) scores ranging from 8-25, with the men who started with a normal SHIM (22-25) reporting the best recovery (Basal, Wambi, Acikel, Gupta, & Badani, 2013).

It is unclear exactly how much and how often the vacuum device should be used. In studies, the device was used for approximately 10-20 minutes a day, pumping up the penis about 5-6 times, allowing it

to sit inside the vacuum device full of blood for a few minutes, then releasing the suction and starting over. No tension rings were applied to the penis during daily rehabilitation, but the penis was filled with blood and kept erect inside the device for a few minutes at a time.

These studies had a relatively small number of participants and further research is needed to determine the role of the vacuum device for penile rehabilitation. Although research is limited and ongoing, use of the vacuum device in combination with oral agents for penile rehabilitation appears promising.

Arterial blood is crucial to bringing oxygenated blood to the tissue of the penis. That is why it is important to get as much arterial blood into the penis prior to putting it into the vacuum pump, since the device will pull both arterial and venous blood into the penis. Remember, the ring is not used during daily penile rehabilitation. When used in conjunction with the vacuum device, oral agents must be taken at least 1 hour prior to using the vacuum device. The penis should be stimulated to bring as much oxygen-rich blood into the penis as possible prior to placing it in the vacuum device.

Keys to Success with the Vacuum Device

- Carefully read and follow the manufacturer's instructions for using your particular device as devices may vary.
- Shave or trim the hair around the penis so you get a good suction seal and hair does not catch in device.
- Always try and get your penis as full or hard as you can before placing it in the device.
- Lubricate penis and device.
- Gravity is helpful; if possible stand or be in an upright position when working with the vacuum device.
- Make sure only the penis is placed in the device. The testicles and scrotum should be pulled free of the device at the start and when readjusting with suction releases.
- Pump 1-3 times and stop. Let the penis fill with blood for a few seconds and then pump a few times and stop. Do not rush; give about 4-5 counts between every 1-3 pumps. Repeat this process until the penis is uniformly full. Do not over-pump. You will feel pressure, but the process should not be painful. If you feel pain or the penis is not filling uniformly, or other tissue is pulling into the device, hit the release button and pull the penis free of the device (this is a suction release and may need to be repeated multiple times). Put the penis back in the device immediately and start over. You can also try a partial release by momentarily pressing the release button, but sometimes this may not work as well. You may need to do multiple releases (20-40 releases) to get the penis to fill properly and evenly all the way down into the head and throughout the shaft to a full erection without pain (every time it hurts, you should release the suction).
- Again, if the penis is getting too thick at the base and the blood is not flowing up to the head of the penis, press the release button and pull the penis free of the device to completely break the suction. Immediately put the penis back inside the device and start pumping

again. You can also try a partial release as noted previously. Multiple partial or full releases may be needed to create an even, uniform erection that lifts off the bottom of the cylinder.

- If you continue to have trouble with extra tissue (skin) pulling into the pump around the base of the penis, you may need an insert for the opening of the vacuum device to keep the extra tissue from drawing into it. There are a variety of inserts available; contact the device manufacturer for assistance. Some devices may have special rings that cover the end of the device with a hole in the middle to insert the penis. These rings may help keep other tissue from pulling into the device. It is important to work with trained professionals to help you obtain optimal erectile function from the vacuum constriction device.
- Take your time with the vacuum device. Do not use the tension rings until you have mastered pumping the penis up uniformly to a full erection without pain.
- Test the various tension rings to see which one will hold the erection best during sex. Preload the ring on the device before putting your penis in the device. When you have achieved a full erection inside the device, hold the device steady against your body with one hand (maintaining suction), while creating a "V" with two fingers to push the ring off the device onto your erection. Do not break the suction seal prior to the ring going on your penis or the penis will not be hard enough for penetration. Never wear the ring longer than 30 minutes.
- If practicing or using the device for penile rehabilitation, do not use the rings! Rehabilitation is about blood flow and muscle movement around the blood vessels and rings are about trapping blood, so you can get your penis out of the device and use it for penetrative sex. Only use the rings when you are trying to have penetrative sex. Carefully pump the penis to full as noted previously, letting it sit in the device erect for 1-3 minutes, and then releasing the suction. Repeat the process, doing about five full erections total (holding each within the device 1-3 minutes) for 10-20 minutes a day.

Chapter 7
Oral PDE-5 Inhibitors

Oral PDE-5 inhibitor agents (such as sildenafil [Viagra®], vardenafil [Levitra®, Staxyn®], tadalafil [Cialis®], and avanafil [Stendra®]) continue to be the treatment of choice for men with erectile dysfunction (ED), but, unfortunately, these agents have failure rates as high as 80% in men after prostatectomy (Baniel, Israilov, Segenreich, & Livne, 2001). This category of medications requires the nerves to work properly. Remember, even when the nerves for erections are spared, they do not always function well after surgery or radiation. As the preserved nerves recover after radical prostatectomy, oral medications may become more effective. In randomized trials for patients complaining of ED after external beam radiation therapy, 55% and 57% of patients using Viagra and Cialis reported successful intercourse (Incrocci, Koper, Hop, & Slob, 2001; Incrocci, Slagter, Slob, & Hop, 2006).

Oral agents are taken by mouth approximately 1 hour (minimum) prior to sexual relations. Viagra, Levitra, and Cialis all take a minimum of 1-2 hours to maximize in the blood stream. Stendra takes 30-60 minutes to maximize. Oral agents work by inhibiting PDE-5, an enzyme that breaks down cyclic guanosine monophosphate (cGMP). Without the PDE-5 enzyme to diminish cGMP, the cGMP is increased. cGMP is released during sexual arousal and is part of a group of chemical mediators that lead to smooth muscle relaxation and erections. Without stimulation through

sexual thoughts or directly on the penis, the chemical is ineffective and erections will not occur.

The greatest advantage to oral agents is that no other treatment is so simple to use, it does not require a man to step away from the sexual situation to administer the treatment, and it is discrete. Think of all the millions of men who use these pills and you can understand how important simplicity and discretion are to them. Traveling with the medication is not problematic since it does not need to be refrigerated. Oral PDE-5 inhibitors using the branded medications can be expensive (Viagra, Levitra, Cialis, Stendra, Staxyn). The good news is that the generic versions of the chemical in these medications are becoming available and are much more affordable. For example, generic 20 mg tablets of sildenafil are available at many local pharmacies for less than $1.00 a pill using a GoodRx coupon (doses can be taken in formulations of 20-100 mg when used for ED). There is also a generic sildenafil 100 mg tablet available. Generic tadalafil (generic Cialis) should be available by the time this book is published and result in a cost savings on that medication.

It is important to continually evaluate the costs of these medications since some of the patents are expiring and may lead to more generic, and less expensive, medications. Many people use GoodRx.com to find low prices by downloading coupons from the website for use at local pharmacies. Some people choose to get their medications using a prescription through verified online Canadian pharmacies. These pharmacies are not governed by American standards, but according to the standards of the certifying organization. Medications often come from other places around the world such as India or Turkey. Brand name medications come from the pharmaceutical

manufacturer in that country, but generic versions come from other companies in other countries. Decide if you feel comfortable and confident with a particular pharmacy or branded or generic products from other countries. It is important to double check the certifications and what they mean and also to know where your medications are coming from in order to make an informed decision. I have seen many patients obtain branded versions of the medications from a certified online Canadian pharmacy and cost savings can be significant. Some of my patients have also used generics from the same certified online Canadian pharmacy and I have heard mixed reports from patients about them. Prices vary among pharmacies, so shop for the best price from a trusted, reputable pharmacy that you feel comfortable using.

The biggest disadvantage to oral agents is that they are not always effective in producing an erection sufficient for sexual relations in men after prostate removal or radiation therapy. Oral agents will only work with preservation of the nerves responsible for erections because they rely on those nerves to activate the chemicals within the penis that will lead to increased blood flow and erections. If the nerves were not spared, oral agents will not be effective. Efficacy of sildenafil (Viagra) in men following radical prostatectomy varies greatly due to many different factors including pre-operative erectile function, extent of nerve sparing, and variations in definitions of erectile response and measurement of erectile function (Hatzimouratidis et al., 2009).

Common side effects include headache, facial flushing, nasal congestion, and stomach upset. These medications should not be used by men taking nitrates for chest pain (McMahon, Samali, & Johnson, 2000). Oral PDE-5 medications should be used cautiously in

men who are taking alpha-adrenergic blocker medications (for enlarged prostate) because of the risk of sudden drop in blood pressure. Caution must also be used in men with renal impairment because the medications are excreted through the kidneys. If you have certain heart conditions, such as QT prolongation, oral PDE-5 inhibitors should be used cautiously and under medical supervision only. It is best to consult your primary care provider or cardiologist before taking these medications.

Penile Rehabilitation with Oral PDE-5 Inhibitors

Emerging research is conflicting in terms of early use of these medications for penile rehabilitation to promote better erectile function. The theory behind penile rehabilitation with these agents is that the drugs may provide improved blood flow and oxygenation to the penis, thereby improving function of the penis. Researchers evaluated ED in 76 men with normal pre-operative erectile function who underwent bilateral nerve-sparing radical prostatectomy (Padma-Nathan et al., 2003). The men took sildenafil 50-100 mg every night for 36 weeks beginning 4 weeks after surgery. Results showed 27% of the men taking sildenafil versus 4% in the placebo group had a return of spontaneous normal erections. Although this is a small study, it did have a placebo comparison group, which improves the strength of these findings. Another study showed men using 50-100 mg of sildenafil nightly had improved nocturnal erections compared with men treated with placebo (McCullough, Levine, & Padma-Nathan, 2008). Evidence for using oral medications such as sildenafil is further strengthened by a study comparing nightly use of sildenafil 25 mg with potency rates at 1 year of 86% versus 66% in the control group who took sildenafil on demand/as needed (Bannowsky, Schulze, van der Horst, Hautmann, & Junemann, 2008).

A study using vardenafil (Levitra, Staxyn) was very complicated in terms of design. Researchers found that taking the medication on demand (5-20 mg as-needed dosing) resulted in better erections than placebo or daily (5-10 mg) use. This has added to confusion about how often the medications should be taken, and optimal dosing of the oral medications for penile rehabilitation (Montorsi et al., 2008). The study is not without flaws, including the fact that participants in the on-demand group were able to titrate up to the highest dose as needed, while those in the daily dose group could not take more than 10 mg. A subsequent large multicenter placebo-controlled study with tadalafil (Cialis) also failed to demonstrate benefit from regular use of PDE-5 inhibitors for penile rehabilitation (Montorsi et al., 2014).

Although research is conflicting about the efficacy and dosing of oral agents for penile rehabilitation, urology specialists around the world commonly use oral agents for penile rehabilitation (Tal, Teloken, & Mulhall, 2011). Providers may instruct the patient to take one of the oral agents either daily or three times a week for penile rehabilitation.

Aside from the lack of definitive research for using oral agents for penile rehabilitation, the drugs can be expensive and it may be financially challenging for patients to use the oral agents daily or three times a week. Men may have to pay for these medications out of pocket. Many insurance providers, including Medicare, do not cover the medications or treatments. Insurance plans that do cover the medications often limit the number of treatments per month for ED and may require a prior authorization from your provider. It is important for men to understand that although they may be using PDE-5 inhibitors for penile rehabilitation after radical prostatectomy, these agents may not fully produce an erection sufficient for penetrative sex. Correct education on the use of these medications

can alleviate disappointment if full erections are not achieved. Men must understand benefits of increased blood flow to the penis so they will continue to use the treatment for that specific purpose. In many cases, the medication will not produce an erection sufficient for sex, but any increase in blood flow increases oxygen to the tissue and may help keep penile tissue healthy. These medications may also be used in combination with other treatment options such as the vacuum device or MUSE®.

Long-term studies of negative effects of these medications have not been done and are needed. A prospective cohort study of 14,912 men reported that sildenafil use may be associated with increased risk of melanoma skin cancer based on 79 cases of melanoma (hazard ratio of 2.24 with 95% confidence interval) (Li, Qureshi, Robinson, & Han, 2014). Further studies are needed to determine a relationship between sildenafil and melanoma, but it is something to keep in mind in terms of risk and regular skin and mole checks should be conducted.

Men said the following about using oral agents:

> ***"So, if I take the Viagra, and sort of everything is working,*** *you know, like the Viagra's working, and I'm not stressed about it – because having sex can be a stressful experience now, and it wasn't ever before – so, if I'm not feeling stressed, and the medication seems to be working, and I've kind of, you know, then, yes, I can get an erection, and we can have intercourse. It's about more than half the time where that works, but not every time."*

*Another man said: **"Since surgery, I've almost always been able,** with the pump, to hold an erection long enough to have an orgasm … And I have had some success with the Cialis of not needing to use the pump. Sometimes I can enter her and then it just doesn't hold, so I withdraw, fire up the pump. Sometimes I don't even need to put a ring on, I can hold it long enough, between the two. Other times I need to use the ring, so we're experimenting a little bit, and it's unfortunate. By now I really hoped I would be perfectly normal, you know."*

Keys to Success with Oral Medications

- Take the medication on an empty stomach or with a very low-fat diet since these medications are absorbed through the stomach and fat content in the stomach may slow absorption. Staxyn (vardenafil) is a FDA-approved medication that dissolves on the tongue and is absorbed through the oral mucosa, not the stomach; therefore the food in the stomach is not a concern for effectiveness.
- Do not exceed the maximum dose of your medication.
- Wait at least 1-2 hours after taking the medication for the maximum medication effect. You must have sexual stimulation for these medications to work. Stendra (avanafil) is a medication that may reach peak effect in 30-45 minutes.
- These medications may decrease blood pressure slightly, so change positions slowly when taking these medications and lie down if you are dizzy or lightheaded. If you have persistent dizziness or

lightheadedness, stop the medication and consult your healthcare provider.

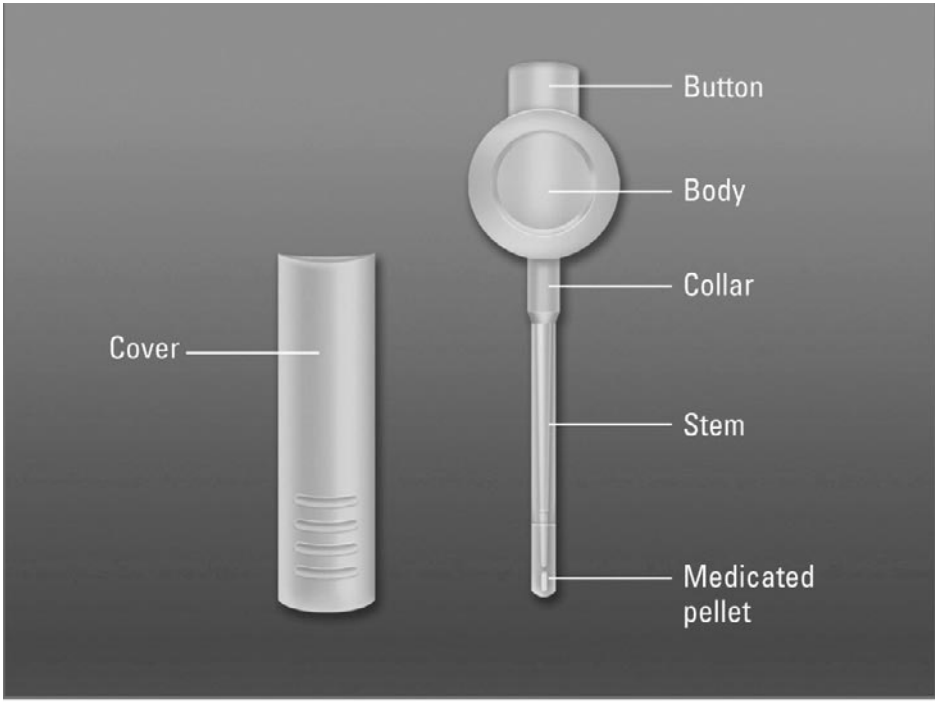
- If you have visual acuity, peripheral vision, or hearing changes, stop the medication and seek medical help.
- Never take any of these medications if you take or carry medications with nitroglycerin. If you have chest pain and seek treatment, tell the healthcare providers that you take oral PDE-5 medications and when you last took a dose.
- Some men have no side effects, but the most common ones for these medications are headache, facial flushing, nasal stuffiness, and/or stomach upset. If you experience a headache from these medications, you might want to take acetaminophen or ibuprofen at the same time you take your ED medication. This may help alleviate headache. If stomach upset is a problem, you might want to take the medication with a low-fat food like a cracker or pretzel. Viagra may cause color

Chapter 8
Intraurethral Alprostadil (MUSE®)

MUSE® (Medicated Urethral Suppository for Erections) is an intraurethral suppository of alprostadil (a prostaglandin) used for treating erectile dysfunction. After urination (when the urethra is wet) the MUSE (see Figures 1-8 & 2-8) applicator is inserted gently into the tip of the penis and passes about 1-2 inches down the urethra. The man depresses the button on the top of the applicator to release the MUSE into the urethra for absorption. After removing the applicator, the penis is rolled between the hands for a minimum of 10-30 seconds to dissolve the MUSE. MUSE is contraindicated in men with a hypersensitivity to alprostadil, men with an abnormally formed penis, or men who have conditions that would predispose them to priapism such as sickle cell anemia, leukemia, or tumors of the bone marrow. Caution must be used in patients with low blood pressure or a history of fainting since the medication may lower blood pressure and cause dizziness, lightheadedness, or fainting. Titrated dosages may start as low as 125-250 mcg and go up to 500-1,000 mcg.

When the medication was given to 384 men with or without nerve-sparing prostatectomy, 57% were able to have successful intercourse at least once at home as compared to 6.6% of the men receiving placebo (Costabile et al., 1998). Another research report indicated that regardless of the amount or ability to spare nerves during surgery, 55% of the patients achieved erections sufficient for intercourse with the treatment (Raina, Agarwal, Zaramo et al., 2005).

Figure 1-8.
Muse® Applicator and Parts



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One of the biggest issues with alprostadil/prostaglandin use in men after prostatectomy is pain. Since nerve endings are sensitized after prostatectomy or radiation, men may be more prone to the pain associated with alprostadil in the first year after treatment. In my experience with men post-prostatectomy, the majority will experience pain with therapeutic doses of MUSE, which typically range from 500-1,000 mcg. Pain with these doses has also been described in the literature in anecdotal reports (Mulhall, 2008). Since pain is common after prostatectomy, the first dose of MUSE should be given in the

Figure 2-8.
Muse® Applicator Head in Hand and Used in Penis

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physician's office or clinic, where blood pressure can be checked before and after administration. Low dosages of the drug should be used initially (Costabile et al., 1998; Raina, Pahlajani, Agarwal, & Zippe, 2008). The reason it is important to begin with sub-therapeutic doses of 125-250 mcg initially in men who have undergone prostate treatment within the last year is to check for and minimize side effects of low blood pressure and/or pain. Pain is dose dependent and may be lessened with a lower dose of the medication. If pain is an issue with this medication at lower doses, titrating upward to a dose that may produce an erection sufficient for sex is not an option because pain will intensify.

The advantage to MUSE is that it is simple to use and does not require a needle injection through the skin, as with the penile injections. MUSE can be unrefrigerated for up to 14 days at room temperatures of 30°-86° F; therefore, it is easy to transport when traveling.

One of the biggest issues in men after prostatectomy is pain with prostaglandin use.

The disadvantages of MUSE are related to the fact that it does not always work to create an erection sufficient for sex in many men, it is expensive if not covered by insurance, and it may cause side effects. Adverse side effects most commonly reported are pain or burning, but may also include hypotension (low blood pressure), dizziness, lightheadedness, and fainting. If the man scratches the urethra during insertion, bleeding may occur from the tip of the penis. MUSE costs about twice as much as the oral medications.

MUSE can also be used in conjunction with a PDE-5 inhibitor in men after prostatectomy to increase efficacy. Check with your provider to make sure it is safe for you to use this combination of drugs before using them. Although research is limited, taking oral agents prior to instilling MUSE may be more effective than MUSE alone. One study included 23 men unsatisfied with sildenafil 100 mg alone who added MUSE 500 mcg (taking the sildenafil at least 1 hour prior) with 83% of the men reporting improved erectile rigidity (Nandipati, Raina, Agarwal, & Zippe, 2006; Raina et al., 2005). Of the men who had improvement in erection rigidity, they were rigid enough for vaginal penetration 80% of the time. In another study of 26 men who failed sildenafil and MUSE alone, men reported improved ability to have an

erection sufficient for sex with the combination of sildenafil and MUSE together (Nehra, Blute, Barrett, & Moreland, 2002).

Although these reports are promising, more research is needed. In clinical practice, I have found that men may or may not get an erection sufficient for sex and if pain is intense enough, the medication will not be a good option for that man.

Penile Rehabilitation with Intraurethral Alprostadil (MUSE)

MUSE also may have a role in penile rehabilitation. There is emerging research on early intervention with MUSE after prostatectomy. The benefits of MUSE or injectable prostaglandin in terms of corporal oxygenation were reported as increasing oxygen saturation in the corpora (shaft) by 37%-57% despite marginal erectile response (Padmanaban & McCullough, 2006). In another study, researchers reported return of spontaneous erections after 6 months of tri-weekly MUSE in 39% of the men compared to 11% in the observational group (Raina, Agarwal, Nandipati, & Zippe, 2005). Another study of men with erectile dysfunction after prostatectomy compared early use of MUSE to delaying treatment and found that at 6 months 40% of men [38 men (a small study)] who continued using MUSE had return of natural erections sufficient for penetration (Raina, Agarwal, Nandipati et al., 2005). One study examined the possible mechanism of penile rehabilitation with MUSE and found that 125-250 mcg doses of alprostadil suppository improved corporal and glanular oxygen saturation levels, even in the absence of penile rigidity (McCullough, 2007). Further research is needed, but these studies provide evidence that MUSE may play a role in penile rehabilitation.

MUSE may play a role in penile rehabilitation.

Keys to Success with MUSE

- MUSE should only be taken with a prescription from, and under the supervision of, a qualified prescriber.
- If using MUSE with an oral agent such as a PDE-5 inhibitor, take the oral agent at least 1 hour prior to MUSE. Check with your provider before trying this combination.
- If you experience pain when using MUSE, it may help to take whatever medication you take for a headache (acetaminophen, ibuprofen, or aspirin) about 30-45 minutes prior to administering MUSE.
- Check applicator to make sure the medication is present.
- Keep the penis upright during installation process and jiggle the applicator as you remove it to help drop the medication in the urethra.
- After administration, ensure the pellet was delivered by checking the applicator to make sure it is gone.
- Walk and stimulate the penis to promote increased blood flow to penis.
- A restrictive device, such as Venoseal, placed at the base of penis to decrease venous return from penis may be helpful and should not be in place more than 30 minutes.
- Lie down if dizzy, change positions slowly.
- Follow all directions in the MUSE patient education instructions/materials.

Chapter 9
Intracavernosal Penile Injections

The man who is searching for a treatment option with a good track record in terms of efficacy, while providing a fairly natural-feeling erection without a constriction ring, should consider penile injections. This therapy includes use of vasoactive medications injected into the side of the base of the penis to dilate the blood vessels of the penis and cause penile engorgement. Injections are more effective than intraurethral suppositories because the drug is delivered directly into the erectile cylinders of the penis rather than down the urethra (where it must travel across the urethra into the erectile cylinders).

Commonly used injectable agents include monotherapy of prostaglandin in the form of Caverject®, Edex® (see Figure 1-9), off-label non-FDA approved compounded monotherapy of prostaglandin E1, or combination therapies using prostaglandin E1, papaverine, phentolamine, and/or atropine. Penile injections are contraindicated for men with a hypersensitivity to the medications; men with conditions that may lead to priapism including sickle cell anemia, multiple myeloma, and leukemia; and men with a penile implant or a severely deformed penis (Actient Pharmaceuticals, LLC/Endo Pharmaceuticals, Inc., 2018).

The advantage to penile injections is their effectiveness in producing fairly natural erections sufficient for intercourse. Penile injections are one of the most efficacious treatment options for men after prostatectomy with success rates reported as high as 85%-95% (Claro

Figure 1-9.
Edex® Dual Chamber Injection Device

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Jde et al., 2001; Dennis & McDougal, 1988). In our recent study of men post-prostatectomy, at 1 month after treatment with penile injections, 80% reported erectile function with the injections (Albaugh & Ferrans, 2010). At 3 months, 75% reported erectile function with injections. Injections resulted in a significant improvement in erectile function and also in sexual self-esteem and satisfaction with sexual relationships. In previous research, patients stated the injections were quick and easy, not messy, and created a fairly natural erection without using tension rings to maintain the erection (Soderdahl et al., 1997).

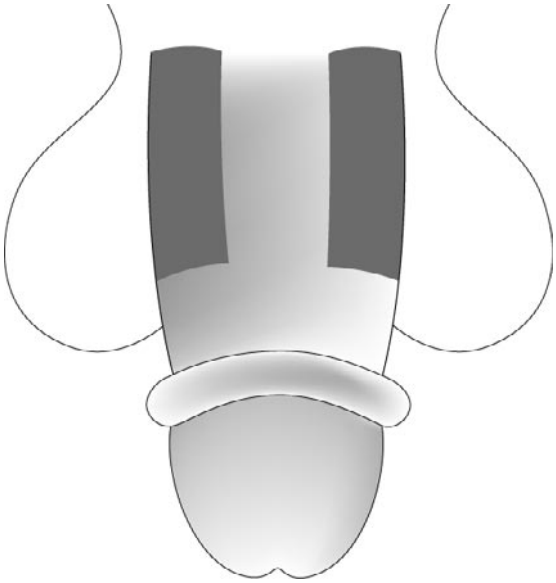
Despite the excellent efficacy profile and penile rehabilitation benefits of injections, some patients do not continue using this option and dropout rates are often as high as 55%-58% (Dennis & McDougal, 1988; Purvis, Egdetveit, & Christiansen, 1999). According to previous research, when comparing dropout rates for injections (not limited to prostatectomy patients, but including prostatectomy patients) with those for the vacuum device, the dropout rates for penile injections (60%) were three times greater than for the vacuum device (20%) (Turner et al., 1992). To increase success with penile injections, a man must be taught to inject the medication safely into the penis. This includes the ability to see injection sites at the base of the penis,

having manual dexterity to inject safely, and cognition to follow instructions for self-injection. The first dose should be done in the physician's office or clinic under supervision to ensure safety with self-injection.

Disadvantages for injections identified by patients in previous research include invasiveness of injections, problems with or fear of prolonged erections, pain, need to refrigerate some medications, and thought of the injections each time before sex (Albaugh & Ferrans, 2010; Soderdahl et al., 1997). Some injectables must be refrigerated and this can make travel with medications challenging. Another disadvantage is the FDA-approved versions of penile injections in the forms of Edex and Caverject are expensive. Compounded non-FDA approved, off-label penile injections are available from various compounding pharmacies and are less expensive (though they are often not covered by insurance prescription plans).

Other patient-identified disadvantages for penile injections (not limited to men after prostatectomy) were inconvenience, lack of efficacy, cost, and side effects (Mulhall et al., 1999; Raina et al., 2003). These reasons for lack of use of injections were also identified in our pilot study with 20 men following radical prostatectomy. In terms of lack of efficacy, a total of seven men from this group (35%) were still struggling to find a consistent, effective dose with their injections approximately 3 months after beginning injections. Titrating injections can take time and require expert assistance from an experienced provider since a variety of injectable drugs have been studied and used since the 1980s. We found that it can take one to eight dosage/medication changes before achieving efficacy (Albaugh & Ferrans, 2010).

Figure 2-9.
Intracaversonal Injection Sites Illustrated in Shaded Area



Reprinted with permission from Albaugh (2006).

Penile injection doses must be titrated carefully to a dose that creates an erection sufficient for sex (Albaugh, 2006). Injection therapy should be overseen by a urologic healthcare professional. Instructions provided here are general instructions to help you better understand penile injections, but these instructions are not meant to replace oversight by a trained healthcare professional.

Injections are given with a 0.5 or 1 ml syringe with 1/2 or 5/8 inch length, 27-30 gauge needle. The injection may be given anywhere from the base of the penis to two-thirds of the way down the penile shaft at the 10 o'clock and 2 o'clock locations on the upper side of the penis (see Figure 2-9). Typically, injections are rotated within that

area and the side the injection is given is alternated with each injection to avoid scarring. Injection therapy can be given as a single agent (monotherapy) with alprostadil (prostaglandin E-1); a multi-agent mixture such as trimixture of phentolamine, papaverine, and prostaglandin E1; quadmixture of phentolamine, papaverine, prostaglandin E1, and atropine; or bimixture of phentolamine and papaverine. Prostaglandin E1 can be compounded generically or as alprostadil either as Caverject or Edex. Lack of efficacy and cost have been described as reasons for using a combination of vasoactive agents instead of monotherapy with prostaglandin (Albaugh, 2006; Seyam, Mohamed, Akhras, & Rashwan, 2005). The FDA-approved medications are sometimes utilized because they are the most likely penile injectables to be covered by insurance.

Initial dosage should be determined by your healthcare provider. The initial dosing as recommended in the package insert for both Edex and Caverject is 2.5 mcg with a second dose of 2.5 mcg to be given if the initial dose is inadequate, but most clinics start dosing at the 5-mcg level. It is recommended the dose be increased by 5-10 mcg intervals at each attempt (a minimum of 24 hours apart) depending on the erectile response with each dose (up to a maximum dose of 40 mcg). Starting doses of compounded medications such as trimix or bimix will be determined by your healthcare provider. Typically trimix (papaverine 30 mg, phentolamine 1 mg, and prostaglandin E1 10 mcg) and bimix (papaverine 30 mg and phentolamine 1.5 mg) are started at a dose of 5-20 units (0.05-0.2 cc) in my clinic depending on patient's age and concomitant problems for ED. The dose is increased by 1-5 units according to erection response during each test dose until a dose sufficient for sexual relations is achieved. The maximum dose of trimix or bimix is usually no more than 100 units or 1 cc.

Investigators have utilized dose volumes of trimix (papaverine 30 mg, phentolamine 1 mg, and prostaglandin 10 mcg per 1 cc) ranging from 0.18-1.0 cc in previous studies (Bennett, Carpenter, & Barada, 1991; Montorsi et al., 1997; Montorsi et al., 2002; Mulhall et al., 1999). If the test dose at home is inadequate, do not reinject more medication, but wait at least 24 hours for the next trial and then try a slightly higher dose.

The main concern with re-dosing or increasing the dose too quickly is priapism (an unbendable erection lasting for greater than 2-4 hours). Priapism is considered a medical emergency and must be resolved to avoid permanent damage to the penis. Priapism has been reported in as many as 11%-18.5% of men using intracavernous injection (Claro Jde et al., 2001; Porst, 1996). Priapism lasting 3-4 hours occurred in 4 of the 20 patients in our study, but the erection resolved spontaneously in all four men without needing emergency treatment. Priapism can be treated successfully within the first 3-4 hours in the emergency department. That is why it is important for men to seek treatment in a timely manner. Some patients in our study struggled between taking enough medication to produce an erection sufficient for sexual relations and an erection that lasted too long (2-4 hours) (Albaugh & Ferrans, 2010).

A Scary Proposition

The thought of sticking a needle in the shaft of the penis is scary. Although it sounds very painful, men do not find the needlestick involved in penile injections to be painful. Pain is typically not related to needle insertion, but rather the side effect of the prostaglandin medication. In one of our studies (not limited to men following prostatectomy), we found 40% of the 65 patients rated the needle insertion pain at 0 on a 0-10 verbal pain scale during their first office

self-injection (Albaugh & Ferrans, 2009). For men who reported any pain from the needle insertion, average pain rating was only 1.33 on a 1-10 verbal pain scale. We found a significantly larger proportion of men following radical prostatectomy experienced pain from the medication compared with men who had not undergone this procedure (51.9% vs. 23.7%) (Albaugh & Ferrans, 2009). In another study that was not limited to men after prostatectomy, pain from injected medication was reported in 29% of patients using monotherapy with a prostaglandin product (Porst, Buvat, Meuleman, Michal, & Wagner, 1998). In our study of 20 men after prostatectomy, only about 25% reported pain from the medication, but many of those men used trimix with lower doses of prostaglandin (Albaugh & Ferrans, 2010).

When pain is an issue for a man, lower doses of prostaglandin in combination with other vasoactive injectable agents (papaverine and phentolamine) may be advisable. It has been reported that although the injections worked in the early months after prostatectomy, pain with prostaglandin was a significant issue and led to discontinuation in the majority of patients (Gontero et al., 2003). If necessary, prostaglandin can be eliminated altogether in patients who continue to have pain even at lower doses by using alternative vasoactive drugs such as a bimix solution of papaverine and phentolamine. Previous research (not limited to prostatectomy patients) has shown that switching to a trimix (papaverine/phentolamine/PGE1) or even a bimix (papaverine/phentolamine) combination is associated with lower incidence of pain (2.9% for trimix and 0 for bimix) (Baniel et al., 2000).

Another promising injectable agent currently under investigation in the United States is a combination of vasoactive intestinal polypeptide

and phentolamine, which is currently undergoing Phase III clinical trials in the United States. Results from the manufacturer shows less incidence of pain (Gerstenberg, Metz, Ottesen, & Fahrenkrug, 1992; Sandhu et al., 1999; Shah, Dinsmore, Oakes, & Hackett, 2007).

Another side effect that may occur is bleeding and/or bruising. Less-common side effects include priapism and penile fibrosis/plaque formation. Priapism was discussed earlier. Peyronie's disease (curvature of the penis related to plaque formation) is not as common, but can be debilitating in terms of sexual activity. For penile fibrosis/plaque/curvature in our recent pilot study, two (10%) patients reported a plaque or slight curve with injections. Rates of up to 14% of fibrosis/plaque/Peyronie's have been reported in the literature related to penile injections (Actient Pharmaceuticals, LLC/Endo Pharmaceuticals, Inc., 2018). To minimize risk of developing Peyronie's disease, it is important to rotate injection sites and hold pressure over injection sites (even if you do not see blood) for 5 minutes as directed in the prescribing information (Actient Pharmaceuticals, LLC/Endo Pharmaceuticals, Inc., 2018).

Men said the following about injections:

> ***"At about 8 months, I became aware of – when I was just completely hopeless, someone called my attention to injectable products;*** *one called Edex and one called trimix. Edex has one active ingredient in it. You inject it into the shaft of your manhood with a half-inch long needle. Because there are few nerve endings down there, it's truly not painful at all. It's less painful than pinching your arm with your fingertips. The other, trimix, has the same single active ingredient as Edex, plus two more. Edex is provided to you by your pharmacy on a prescription basis,*

prepackaged and handed to you and, in my case, was paid for fully by insurance every month for the rest of my life. But trimix is always made in a compounding pharmacy under a prescription. Edex can be kept in your closet or wherever you want, except in a place of extreme heat, at room temperature. Trimix has to be refrigerated. Not a big deal, but there are some subtle differences. Edex turned out to be the closest thing to a miracle, almost the closest thing to a miracle I'd ever experienced in my life. I didn't notice the pain because I was eager to try it. I've used it for 5 months, sometimes two or three times a week."

Another person described injections: ***"My urologist has what he thinks to be the solution*** *is to inject my penis with some kind of something and that's not free either I understand ... I will go into a monastery before I start sticking my penis – I'm definitely afraid. I can't even bear people drawing blood from me you know without sitting down and looking away. I just don't see myself injecting my penis."*

Another man said: ***"The result I achieve with the needle is exactly as I said;*** *it's just like a natural erection you achieved when you were as hard as mahogany … Everyone should pick their own course through life and try everything and reach your own conclusions."*

Penile Rehabilitation with Intracavernosal Penile Injections

Regarding penile rehabilitation, injections were the first medical ED treatment to be used successfully for penile rehabilitation after prostatectomy to improve return of spontaneous erections (Montorsi et al., 1997). This was a small study, but it showed encouraging results. After 6 months the group receiving the penile injections had a 67% return of spontaneous erections sufficient for intercourse versus

a 20% return of spontaneous erections for the control group. Researchers hypothesized the injections improved oxygenation to the tissue to enhance return of spontaneous erections.

In another study, 101 patients used prostaglandin E1 injections resulting in increased penile oxygen saturation in 37%-57% of patients (Padmanaban & McCullough, 2006). Another study reported 56% (10 of 18 patients) who used a combination of oral agents and injections of alprostadil had return of partial erections at approximately 6 months, but they still needed treatment to have sexual intercourse (Raina et al., 2008). Researchers also used trimix injections with four additional patients and reported that of the 22 total patients on either alprostadil or trimix, 50% had return of natural erections at 6 months. In another study using oral PDE-5 inhibitors for penile rehabilitation, patients who failed oral agents were treated with intracavernosal injections (Mulhall, Land, Parker, Waters, & Flanigan, 2005). After 18 months, men undergoing penile rehabilitation had a greater percentage of success engaging in intercourse unassisted by medication (52% vs. 19%). These were small studies, but they did have comparison groups.

A significant difficulty with penile rehabilitation using penile injections is convincing men to self-inject approximately 3 times a week, since injections are perceived as invasive and sometimes associated with pain in the early period after radical prostatectomy. Even with close observation and titration, pain was still a barrier identified by 4 of the 20 men in our study (Albaugh & Ferrans, 2010). Although researchers found that starting injections in the first month after surgery resulted in better erectile response, participants also reported more pain (Gontero et al., 2003).

In recent pilot study, patients used the injections an average of four times per month (Albaugh & Ferrans, 2010). Despite agreeing to use the injections a minimum of at least four times a month, seven men did not use the injections even once per week.

Not all men will use the injections regularly for penile rehabilitation. Some men using injections will use oral agents for penile rehabilitation on the days they are not using the injections, so they are regularly using either oral medications or injections. Injections and pills may have a synergistic effect leading to priapism and, therefore, it is best to not take the pill within 24-36 hours of the injection. It is important to work closely with your healthcare provider on your injections to determine the safest and best way for you to treat your ED and achieve penile rehabilitation.

Keys to Successful Injections

- Please be very careful and follow all the written and verbal instructions you were given for your injections from your provider/caregivers.
- Do not inject more than one time in a 24-hour period or two to three times a week maximum regardless of whether or not you achieved an erection with injections.
- Rotate sites in the areas you were taught to inject.
- Press on the injection site for about 5 minutes after injection with the fingers on one side of the penis pressing against the thumb on the other side of the penis, so you are encircling the penis with your fingers and thumbs pressing over the injection site.
- Follow all instructions if you experience a priapism (see next bullet point). If you have questions about the instructions and/or if the erection persists after 3-4 hours, go to the emergency room with the instructions you were given.
- Priapism (an erection lasting 4 hours or more) is a very serious medical condition and must be resolved. After 6-8 hours a prolonged erection (priapism) can cause permanent tissue damage and becomes more difficult to treat. It is easier to treat within the first 4 hours. After 4-6 hours, the blood can clot within the erect penis requiring more work to get the blood flowing again. You should be in the emergency room getting professional treatment for your priapism if the erection has been persistently unbendable and hard for 3-4 hours. This is a medical emergency and if things you have tried at home are not working, you must go to the emergency room for treatment. Sometimes it helps to increase activity and move around to try and get the blood to move out of the penis (for example, some men will run up and down the steps a few times or jog in place). It may also help to lie on your back, allowing blood to drain out of the penis. Sometimes a warm or cold pack may help resolve the erection, but if these efforts are not successful, you need to do something further. If the priapism

lasts for 2 hours, some patients have found it helpful to take one of the following medications (these medications are used for other purposes, but have been used by patients outside the medication's primary indication as an antidote for a priapism).

  - Pseudoephedrine (Sudafed®) 30 mg tablets (no prescription needed, but you must ask the pharmacist for this medication). Take one to two tablets by mouth. (Do not exceed 60 mg total unless your healthcare provider specifically told you to take more than 60 mg). If you cannot take pseudoephedrine related to allergies, uncontrolled high blood pressure, heart problems, or any other reason, proceed to the emergency room for treatment (read label information on pseudoephedrine before taking it to see if you can safely take this medication). If the pseudoephedrine doesn't work after 1 hour, go to the emergency room for treatment.
  - Terbutaline 5-10 mg may be taken orally to treat a priapism. This medication requires a prescription. If the medication does not work after 45 minutes, go to the emergency room.

- Do not inject into your penis when under the influence of alcohol or drugs.
- If you are having problems with injections, stop injecting and call your healthcare provider for further instructions. Injections must be done under guidance of an expert provider.
- These instructions are in no way meant to substitute for expert one-on-one education with a qualified provider.

Chapter 10
Penile Prosthesis

The penile prosthetic implant was one of the first treatments for erectile dysfunction. The implant is surgically placed within the penis within each corpora cavernosa (column of erectile tissue). The malleable implant was one of the first designs (see Figures 1-10 & 2-10) and is very simple to operate. The man bends the penis upward when he wants to have sexual relations and bends the penis out of the way when he is not sexually active. The malleable implant is always semi- erect so it does not ever become flaccid. Subsequent designs in protheses eliminated this disadvantage by creating an inflatable implant (see Figures 2-10 to 5-10) that utilizes a manual pump in the scrotum to draw fluid into the cylinders of the penile implant for inflation and a release mechanism to drain the fluid back into the abdominal reservoir. This implant more closely mimics the normal flaccid and erectile state, although the cylinders never completely deflate. Even when a man is flaccid the cylinders provide a little bit of length and girth in the penis.

The advantage to a penile implant is that it is effective, more spontaneous, and patients are typically satisfied with this treatment. Satisfaction rates with penile implants are high at approximately 83%-85%. Complication rates, such as mechanical failure or infection, remain low at 6.4%-13.7% and 1.7%-1.8% respectively (Montague & Angermeier, 2000, 2003). Although penile prosthesis implantation makes the return of spontaneous erections impossible, simultaneous implantation of a penile prosthesis at the time of prostatectomy has

Figure 1-10.
Spectra Concealable Penile Prosthesis

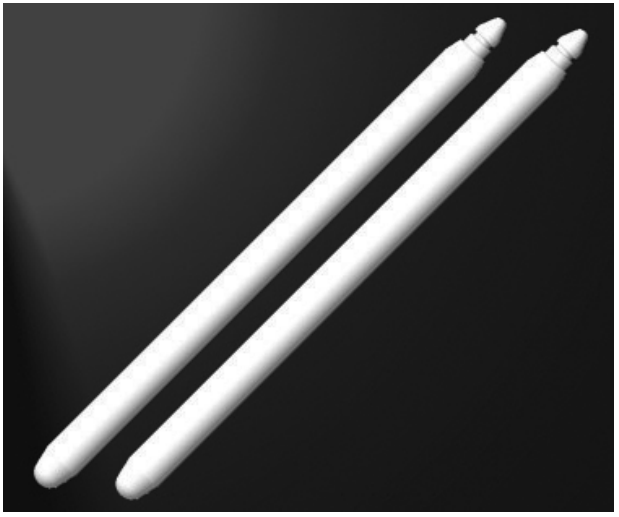


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Figure 2-10.
Spectra Prosthesis

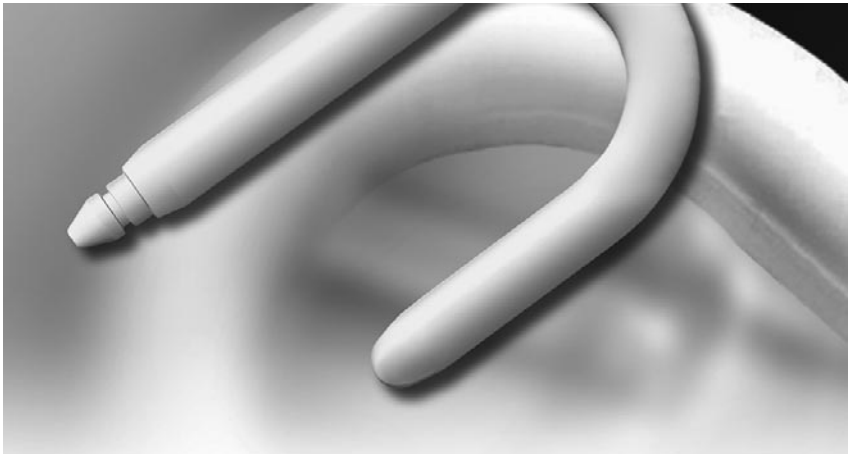

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Figure 3-10.
AMS 700 Series Inflatable Penile Implant

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Figure 4-10.
Titan OTR® Inflatable Penile Prosthesis

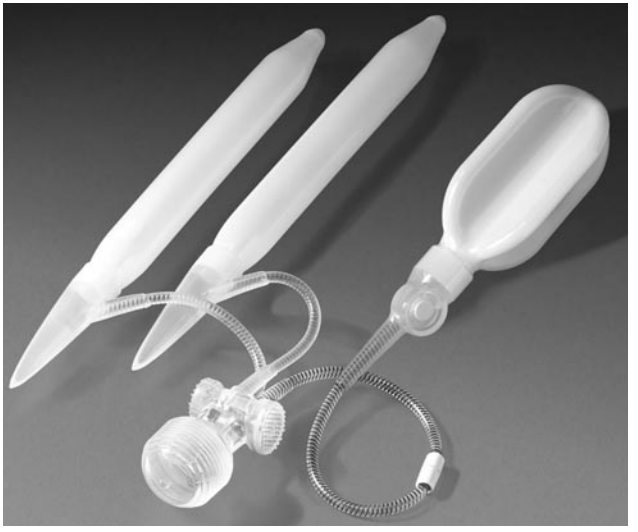

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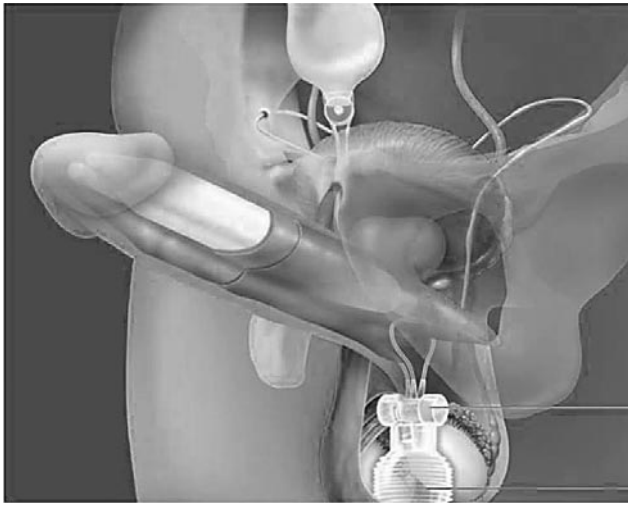
Figure 5-10.
Titan OTR® Inflatable Penile Prosthesis



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been associated with improvement in quality of life (Ramsawh, Morgentaler, Covino, Barlow, & DeWolf, 2005). It is a reliable treatment, but because it is the most invasive treatment and surgery permanently alters the corpora cavernosa, preventing the use of other medical therapies, most patients considered it the final line of treatment after medical treatments have failed.

The patient who wants to undergo an implant must be a good candidate for surgery and needs to be prepared and accepting of the permanency of the implant. Travel is not an issue since the prosthesis is implanted in the body. The prosthesis can be used at anytime and involves a one-time cost. The implant is an accepted treatment covered by most insurance plans.

Disadvantages to the implant include pain after the procedure and, less commonly, mechanical failure or infection (Montague & Angermeier, 2003). The most common adverse effect of the implant is pain after the implant surgery that typically resolves a few weeks to a few months after surgery. The implant also involves the typical risks involved with any surgery. The penile implant surgery costs about $15,000-$20,000 (costs and insurance coverage may vary).

One man said the following about the implant:

> ***"I know that there are other things out there that I can do in addition to the mechanical pump.*** *I'm thinking in particular implants. I mean, I haven't thought about it a lot, but if nothing else works then I believe I'll probably look for somebody to do an implant and that's kind of my plan."*

Keys for Success with the Penile Implant

- Follow all specific instructions from your caregivers. Keys outlined here are only meant to be basic guidelines.
- Some men may use the vacuum device daily for tissue stretching for about 10 minutes a day for several weeks before surgery as described in the vacuum constriction device section (without a tension ring) to stretch the penile tissue in preparation for penile implant.
- Immediately following surgery, you may need to wear snug-fitting jockey shorts or an athletic supporter (check with your surgeon).
- You may need to apply a cold pack to the groin area (on top of your jockey shorts or supporter) to decrease swelling and bruising for the first 24 hours. Do not put the cold pack directly on the skin, but be sure to apply clothing or a towel between the skin and cold pack.

Often the penis and scrotum will swell (double in size) and become bruised despite using ice packs. You will be given pain medication to use as needed.

- Take showers or sponge baths for the first 7-10 days after surgery. After 7-10 days, you may take warm baths, which might relieve any pain and soreness, especially after being on your feet for a while. Apply antibiotic ointment to your incision twice a day or as directed by your provider, especially after showering or bathing. You may have a slight amount of drainage from the incision site, but if you notice persistent drainage, increasing redness, increasing pain or burning at the incision site, call your provider or seek medical help.
- Take your medications as prescribed. You will be given an antibiotic that must be taken until the pills are gone.
- Do not have sexual intercourse for at least 6 weeks after the operation, or until your doctor tells you the surgical site has healed.
- At some point after surgery (within a few weeks), you will meet with your healthcare provider or urology staff to inflate and deflate the inflatable prosthesis for the first time. They may have you practice inflating and deflating at regular intervals during the healing process, but follow the instructions of your provider carefully for the best outcome. You may have some pain for several weeks when inflating or deflating after surgery, but the pain will generally improve over time and as you become skilled at inflating and deflating the prosthesis.
- Watch for signs of infection:
  - Fever
  - Increasing pain
  - Increasing swelling in the penis or scrotum
  - Increasing drainage from penis or incision area (area that was cut)
  - Inability to urinate
- If you notice any signs of infection or have any other problems, call your healthcare provider or go to an urgent care center or emergency room.

Chapter 11
Urinary Incontinence

Urinary incontinence is an accidental loss of urine. Research reveals 15%-18% of men are incontinent 2-15 years following radical prostatectomy, whether the procedure was open, laparoscopic, or robotic (Resnick et al., 2013). For men who eventually regain continence, it can take as long as 2 years for patients to regain continence (Jacobsen, Moore, Estey, & Voaklander, 2007; Sacco et al., 2006). Men treated for prostate cancer know that when the catheter comes out, leakage may begin. For many men, this leakage may resolve over the next year, but for some men the issue may last longer. During prostatectomy, part of the mechanisms that maintain urine in the bladder are removed. As a result, the remaining pelvic floor muscles must work harder to maintain urine in the bladder with activity, coughing, sneezing, and laughing. Men may also have a more urgent need to urinate and/or may not be able to get to the bathroom before leakage occurs after radiation therapy or after surgery. If a man has had radiation therapy, he also may have bowel urgency or frequency.

To help understand urinary incontinence, this problem can be divided into different categories. Each type of incontinence is different and has a different approach to treatment. Urinary incontinence can often be a mixture of more than one type of incontinence. *Stress urinary incontinence* involves accidental leakage of urine with activity, coughing, laughing, and sneezing. This type of incontinence is the most common in men after prostatectomy because they lost part of

the mechanisms that maintain urine in the bladder. *Urge incontinence* is an accidental leak of urine associated with a strong urge to urinate. A man with urge incontinence has a sudden, uncontrolled need to urinate. Urge incontinence and urgency can occur after prostate treatment with either radiation or prostatectomy. *Overflow incontinence* occurs when the bladder never empties completely. Once it is filled to capacity, urine overflows, causing leakage. This can happen when scar tissue from radiation or surgery obstructs the outlet of the bladder. Some men may also complain of urine leakage during sexual relations or with orgasm after prostatectomy. Although urine is sterile and a small amount of leakage is not problematic, along with erectile dysfunction after prostate cancer treatment, leakage can impair a couple's ability for sex and intimacy.

Treating Incontinence

Incontinence can be treated successfully for the majority of men. Pelvic floor muscle/Kegel exercises are a series of pelvic muscle exercises designed to strengthen muscles of the pelvic floor. Dr. Arnold Kegel, a gynecologist, developed these exercises in 1948 as a method of controlling incontinence in women after childbirth. Pelvic floor exercises strengthen muscles of the pelvic floor to improve urethral and rectal sphincter function. Success of pelvic floor exercises depends on proper technique and adhering to a regular exercise program. Pelvic floor muscle exercises can be helpful in treating both urge and stress incontinence. There are both quick and slow-twitch fibers in the pelvic floor muscles and so both quick and slow pelvic floor exercises should be practiced. It is important to do the pelvic floor exercises correctly, and this may require you to see a specialist nurse or physical therapist who can teach you how to do

the exercises appropriately and consistently. Your healthcare provider can also recommend online resources to assist you.

The Agency for Healthcare Research and Quality guideline, *Urinary Incontinence in Adults: Acute and Chronic Management* (Fantl et al., 1996), recommends primary treatment options for incontinence should be bladder retraining, timed voiding, and pelvic floor exercises. For urge incontinence, there are several prescription anticholinergic medications that may help control the urge to urinate. There currently are no FDA-approved medications for stress urinary incontinence. Surgical interventions for stress urinary incontinence include various sling procedures and artificial sphincters. Although urinary incontinence is common after prostate cancer treatment, both problems can often (but not always) be treated successfully. It is essential for men with these problems to undergo a full evaluation and treatment of urinary incontinence by a urologic healthcare provider.

Men said the following about incontinence:

> ***"I was pretty incontinent,*** *but none of that really bothered me that much because it was just so great to have that over with (surgery) and come out negative (cancer free) … I was so glad when I saw my numbers from the pathologist that I was clean that it was like all right, this is great. The incontinence is gone within 12 months. I have a little drippage here and there once in a while, but I don't wear any pads at all."*
>
> *Another man said:* ***"I realized that there was a risk to both incontinence and impotence.*** *I started doing Kegels as soon as I was diagnosed. And it was 3 months later that I actually had the*

operation. And that was at the suggestion of a cancer institute where I went for a second opinion. They said I could kick it down for a few months – no hurry here – and let your prostate heal up, before the operation. And I did that. During that time I took the time to learn and do my Kegels and I can't stress strongly enough I'm glad I did that."

A partner said: ***"And I think as a woman you have to just put some stuff to the side,*** *and we're used to doing it anyway, and you've got to help him get over it. Now, you've gotta get over it first. And I think that's the biggest thing I've gotten out of this is, that I have to be okay with stuff so he can be okay with it because that's what was going on. Because for a while we had this problem in the beginning where I saw him pulling away, and I was like, 'We can't do this.' Physically and it was because he was weirded out because he was wearing pads, and because he was leaking. And you have to get on them, too. Men are men, and he was supposed to be doing his Kegel exercises. Well, was he doing them? No. I was like, 'Well, why aren't you doing them? Why are you not doing them? Well… Well, guess what? If you want to stop leaking, you're complaining about leaking, this is the answer, so come on. You're a brilliant guy. Figure it out.'"*

Keys for Success with Pelvic Floor Exercises

- Success of pelvic floor exercises depends on proper technique and sticking to a regular exercise program. There are both quick and slow-twitch fibers in the pelvic floor muscles so both quick and slow pelvic floor exercises should be performed.
- Do not contract your abdominal, thigh, or buttocks muscles while doing the exercise.

Performing Pelvic Floor Exercises

- These suggestions are meant as general guidelines. Ask your provider if he or she has any specific instructions for doing the exercises and how soon after treatment you can do them. Some men may benefit from working with a trained professional such as a nurse or physical therapist who can make sure they are doing the exercises correctly.
- Tighten pelvic floor muscles and relax them immediately for a quick contraction. Repeat 10 times.
- Do 10 slow contractions and relaxations: Holding for 4-5 counts minimum and relaxing for 4-5 counts.
- Do three sets a day of both the quick and slow pelvic floor contractions.
- Increase contractions by five repetitions each week until you reach a goal of 20-25 quick and 20-25 slow pelvic floor contractions three times a day.
- You can do these exercises at any time and any place. You can do them sitting, standing, or lying down. After 4-6 weeks, most people notice some improvement. It may take as long as 3-4 months to see a major change. Once you feel you are doing much better, drop to one set of 20-25 quick and 20-25 slow contractions a day for maintenance.

- *A word of caution:* Some people feel they can speed up the progress by increasing number of repetitions and frequency of exercises. However, over-exercising can cause muscle fatigue and increase urine leakage.
- When done properly, Kegel exercises may be effective in improving urinary continence.

Chapter 12

The Mind Is the Most Powerful Sex Organ in the Body

You may have heard this phrase before, but it is true. The brain controls everything in our bodies including the various aspects of our sex lives. Physiological drive, in terms of testosterone, is impacted if androgen deprivation therapy is a part of treatment. Testosterone is not typically affected by prostate surgery or radiation therapy. Drive may also be impacted by many other factors including depression, anxiety, grief, adjustment to physical limitations, and body image changes. Men with sexual issues feel a variety of frustrations and concerns about erectile function during sex and this can lead to further erectile issues. Sexual dysfunction after prostate cancer treatment has been associated with decreased health-related quality of life (Hu et al., 2004; Meyer, Gillatt, Lockyer, & Macdonagh, 2003; Penson et al., 2003; Penson et al., 2008; Yarbro & Ferrans, 1998). Sexual dysfunction can impact life satisfaction.

You may feel many emotions after prostate cancer treatment. After hearing that surgery went well and the cancer was removed, some men feel relief and comfort. Feelings and emotions may vary depending on which treatment you underwent and side effects such as sexual dysfunction and urinary incontinence. Both urinary incontinence and sexual dysfunction after prostate cancer treatment have been associated with decreased health-related quality of life, depression, and anxiety (Green, Pakenham, Headley, & Gardiner, 2002; Hu et al., 2004; Penson et al., 2008; Wettergren, Bjorkholm,

Axdorph, & Langius-Eklof, 2004). Researchers have found that, compared to other treatments, androgen deprivation therapy (hormone ablation therapy) was associated with decreased health-related quality of life and more distress (Couper et al., 2009). It is important to seek help from a qualified professional if you are experiencing ongoing depression and/or anxiety because research has shown treatment can improve your quality of life (Armes et al., 2009; Blank & Bellizzi, 2006; Giesler et al., 2005; Mehnert, Lehmann, Graefen, Huland, & Koch, 2010; Mottet, Prayer-Galetti, Hammerer, Kattan, & Tunn, 2006; Sharpley & Christie, 2009; van den Bergh, Korfage, Borsboom, Steyerberg, & Essink-Bot, 2009).

Time and Space to Communicate

Worrying about erections during sex can lead to further erectile dysfunction. During sexual stimulation, men need to stay focused on the pleasure of the experience because distractions such as concerns over erectile hardness can be an erection killer. Staying in the moment to enjoy sex is important. Keep the time and space for sexual experiences separate from the time and space when you have discussions about sex. Talking about sexual issues in the heat of the moment during sex will change the focus of your sexual time away from pleasure and arousal.

Some men worry about satisfying a partner and put unneeded importance on the role of erections in bringing sexual pleasure. Talk to your partner about your concerns related to fulfilling her or his needs. Intimacy (deeper communication on all levels) may be more important than sex to some partners.

It is important to talk about sex and to think about where, when, and how you talk about it. Talking about sex may be new and challenging for you and your partner and these discussions take time. Even though it is difficult to talk about sex, it will get easier the more you communicate about it. The timing, place, and approach to the sexual discussion can be crucial to successful communication. Plan time for this discussion in a location other than the bedroom or where you are typically sexual. Find a comfortable space away from the bedroom. It may help to sit face-to-face and in close proximity to each other during the discussion. Focus the conversation in terms of your feelings and needs, using terms such as "I feel frustrated when _____ and I need _____ " If you both read this book, discussing the different topics presented will help open up a conversation about sex.

Climax Concerns

Both men and women can climax with or without the man experiencing an erection. Erection is not crucial to sexual satisfaction. Non-penetrative forms of sexual arousal can be very enjoyable for many couples. If you and your partner work together, you can discover new and exciting ways to enjoy your love play together. Focusing on the present and pleasure during each of those moments during sex can lead to greater satisfaction, rather than worrying about what is different now. Allow yourself to fully engage in each moment of pleasure during sex and do not let your mind drift to concerns about possible problems. Find a comfortable time to talk to your partner about any worries you have about problems during sex. These conversations should be ongoing and you both should be comfortable initiating a discussion. Remember, you are still a vibrant man capable of enjoying sex.

Most men do not have problems reaching climax (the feeling associated with culmination of sex) after prostate treatment, but it may need to be achieved through different methods of stimulation (such as manual stimulation) in the absence of an erection. Some men may be used to climaxing primarily from intercourse or penetrative sex, but with erectile dysfunction that may not be the primary way he reaches climax. The changes in how a man reaches climax and/or the intensity changes with climax may be problematic for some men. Understanding it may be different and keeping an open mind to exploring and enjoying climax can be helpful.

One FDA-approved vibratory medical device, Viberect®, has shown to provoke penile erection and/or ejaculation in spine-injured men and in a very small series of urology patients (10 men total, 5 of which had prostate cancer) with erectile dysfunction. It was found to be safe, easy to use, tolerable, and highly satisfying (Tajkarimi & Burnett, 2012). The device can be costly compared to a non-medical vibrator, but it is more powerful and has limited research to show it may help. Further research is needed, and is being done, to support the use of this device.

Quotes about climax:

> ***"The one thing that's really bothered me, and it won't come back, is dry ejaculation.*** *I don't like it. It really is not the same feeling. And that's actually very frustrating to me because I know that's not going to change. So even though I'm working to get better erections, the dry ejaculation is a totally different feeling. And I find it, at least right now, an unsatisfactory feeling. Maybe the satisfaction level of a dry ejaculation will get better but that's very frustrating to me. So, I hope the sensation at least becomes more pleasurable."*

Another man said: ***"It did start early on, maybe 2 months afterwards*** *where I'd feel like I was going get hard but it didn't happen, nothing happened. Exacerbating the fact that I could climax – I did climax – well, I don't think I did anything much for months. I was concentrating on other things. And so then after that I did climax just by rubbing the head of the penis but there was no erection whatsoever."*

Another man said: ***"And then, sometimes, it is more satisfying,*** *but it has never been like it was before, in terms of the intensity of the orgasm and also the feeling afterwards that you're really completely satiated and relaxed afterwards. So, it's a pretty different way to relate to your sex life."*

Depression and Anxiety

You may need to grieve the loss resulting from the many changes associated with sex following prostate cancer treatment. Remember, you experienced erections every day of your life since you were born, so a dramatic change in this experience may be upsetting and frustrating. You are entitled to grieve over any loss of function. Other changes, such as penile shrinkage, lack of ejaculation, and changes in sensations during climax, may also occur and be upsetting. Although most men climax even without erections, sensations may be different for some men and this may be frustrating.

Some men may experience anxiety or depression. Your feelings are real and valid, and you should explore those emotions with your partner and other key people in your life. Acknowledging and learning to cope with anxiety and depression can be important to your overall health when living with prostate cancer because these

conditions negatively impact your immune system and your life satisfaction. It is important to take action and reach out to others if you experience these emotions. Depression in particular makes it difficult to seek help and may cause you to isolate yourself from others (which is not helpful). Some actions that may help with anxiety or mild depression are talking to others for support, exercising, following a healthy lifestyle including diet, challenging negative thinking, and doing things that are meaningful to you. It can be very valuable to talk to other men who have experienced prostate cancer. Prostate cancer peer support, information, and services are available through Us TOO International. This non-profit organization can provide needed encouragement from other men who have experienced similar challenges. There are Us TOO chapters worldwide, a help line (1-800-808-7866), online groups, and groups that meet on toll-free conference calls. Find a group near you and/or consult their online resources by visiting www.ustoo.org.

If you experience persistent symptons of anxiety or severe depression, it is important to seek help from a mental health professional. It is critical to obtain professional help if you feel hopeless, very angry, consider harming yourself or others, or feel life is not worth living. Do not hesitate to seek whatever resources will help you live a most fulfilling life. You are a prostate cancer survivor, and you deserve the best life you can live.

Quotes about depression and anxiety:

"The other thing that happened, and again I was not told to expect this, was depression. *I had a very serious bout of depression, post op, when I found out the things that were going on with me physically and the time it was taking to get to what I hoped would be healing. I didn't understand depression. I didn't know I had it but I suffered with it for several months until I got to the point where I became suicidal. And at that point I went back to my surgeon and I just talked about what was going on with me. I sent him an email and I said what can I do about this? And I said please don't tell me to be patient again because it makes me want to ride my motorcycle off a bridge. And I asked him – I said do you think a mental health referral is in order at this point? … But then he gave me the name of somebody so I called the doctor that day and got on some medication and started on some therapy with him."*

Another man said: ***"First of all, I was kind of surprised to see how tightly wound our libido and our male psyche is.*** *In particular, how as a man I am able to do manly things and the things I really used to enjoy, sex in particular, I couldn't do that anymore. And that made me very depressed. I was really surprised about that because nowhere in our research prior to my surgery did I run across that a whole lot about how one of the side effects mentally would be depression. And even now I still have some issues with depression, but it's been over a year and a half and I think I've adjusted somewhat because I found that to combat depression I need to stay active, find things that I used to enjoy that I still enjoy, and not focus so much on the depression aspect because I had a lot to be pleased about."*

Quotes about support:

One man said this about the support group meeting: ***"And because of what those guys gave to me*** *is the main reason why I have never missed a meeting and don't intend on missing one with the hope of giving somebody else – there's always guys coming in that I can impact them with that same energy to let them know that hey, you're not by yourself … And that if I did it and can come through it, you can do it. And so that's me, man. That's why I'm here (at the Us TOO support group meeting)."*

Another man said this about the support group meeting: ***"I come here shaking like a leaf, man.*** *I get in here with a bunch of guys that had been where I was about to go and man they gassed me up with that strength. And like I said, when I came in I was shaking like a leaf. When I left I was empowered."*

Another man said: ***"I think support would be good. I think it depends on the individual but I think support is positive,*** *whether it would be just a men's support group or your spouse being supportive, or someone to talk to about that issue. I know before I had the surgery I had a friend who went through it, and he was very helpful when I talked to him about it. And I think the Us TOO part is a great pick-me-up after surgery to say, 'These are all guys that have been through it.' It's been great, so I think that's been a big help, too."*

Chapter 13

A Message for Partners of Men with Erectile Dysfunction after Prostate Cancer Treatment

This chapter is especially for partners of men who have undergone prostate cancer treatment. You have lived through every phase of prostate cancer survival and it has been challenging for both you and your partner. It is not easy to watch someone you love suffer from a prostate cancer diagnosis. Partners often feel like an outside observer experiencing the effects of prostate cancer treatment along with their mate, yet they also feel significant emotional distress themselves. In a study of 1,201 patients with prostate cancer treated with surgery or radiation and 625 partners, researchers found improvement in erectile function may improve health-related quality of life of *both* men with prostate cancer and their partners (Sanda et al., 2008). In a small study from Australia of 50 female partners of men with prostate cancer, women were very resilient in coping with their partner's prostate cancer, but 22% showed signs of depression and anxiety and reduced coping levels (Street et al., 2009).

You may experience a myriad of different feelings at different times. Although prostate cancer is very survivable, there can be many difficulties in dealing with side effects of treatment. It is not unusual to feel insecure about affection, intimacy, and sex. Sometimes you can become so concerned about upsetting your partner that you stop being physical and affectionate. Both of you need to find a way to support each other physically and emotionally. If you and your

partner do not talk about these feelings and vulnerabilities, you will not understand your partner's needs in terms of support. Your partner can not understand your vulnerabilities and needs if you do not communicate those issues to him. Support in terms of emotional and physical affection is very important to both you and your partner.

Communicate

It is important to discuss your feelings and communicate concerns about physical contact. This may be something new for both you and your partner since many people do not talk about sex very much. Communication is important even when a partner withdraws (which men sometimes do when experiencing depression, anger, and/or dealing with loss). Sexual dysfunction and continence issues can be among the most personal and isolating a man can face.

Communication can be key to decreasing misunderstanding. Your loving and accepting approach to your partner can decrease the pressure he puts on himself about sexual performance. Let your partner know that affection and intimacy are important too and are not compromised by erectile dysfunction (ED). You and your partner can cuddle and be sexual in ways that do not require erections. Sex and intimacy can provide a deeper connectedness with a partner, in addition to pleasure and orgasms. All sex can be enjoyable and most men and their partners can climax without penetrative sex. Climax is independent of erections and men who have ED from prostate cancer treatment are typically able to climax even with no erection at all. Women primarily climax from clitoral stimulation and do not need a hard penis in the vagina to climax.

Think of this experience as a fresh opportunity to discover new ways to be sexual and bring pleasure to each other. Erections are not

needed for oral or manual sexual stimulation and many techniques can be enjoyable for you and your partner. With the attitude that "it is all enjoyable," you and your partner can enjoy sexual exploration and affection in new ways. If erections happen, that is great; but if erections do not happen, sex can still be very enjoyable. Remember, an erection is not essential to sexual enjoyment. The only thing you can't do without a full erection is penetrative sex, but you can achieve connectedness, pleasure, and orgasms through non-penetrative sex.

Partner quotes:

"I can't say I can put myself in his shoes because I can't, and I can just be there for him. *And I think in the beginning he felt we weren't there for him, the family, because the family – again, the family does think that the man or father or the husband is strong, – he doesn't get sick. He's there, he has the answer, this is how he is. And then he gets sick and it's like, okay, you're done, you're fine, you had the surgery, it's okay. But it wasn't okay to him, but we felt, no, you're strong, you're okay. And that kind of wasn't good because he felt we didn't care. And we really didn't understand him. A big thing is understanding what this is. But this whole thing, it's like an adventure kind of thing, or just realizing what this whole thing – it's not just, okay, here's the surgery and it's done. It's like all of these little things, the complications, the sex, what happens with emotions and everything. It's just – it's something."*

Another partner said: ***"I was the one that was very pushy about maintaining intimacy.*** *He would get very upset if we would start fooling around, and he started leaking. And I said, 'You know, if it doesn't bother me why does it bother you?' And I know that's probably not the average of what most guys are hearing because most women are weirded out by stuff like that, but at the end of*

the day I was like, 'If we're going to get through it I've got to put my stuff aside, and you've got to put your stuff aside, and we'll get through it because the leaking is not gonna be forever. That's just something that's going on now.' And so I was very pushy and said, 'Just get a towel, and cut it out, and let's proceed.' And we found our way through it. We navigated our way through it. There's never been a time since the surgery that I was not sexually satisfied because we had intimacy. We did other things. We did what we had to do. There was never a time where I felt like, 'Oh, man. This is just – this just sucks.' I was like, 'Okay, there's a new normal now. We can't do that, but we can do this.' And then it was kind of like a game trying to figure out what we could do, and what we couldn't do, and you just, you navigate. It's different, but in some ways it's better, but it's just different."

Another partner said: ***"I didn't know how to verbalize it to him that what I was missing was the contact.*** *I was like, 'I don't care so much about the erection. I'm missing looking in to your eyes, and feeling you,' and I cried about it. And then we figured it out, and then guess what? We fixed it. So, it's just ongoing. Just ongoing, but you know what? You've got to stay connected as a couple. You'll get through it, and just make sure you love somebody because it's going be a journey though, but it's worth it."*

Maintaining Attraction

As discussed earlier, the goal of penile rehabilitation is to improve blood flow to the penis while the nerves recover after prostate surgery or during diminished erectile function after radiation therapy. Men who have undergone prostate cancer treatment are using erectile treatments to improve penile blood flow and preserve erectile function. Regular use of medications or the vacuum device may improve penile blood flow. You can help your partner by encouraging

him to use these treatments along with regular stimulation to promote penile blood flow. Your partner may be embarrassed about needing to regularly self-stimulate and may desire some help from you.

You also have sexual needs and concerns, and it may be important for you to think about how you can deal with your own sexual desires while being supportive to your partner. Many men with ED worry about meeting their partner's needs. Communication about these topics can alleviate some fears and concerns. Attraction toward each other does not have to be impacted by prostate cancer. Letting each other know that you remain attracted to each other and that you find each other sexy can improve sexual self-esteem. It is important to continue to be affectionate and have fun in the many ways you always had fun together. Your attraction to each other and sexual life together are unique characteristics that set your relationship apart from your relationship with others, so maintaining these aspects of your relationship is very important.

Seek Help

Partners may also find that they have their own sexual issues. It is not unusual for women to have changes in desire and arousal before, during, and after menopause. Common problems include vaginal dryness, stress urinary incontinence, changes in ability to become stimulated, and difficulty reaching climax. Diminishing hormones such as estrogen and testosterone can cause some of these problems. Many men experience ED related to medical conditions that occur in the later years of life, such as diabetes, high cholesterol, high blood pressure, heart disease, and obesity. Some men also experience diminished sexual desire. It is important for you (just like your partner with prostate cancer) to speak to a healthcare professional about any sexual issues as many of them can be addressed successfully.

Chapter 14

Adjusting to Changes and Expanding Your Thinking About Sex and Intimacy

After prostate cancer treatment and as people age, sex is different, but it can still be wonderful. Sex and intimacy are about pleasure and feeling connected and loved by a partner. As discussed previously, there are many ways to experience sex outside of intercourse and penetration. Connectedness and pleasure can be experienced though affection, kissing, sensual touch, and genital play regardless of erections. Desire is heightened when partners vary their sexual experiences, increasing the mystery of where each encounter will lead. Working together with a partner in various ways to achieve the goals of connectedness and pleasure through intimacy can be delightful and satisfying for each person.

Although sex does not take much more exertion than the energy to climb stairs or carry a heavy bag of groceries, it does take effort and you do burn calories. As a general rule, if you can safely climb two flights of 5-10 steps comfortably without chest pain, you can probably engage in intercourse (but if you have a heart condition or other medical conditions, consult your doctor before engaging in sexual activities). Some positions and activities may become more challenging if your mobility decreases or you experience other physical limitations. You might try an intercourse position that requires less energy such as lying side by side or sitting with your

partner in your lap. If one partner has more energy or stamina than the other, that partner may be better able to handle the capacity requirements of being on top during intercourse. These positions may be better for couples with decreased energy levels or conditions that affect stamina.

You also may experience better erections in upright positions. Although you may prefer certain positions (those you have used your entire life during sex), others may work better in cases of erectile dysfunction. If you are on top of your partner, your penis gets more blood and may remain harder. The penis may also be harder when you are standing or kneeling rather than lying down. Your partner may kneel and you can have intercourse from behind in a more upright position. Using a tension ring device during sex may help maintain an erect penis in various positions.

Sex can be very fulfilling after prostate cancer treatment, even though it may be different. Trying different positions or ways of being sexual can be exciting and fun. The mystery of what you will explore and do together can increase desire. Try not to become frustrated and upset that things are different now because anxiety increases adrenaline in your body and adrenaline is part of your body's *fight or flight* response. Your erections will dissipate with anxiety. Work on staying focused and present, enjoying every sensation and feeling during intimacy. If your erections are not cooperating, you can still be sexual with your partner. Oral or manual sexual stimulation (using hands to stroke the penis or clitoris or rubbing your genitals together) can be very enjoyable and lead to climax. Some men and women also enjoy adding vibration into love play with a partner. Vibration can lead to enjoyable climax for both men and women. If you are hard enough for intercourse, enjoy it; but if you are not, explore non-penetrative

sex for pleasure and connectedness with a partner. Keys to enjoying sex in different ways are open communication with your partner, willingness to explore and enjoy each other in different ways, and working together to try positions or sexual stimulation that is enjoyable for both of you.

*One man said: **"It will be 4 years next month since my surgery.** And we have never – I've never been this close with anybody or felt this connected with anybody as I have with [my partner]. And I think part of it is because of the support that has been shown for me over these past few years."*

*A partner said: **"I find the experience has brought us a lot closer** for the simple reason is you get a little more creative, and also the desire is always there. And, sometimes, it's not even the act of whatever we do. It's more just the intimate part of getting together, seeing where it leads. If it concludes, if it does not conclude, it's great just getting there. And I think also, there's a million ways to have sex now. Sometimes, it's just holding hands, and it can be the same experience … I don't know how to say, like I think his sexual experience has been greater since it's happened. He's more sensitive. He's had more feelings and is more powerful, either that or he's a great actor because it's a big change from pre to post. So that part's been good."*

Chapter 15
Conclusion: Be Informed

Knowledge is power. This book was written to enlighten and inform you about the impact of prostate cancer treatment on sexual function and evidence-based treatments to address these problems. Erectile dysfunction (ED) is one of the most common adverse side effects following prostate cancer treatment. Although some men might not be concerned about erectile function, others are distressed about this problem and need assistance in determining the best way to move forward to promote and preserve erectile health. Each treatment option has both positive and negative aspects. Ultimately, you must make the best, informed decision for yourself. You need to decide how and if you want to treat ED, and make choices regarding penile rehabilitation and promoting blood flow to your penis to encourage return of spontaneous erections. Each man has his own unique sexual expression. Together you and your healthcare professional can carefully determine how a potential treatment would work within your life.

Penile rehabilitation may improve return of spontaneous erections and your response to some ED treatments. However, there is no clear evidence to support any particular treatment for ED or penile rehabilitation. So, you must look at the pros and cons of each treatment and make decisions that are best for you and your partner. Generally, patients tend to start with less-invasive or less-cumbersome options.

The following comments were shared by men and partners about treatments:

"I can get fairly good erections with the needle injections. *My erections are getting better and better with Cialis. I don't do it nearly as systematically as I should, but I do it regularly and that is take the drugs and manipulate myself and have orgasms and what not. So, I feel like I'm trending in the right direction. I feel like I'm in this kind of hope springs eternal space. I'm seeing movement in the positive direction, which makes me think that I'm going to get back to normal. My biggest complaint, my only complaint, is that my erections are not – well, with the injections they're pretty good, but on my own, I don't get an erection robust enough to be able to penetrate; it just doesn't get hard. With the Cialis, which is easier, they get harder but still not hard enough for good penetration. With the injections, pretty close. Hard enough to penetrate but not the killer boners that I would have liked to have had."*

Another man said: ***"My partner and I are very active sexually.*** *We do a lot of things with a vacuum pump. My surgeon had me on Cialis and a 5 milligram daily dose of Cialis for a while after surgery. That didn't do anything for me. I had the full dose a few times, it didn't help me achieve an erection. A little bit of success with some Levitra and I just bought that again. I've tried it once in the last couple of weeks but in terms of the physical function, I'm still not able to achieve an erection [without the vacuum device]."*

A partner said: ***"I don't need for him to have a huge erection for me to be taken care of.*** *He knows how to please me and I try to please him. Lately he's getting more feeling even though he can't get the erection that he had before, but he's at least getting feeling. He's having orgasms. That's a good thing. I think maybe it is more intimate, not so much physical intimacy, but because we've been through this together now and every day is a great day – every time we get a new PSA, it's oh okay, we've got another 3 months and this is a really great thing. So, there's a different feeling in the intimacy because we are sharing that success together versus just the sexual success, but the sex is still good. It's always been good. It's just different."*

Most men prefer oral agents because they are discreet and easy to use, and these medications can be a first-line treatment. Keep in mind failure rates for oral agents can be high in men right after prostate removal and sometimes after radiation therapy. You will probably need more effective options instead of oral agents (or in combination with them) to provide sufficient erectile function for sex. Nevertheless, despite the fact oral agents do not always provide sufficient erectile rigidity for penetrative sex, they may provide improved return of spontaneous erections after prostate cancer treatments (Montorsi et al., 2000; Schwartz, Wong, & Graydon, 2004). In addition, other treatments such as the vacuum device or MUSE can be used in conjunction with the oral agents to enhance erections and penile rehabilitation.

As a next step, some patients may prefer a less-invasive treatment such as the vacuum constriction device. Although the vacuum device is the least-invasive treatment option, it is cumbersome, requires the user to wear a tension ring during sex, and entails much patience and

work to master the use of the device. Another less-invasive treatment that is simple to use is MUSE. An important factor about MUSE to keep in mind is the issue of pain with alprostadil use after radical prostatectomy.

If you are looking for efficacy and are motivated to carefully use a treatment that is a little more invasive, injections may be an option. You need to understand serious complications are rare, but may occur with this therapy. If you are motivated to regularly prepare and give yourself the injection, this treatment provides consistently effective erections that feel and look fairly close to natural erections. Finally, when medical treatments have failed, it is time to consider the penile implant. The implant provides an effective treatment that is associated with high patient and partner satisfaction, but not all men are willing to undergo this surgical intervention.

Importance of Treatment

Your circumstances with prostate cancer, intimacy, and life are unique to you. Only you can decide how much or little you feel comfortable doing in terms of penile rehabilitation and treating your ED. It is important to understand that *not* utilizing any treatment in the early months after prostate cancer treatment to promote cavernosal blood flow and oxygenation may have long-term ramifications for regaining erectile function in the future. Some research continues to reveal the importance of regular increased blood flow to the penis through the use of treatment for ED to promote corporal tissue health and diminish atrophic changes to penile tissue. Results for using these therapies are mixed, but studies do indicate that early intervention after prostate cancer treatment can be the most helpful.

After prostate surgery, nitric oxide synthesis is diminished due to nerve trauma to the cavernosal nerve (Yiou et al., 2012). Lack of nitric oxide and neuropraxia (nerve no longer transmits impulses) lead to diminished blood flow and oxygenation of penile tissue, which leads to cavernosal fibrosis and collagen synthesis (Leungwattanakij et al., 2003). Atrophy and penile fibrosis cause further ED after radical prostatectomy. Therefore, re-establishing blood flow to the penis while the nerves are recovering is important to preserve and promote optimal erectile function following prostate cancer treatment. The advent of earlier rehabilitation supports better return of spontaneous erectile function, or at least ED that can be treated with less-invasive therapies such as oral medications.

By understanding each treatment option and determining the best choice for treatment, you can find the optimal treatment option for ED and penile rehabilitation. As you consider options, carefully consider your unique sexual lifestyle and how you will incorporate ED treatment into your sexual experience. Enjoying intimacy regardless of erections is very important. You and your partner can feel the connectedness, pleasure, and orgasms associated with intimacy without erections through non-penetrative sex (oral, manual, and/or vibratory stimulation). The more you worry about erections, the more likely anxiety will negatively impact your ability to get and stay hard during intimacy. If you are hard enough for penetration, you can enjoy that. If you are not hard enough for penetration, you and your partner can certainly enjoy intimacy and sex in other ways. This important component of life need not be lost following treatment of prostate cancer.

As one participant said:

> ***"This makes a big difference in my life.*** *The information that I got here, if people could go through this before they have the stress of having it taken out, it would make – it would have made a hell of a difference in my life…"*

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Reclaiming Sex & Intimacy After Prostate Cancer

A Guide for Men and Their Partners

Photo by Thomas Smugala

Jeffrey Albaugh is a board-certified Advanced Practice Urology Clinical Nurse Specialist, Researcher, and Director of Sexual Health at NorthShore University Health System near Chicago, IL. He is also a certified sexuality counselor. In addition to his role at NorthShore, he has led the Sexual Health Clinic at the Jesse Brown VA Medical Center in Chicago for over a decade serving our Veterans. He previously worked at Northwestern Memorial Hospital for almost 25 years.

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