KEN GRIFFEY, SR.

An MLB All-Star speaks about advanced prostate cancer. Come and meet him at our September Conference! (page 8)

Also in this issue:

Mark Moyad, MD, Discusses Ginseng for Cancer Related Fatigue
An Expert’s Tips for Sexual Recovery after Prostate Cancer
2016 Prostate Cancer Conference
Letter from Actor Ryan O’Neal
Mark Scholz, MD, Talks about Prostate Cancer Emergencies
A Letter to our Helpline
GREETINGS RESEARCHER, and welcome to Prostate Insights! This publication is full of information concerning issues that surround prostate cancer. When dealing with a cancer diagnosis, the main focus is usually the cancer itself. While deciding what treatment to choose, patients may overlook critical issues; issues that most are not prepared to tackle. Prostate cancer treatments have side effects that can undermine intimacy in relationships, and some can cause fatigue that can limit one's ability to live a normal life. Many times men do not talk about the symptoms of advanced cancer that they are feeling, and as a result do not get the support and care that they need. There are even some uncommon but very real emergencies that patients need to be aware of when dealing with advanced cancer.

Thankfully, we have experts to address these problems. Additionally, the authors featured in this newsletter will be speaking at our 2016 Prostate Cancer Conference next month, if you are interested in pursuing these topics in greater detail.

Patients often feel reluctant to talk about the issues that affect them. Addressing this issue, Ken Griffey Sr., a three-time MLB All-Star and spokesman for the Men Who Speak Up program, encourages men with advanced prostate cancer to learn about the symptoms of progressing disease so they can receive necessary treatments. In his article, Mr. Griffey shares his personal story dealing with prostate cancer. At our 2016 Prostate Cancer Patient Conference, he will cover available resources that can help men be more forthcoming about their situation. Mr. Griffey is also looking forward to greeting patients at the Men Who Speak Up booth directly after his presentation.

Also in this issue, Mark Moyad, MD, an expert on diet and supplements, shares an effective natural solution to cancer-related fatigue using ginseng. Ginseng has been shown to counteract fatigue in multiple clinical trials. Dr. Moyad explains these trials and their effects in his article. For those who want additional information, Dr. Moyad will be covering the topic of diet and supplements at the 2016 Conference.

Sexual dysfunction occurs commonly with prostate cancer treatment. This problem must be recognized as a couples' disease, as it affects intimacy and can stress relationships in unexpected ways. Dr. Erica Marchand, a practicing therapist who specializes in sexual intimacy after cancer treatment, shares nine practical tips to help you and your partner build intimacy in the wake of cancer treatment. Dr. Marchand will also be leading a Sunday breakout session on correcting sexual dysfunction function at the 2016 Conference.

Lastly, prostate cancer specialist, Mark Scholz, MD, highlights rare but significant emergencies men with prostate cancer can potentially face. Men with metastatic prostate cancer and their caregivers need to be aware of these issues.

Near the end of this issue, we have published a letter we received from a prostate cancer caregiver which highlights the impact of the PCRI's free Help-line. As you read, you will discover that you are not alone in your battle against prostate cancer and there are numerous resources available. We encourage you to keep researching. There are many things you can do to maximize your quality of life and your relationships.
FEATURED ARTICLE: USING GINSENG FOR CANCER RELATED FATIGUE
Mark Moyad, MD
The Cheapest, Best, Safest Available "Drug" for Cancer-Related Fatigue (CRF) that no one knows about until now, despite being proven to work at the Mayo Clinic, MD Anderson Cancer Center & 40+ other medical centers many years ago!?? What the heck is Moyad talking about?!

FINDING MY VOICE TO SPEAK UP ABOUT PROSTATE CANCER
Ken Griffey Sr.
Ken Griffey Sr. is a three-time baseball All-Star, a prostate cancer survivor, and a spokesperson for Men Who Speak Up, which encourages men with advanced prostate cancer to know the symptoms of progressing disease and offers resources to help them feel more comfortable speaking up about it.

2016 PROSTATE CANCER CONFERENCE
The September Conference is approaching, and we have an amazing lineup of speakers and celebrities showing up at the Los Angeles Airport Marriott. You do not want to miss this one of a kind event!

2016 MID-YEAR APPEAL LETTER, RYAN O’NEAL
Ryan O’Neal
Patients and their families are rarely prepared to handle the stress and uncertainty that comes with the diagnosis of prostate cancer or a recurrence. They feel pressured to choose the first treatment recommended and often never hear all their treatment options.

FEATURED ARTICLE: SEXUAL RECOVERY AFTER PROSTATE CANCER: 9 TIPS FROM A SEX THERAPIST
Erica Marchand, Ph.D.
If you or your partner have experienced prostate cancer, you might have questions and concerns about sexual recovery and rebuilding your sex life. This article will help identify things you can do now, wherever you are in your recovery, to start to create the sex life you want.

HELPLINE CORNER: A LETTER FROM A CALLER
This is a letter that we received from a recent helpline caller. It demonstrates the critical importance of support, empowerment, and information and how it prepares you for partnership with your medical professionals.

ERECTIONS LASTING 4 HOURS AND OTHER EMERGENCIES
By Mark C. Scholz, MD
Since prostate cancer is predominantly a slow growing and often asymptomatic disease, emergencies directly caused by prostate cancer are relatively rare. But there are a few conditions that can arise and it is good to be aware of them. Dr. Scholz highlights them.
Using Ginseng for Cancer-Related Fatigue

Mark Moyad, MD, MPH
University of Michigan Medical Center

The Cheapest, Best, Safest Available "Drug" for Cancer-Related Fatigue (CRF) that no one knows about until now, despite being proven to work at the Mayo Clinic, MD Anderson Cancer Center & 40+ other medical centers many years ago!!?? What the heck is Moyad talking about?! (Shameless plug #235-See "The Supplement Handbook" by Moyad on Amazon after reading this article).
INTRODUCTION

I often get the following question: Hey Dr. Moyad you look like a perfectly sculpted international male middle-age model, so why continue working in medicine and even with PCRI when you could make more money just having magazines and world renowned fashion designers take pictures of you and lionize you 24 hours a day? Okay, actually that is not the question people ask me, but in my dreams, I am often asked that exact question by my wife, friends, parents, dog, kids, neighbors, and celebrities.

The question I really get often is “Why is there no single, cost-effective, safe, and effective treatment to reduce fatigue from cancer treatment?” This condition is known as CRF officially, or Cancer-Related Fatigue. And, the amazing answer is that for many years there has been something that could help, and it is really cheap and safe, but no one knows about it because it is a DIETARY SUPPLEMENT!!! What the HE—DOUBLE TOOTHPICK!! That is right! This is probably going to be more surprising for you than finding out that Big Foot and Elvis are still alive (they are still alive by the way, and live together in the Upper Peninsula of Michigan in a small cottage on Lake Superior—I read it in one of those magazines by the check out counter at the grocery store yesterday—and we all know how accurate those magazines are—the article on Big Foot and Elvis was right next to the bigger article on page 1 of the man that locked himself in his new empty refrigerator on accident and could not escape for 2 months but survived by eating his own left foot).

PREVALENCE OF CRF

So, how bad is CRF really Doc Model Moyad? In clinical studies and in real life, it can occur in as many as 60-90% of patients! And it is also one of the most common or primary side effects of one of the best prostate cancer drugs ever invented known as “Xtandi,” and it is a common side effect of most of the other incredible prostate cancer drugs from hormone therapy to Zytiga, and of course chemotherapy. Basically, it is this fatigue side effect that all the prostate cancer drugs have in common but not a single effective CRF option exists in cancer? WRONG! WRONG! WRONG! (3 times should be enough for emphasis and annoyance).

So, let me now provide a recent quotation from famous Mayo Clinic doctors in the most prestigious cancer medical journal in the world: “Nevertheless, for patients who want to try a pharmacologic product and physicians who are early adapters of new promising agents, the pure ground root American ginseng product, as used in the above studies, might be an option to consider” [1]. This was an editorial or comment from some of the top experts in the field of conventional treatments for CRF from the #1 oncology medical journal in the world, which is arguably one of the strongest potential endorsements of a dietary supplement to prevent or treat a common cancer treatment side effect not explained by other factors.

CLINICAL TRIALS FOR GINSENG

Why such verve for American ginseng (also known as “Panax quinquefolius”... thank you to my Latin teacher from 7th grade and sorry for always being late to class!)? The excitement was based on two strong-in-methodology clinical trials, somewhat similar to phase 3 drug trials [2,3]. A total of 364 participants were enrolled from 40 MEDICAL CENTERS (not four but 40, folks!) in the most recent trial and patients were dealing with breast, colon, or prostate and even other types of cancer [2]. After approximately two months a significant difference (aka twice the effect at reducing fatigue compared to placebo) was observed with ginseng. Side effects were similar to placebo! Participants received 2000 mg of Wisconsin ginseng (a type of high-quality American ginseng) or placebo in that trial.

“Nevertheless, for patients who want to try a pharmacologic product and physicians who are early adapters of new promising agents, the pure ground root American ginseng product, as used in the above studies, might be an option to consider”

Mark A. Moyad, MD, is the Jenkins/Pokempner Director of Complementary & Alternative Medicine at the University of Michigan Medical Center and he has written many popular books on the subject of diet, supplements, and overall health. His most recent book is: The Supplement Handbook: A Trusted Expert’s Guide to What Works & What’s Worthless for More Than 100 Conditions. He will be moderating the 2016 Prostate Cancer Conference in September. Don’t miss it! Learn more on page 10.
This same research group from the Mayo Clinic (I love the Mayo—it is my favorite condiment to use in my weekly sub sandwich) also observed anti-fatigue effects at 1000 mg per day in a previous clinical trial of 290 cancer patients [3]. And, the pure ground root ginseng in these clinical trials was donated by the Ginseng Board of Wisconsin (Wausau, WI, go to www.ginsengboard.com to get more information or go to www.ginseng-herbco-op.com to purchase the exact cheap product used in the clinical trials...oh and I have no commercial interest in this company at all). It is also of interest that in these large clinical trials patients appeared to receive greater anti-fatigue benefits when ginseng was used earlier in the course of conventional cancer treatment (as opposed to later or after treatment).

Another small, single-arm clinical trial of 800 mg per day of another type of ginseng known as "Panax/Asian Ginseng" (from Indena S.p.A. Milan, Italy) at MD Anderson Cancer Center found a significant reduction in CRF within one month in cancer patients. This study needs confirmation in a larger randomized trial [4]. This supplement also appeared to significantly improve quality of life and also appeared to improve sleep, appetite, pain, and other issues related to CRF in 30 days. WOW spelled backward!

Thus, the cumulative evidence from the Mayo Clinic directed and MD Anderson Cancer Center studies are more than sufficient evidence to offer ginseng as a primary anti-fatigue option, especially since patients have few options in this area, and some of the more expensive pharmaceutical based products (stimulants, anti-depressants...) have been disappointing when further studied and some cost more than a Porsche filled with money (okay I embellished that slightly but they cost "mucho dinero"—thank you Spanish teacher from high school and sorry for making dumb jokes in class like what is the weather forecast for Mexico City..."Chili today and Hot Tamales" or what happened to the Spanish fisherman that said "yes" too much...well he got "Si-sick" or what happened when the Spanish boy dropped the mayonnaise jar in the pool...he shouted "Sinko de Mayo"!...Ouch...I know...I should stick to my night job...you are lucky I did not tell my French jokes like what happened when 3 cats fell through the ice in Lake Michigan...well the Spanish Sheriff said told the media that "un deux trois quatre cinq"...if you do not get it then google it cause it is hilarious).

**HOW GINSENG AFFECTS FATIGUE**

Ginseng appears to reduce the inflammatory process associated with cancer or chronic fatigue due to inflammation in general [1-5]. Ginseng may reduce cortisol and thus reduces stress overall to improve energy levels. Whether or not the primary anti-fatigue effects are being derived from the standardized ginsenoside and/or polysaccharides content or another specific active compound in the supplement is a matter of debate and more research. Again, the fact that there were no side effects beyond placebo and American ginseng has been found to have no real current strong drug interactions or interfere overtly with major drug metabolism is noteworthy. Ginseng from water extraction or from pure ground root has been associated with the best results and safety, and ginseng extraction methods due to alcohol or methanol based procedures could be less effective, and some researchers believe toxic with long-term use [2]. Additionally, ginseng (American or Panax ginseng) has a long history of having an ability to improve energy levels in healthy individuals, but again because it worked for more extreme fatigue from cancer treatment, it can help with many types of fatigue from my experience. Ginseng can be ingested with or without food, but with a meal could reduce gastrointestinal side effects like acid reflux caused by pill consumption in general. Cut the capsules in half to
make them easier to swallow if the pill is too large (use a pill cutter please). AND THE BEST PLACE TO BUY IT IS FROM THE GINSENG BOARD OF WISCONSIN (Wausau, WI, go to www.ginsengboard.com to get more information or go to www.ginsengherbco-op.com to purchase the exact cheap product used in the clinical trials) because we want to reward the research (like we would with a drug) and use the same cheap and effective product used in the Phase 3 Mayo Clinic trial of cancer patients. And, you will not have to deal with the potential quality control issues with ginseng that you can get by just buying some random ginseng product from the health food store down the street or your local drug store that could be filled with contaminants and does not contain the standardized drug-like ingredients used in the Mayo clinical trials.

Finally, lets solve the final mystery (not of Jimmy Hoffa or the Loch Ness monster...oh and both of them are also alive by the way and living near Malibu Beach, CA and yes I read that from another high-quality magazine near the checkout counter at Walmart right next to the article of the man that claimed he has been in a UFO many times as they buzzed through Iowa cornfields to make those weird, mysterious shapes and the government told him not to say anything), no, the mystery of why no one really knows why the best, safest, cheapest drug/supplement in the world for CRF gets no attention or love? It is because a dietary supplement is not allowed to claim to prevent, treat, mitigate, or cure a medical disease or condition despite the fact that most of the best-selling effective supplements in the U.S. are just prescription drugs in other countries and that doctors generally recommend supplements for medical conditions [5]. Still, a recent survey of U.S. oncologists demonstrated that most admit that they do not talk about herbal supplements with patients because they do not believe they know enough about them [6].

So, who loses here? Health care professionals lose (unless they attend a Moyad course on dietary supplements or read this article) and so do patients because they do not get the information from some of the wonderful doctors they trust the most! THIS IS SAD, BUT IT IS THE REALITY of some of the silly and dumb rules that govern dietary supplements. NO ONE REALLY WINS!!! However, this article is one of the many reasons why I believe a little education can change this silly game quickly so that patients and health care professionals win! SO, LETS START WINNING. SHARE THIS ARTICLE WITH EVERYONE INCLUDING YOUR PATIENTS, DOCTORS, CATS...!!! YEAH!!! WINNING IS FUN!!! See you at the PCRI September 2016 Meeting! Winning!!!

CONCLUSION

So, I need to go now because this article is way too long, and I am experiencing what is now known as “FTFPCS” or “Finger Tip Fatigue from a Personal Computer Syndrome” which an attorney on TV just told me that a pharma company is responsible for, and as long as I call the number on the screen I could make millions! Oh boy! WINNING AGAIN!!!

Finding My Voice to Speak Up about Prostate Cancer

By Ken Griffey Sr., MLB All-Star
2016 Prostate Cancer Conference Speaker

Ken Griffey Sr. is a three-time baseball all-star, a prostate cancer survivor, and a spokesperson for Bayer’s Men Who Speak Up program, which encourages men with advanced prostate cancer to know the symptoms of progressing disease and offers resources to help them feel more comfortable speaking up about it. Mr. Griffey, who is conducting a nationwide Men Who Speak Up tour with his son, Hall-of-Famer Ken Griffey Jr., will be a guest speaker at the 2016 Prostate Cancer Conference on September 10.
**PROSTATE CANCER** is an issue that’s close to my heart. As someone who has lost four uncles to the disease, I learned the importance of advocating for my own health early on. My mother drilled into me and my brothers that prostate cancer was something we needed to be aware of, given our family history.

That’s why I always asked for a prostate exam at each annual physical, even when it wasn’t required. In 2006, I was thrown a curveball during a routine screening: My doctor told me I had prostate cancer. I had difficulty processing my own diagnosis. I didn’t know what to do with the information, let alone talk about it. It took a great deal of encouragement from family for me to open up about how I was feeling. Especially in the first year after my diagnosis, there were moments I didn’t think things would improve. But fortunately, I responded well to treatment and felt better over time.

I’m lucky that my doctor caught and treated my prostate cancer early, but I know that not all men have the same experience. There are times when prostate cancer advances and becomes life threatening. Prostate cancer is not just the second most common cancer diagnosed; it’s also the second leading cause of cancer-related death among American men. That’s why it’s critical for men to speak up if they experience any symptoms or physical changes, as they could be signs the disease is progressing.

One of the biggest lessons I learned after my diagnosis is that health issues, especially those that are cancer-related or linked to sexual health, can be very uncomfortable for men to talk about. When it comes to prostate cancer, it’s hard for men to admit they have this kind of a problem. I have seen this firsthand; only after my prostate cancer was publicly announced did I learn that three of my golfing buddies also had prostate cancer. They hadn’t felt comfortable sharing the information until it had made headlines with me. But the reality is that no one should be scared to speak up about their health.

Prostate cancer has touched so many around me: my uncles, my golf buddies, and — just recently — my younger brother. Because of that, I joined Bayer’s Men Who Speak Up campaign to help men be empowered to talk about their advanced prostate cancer symptoms. Through my partnership with Bayer, I learned a lot about the disease that I had never really thought about before, such as how it can progress, and what symptoms are associated with that progression. Some of those symptoms, such as fatigue, difficulty walking or sleeping, unexplained pain, or difficulty doing normal activities, often don’t emerge until the disease has advanced. What’s more, the cause of these symptoms is not always obvious. Doctors can help men recognize the symptoms of advanced prostate cancer and manage their disease — but only if men are willing to speak up about them.

Men Who Speak Up is a program dedicated to men with advanced prostate cancer and their loved ones. What appeals to me about Men Who Speak Up are the tools and resources that have been created to help men who have progressed to this stage. The symptoms tracker and the discussion guide in particular can make it much easier to prepare for doctor appointments. I don’t think anyone going through this would disagree that it can sometimes be difficult to gather your thoughts before an appointment. There’s a lot going through your mind, and a lot to cover in a relatively short period of time.

I’m proud to share my personal story with men around the country, and I encourage them to do the same. For more information on Men Who Speak Up, visit www.MenWhoSpeakUp.com.
A COLLABORATIVE LEARNING EXPERIENCE FOR PATIENTS + CAREGIVERS

SEPTEMBER 9-11, 2016 // LOS ANGELES AIRPORT MARRIOTT
The Prostate Cancer Conference is an event where you can interact with leading doctors and have your questions answered. Presentations cover every prostate cancer topic from treatment options to side effect management. Multiple Q+A and breakout sessions put you in contact with practicing physicians and leading researchers from around the world. You will also glean from the experiences of your fellow patients and caregivers in support groups, breakout sessions, dinners, and excursions.

The interactive nature of the event is a breath of fresh air on your journey and a source of hope and encouragement. You will find empowering information that is relevant to your case. We look forward to seeing you in September!

[Event Overview]

[Travel + Lodging]

The conference is held at the Los Angeles Airport Marriott. Rooms are available for reservation by calling the Marriott directly at 310.641.5700 or by visiting www.PCRI.org for the online booking link.

- Discounted airline booking with Delta is available via www.delta.com. When booking online, select Book A Trip, click on Advanced Search and use the meeting code NMKZ8
- Discount car rental through AVIS using discount code #D374541
- There is a complimentary shuttle from LAX terminals to the Marriott
- A reduced self-parking rate of $19/day is available for those who are driving to the conference

[Featuring]

- Presentations from practicing physicians and leading clinical researchers on new developments, treatments, pharmaceuticals, and clinical trials for every stage of prostate cancer
- Presentations on reducing treatment side effects and maximizing quality of life
- Interaction with experts in extensive Q+A and “Ask The Experts” breakout sessions
- Support groups
- Informational sessions for caregivers
- Exhibit hall featuring resources and products from our industry partners
- Explore Los Angeles by signing up for our Malibu Winery excursion
- Celebrity guests

FOR INFO + REGISTRATION VISIT: www.pcri.org/2016-conference or call 310.743.2116

Speakers and topics on the next page →
Conference Speakers + Topics

We are proud to welcome this esteemed faculty to present at the conference:

Mark Moyad, MD
*University of Michigan Medical Center* // TOPIC: Conference Moderator + Moyad’s Magical Mini Review of Alternative Therapy: From Marijuana to Multivitamins

Mark Scholz, MD
*Prostate Oncology Specialists* // TOPIC: Conference Moderator and Prostate Cancer Expert Q&A

Mark Emberton, MD
*University College London Hospital* // TOPIC: Hifu & Other Novel Prostate Cancer Treatments: Are These Really Options For Me?

Eugene Kwon, MD
*Mayo Clinic* // TOPIC: The Revolution in Prostate Cancer Imaging: What Do I Need to Know?

Gary Leach, MD
*Cedars-Sinai* // TOPIC: Fixing Incontinence After Prostate Cancer Treatment: What Are My Options?

Howard Sandler, MD
*Cedars-Sinai* // TOPIC: Early Stage Chemo & Breakthroughs in Radiation: Can These Really Be Combined?

Charles Myers, MD
*American Institute for Diseases of the Prostate* // TOPIC: Snuffy Myers, MD vs. Mark Moyad, MD: Mayhem At The Marriott

Nicholas Vogelzang, MD
*Comprehensive Cancer Centers of Nevada* // TOPIC: Hormone Resistance and Bone Metastases: What Are My Options?
Dear PCRI Supporter,

When you or a loved one is diagnosed with prostate cancer, the Prostate Cancer Research Institute can provide empowerment, emotional support, and educational information. Thousands of men are in desperate need of information they can trust. Your donation enables PCRI to continue its outreach impacting the lives of patients and caregivers facing this disease.

For 20 years, the PCRI’s Helpline, patient conferences, website, and newsletters have provided emotional support and state-of-the-art information for patients and caregivers. The PCRI’s patient-centered outreach empowers patients to achieve better communication with their doctors leading to better healthcare decisions.

Patients and their families are rarely prepared to handle the stress and uncertainty that comes with the diagnosis of prostate cancer or a recurrence. They feel pressured to choose the first treatment recommended and often never hear all their treatment options.

The PCRI bridges educational gaps, gives support, and provides a compassionate and listening ear. All of this is made possible by support from caring people like you. Please send a generous donation to the PCRI and help fight the battle against prostate cancer.

Sincerely,

Ryan O’Neal

Donate To PCRI today!
Visit www.pcri.org/donate or call 310-743-2116

Receive a free copy of the educational DVD from our 2016 Mid-Year Update with your donation of $50 or more!
Sexual Recovery after Prostate Cancer: 9 Tips from a Sex Therapist

Erica Marchand, Ph.D.

If you or your partner have experienced prostate cancer, you might have questions and concerns about sexual recovery and rebuilding your sex life. This article will help identify things you can do now, wherever you are in your recovery, to start to create a sex life you want. With prostate cancer, as with many things in life, there are the physical realities of the situation, and there are options for dealing with those realities. How we deal with the realities influences how they affect our lives. Try to adopt the mindset that you will do your best to create what you want sexually, within the boundaries of what’s physically possible.

What do you think of when you think of life after prostate cancer? For many people, sexual concerns are at the top of the list. What are some common concerns related to sexual functioning after prostate cancer?

- Erectile dysfunction
- Changes in orgasm & ejaculation
- Loss of desire
- Feeling less masculine
- Fatigue
- Partner communication issues
- Fear or anxiety
- Sadness or loss

PHYSICAL AND MENTAL FOUNDATIONS FOR HEALING

Let’s talk about physical care first. For many people, there’s a period of physical healing from 6-24 months after surgery or radiation. During that time your doctor may prescribe medications or activities that are intended to help with healing and sexual recovery. Be sure to do the things your doctor has recommended. Be consistent. This will give you the best chance of recovering full sexual function. If your doctor hasn’t talked to you about sexual recovery, ask him or her about it specifically.

For many people, there’s also a period of mental and emotional adjustment after treatment. You and your body have been through a lot. Give yourself time and space to feel whatever you feel. Sadness, fear, loss, worry, grief, anxiety, anger, and other difficult emotions might be part of your experience.

We can place a lot of pressure on ourselves to minimize difficult feelings and “push through” or “keep your chin up.” However, it’s not possible to skip over hard feelings when something difficult happens. They’re still there, and if we don’t acknowledge them, they tend to come out in other ways. So if you’re feeling shaken up, know that it’s normal, and give yourself time to process it. You might talk with a friend, write about it, make some art, play some music, move your body, or just sit with yourself and experience what’s going on inside. Trust that the feelings won’t consume you, and you’ll come out the other side stronger.
9 TIPS FOR SEXUAL RECOVERY

When you’re ready to think about sex again, these tips can help:

**Define what you want.** What do you value and want in your sexlife? It’s easy to get caught up in fearing what we don’t want, but it’s more helpful to define what we want. Even with physical changes, how would you like your sex life to be following prostate cancer? Think of some adjectives – hot, fun, pleasurable, sexy, active... Think of some activities you’d like to include, and how you’d like to feel. Spend some time visualizing all this, so you’ll know what you’re aiming for.

**Manage fear and anxiety.** Notice what happens when you visualize what you want. You might feel a mix of emotions, including fear and anxiety. You might be thinking about how you’re ever going to get back to what you want sexually. Accept these thoughts and feelings, but don’t let them stop you. If you have doubts and fears, try thinking of them as your inevitable companions on this journey back to better sex.

We can place a lot of pressure on ourselves to minimize difficult feelings and “push through” or “keep your chin up.” However, it’s not possible to skip over hard feelings when something difficult happens. They’re still there, and if we don’t acknowledge them, they tend to come out in other ways.

**Talk with your partner.** If you’re concerned about changes in sexual function, or differences in how you feel, or wondering what your partner might be thinking, the best thing to do is to talk about it. Pick a good time, when you’re not tired, not pressed for time, and your partner is available to talk—maybe over coffee or a glass of wine. You might start by saying something like, “Hey honey, I want to talk to you about something... Our sex life is really important to me and I know that prostate cancer has changed things... I want to talk about what’s on my mind, and anything that might be on your mind, and where we should go from here.” You might tell your partner about what you want in your sex life at this stage, and ask what they want as well.

**Explore your body.** Once you’ve healed enough that it’s safe to do so, spend some time with sexual self-stimulation to see how your body responds. What do you notice about what kind of stimulation you need to get aroused? The amount of time needed to get aroused? How your physical response matches your mental response? How orgasm feels? Try to do this with an open mind and a sense of exploration. This will help you know what to expect in a sexual encounter, and any changes you might want to tell your partner about.

**Identify what would feel good.** What might you want to do with your partner, after knowing a little more about how your body is responding right now? For many guys, erections don’t return right away, or they may return but be different that what you’re used to. It can be tempting to put off sexual activity until things feel more “normal” again. In doing
so, though, you and your partner might be missing out on opportunities for pleasure and connection. If you’re willing to experiment, identify some activities you and your partner might enjoy that don’t necessarily require an erection. Then, try them. And enjoy.

**Play.** Take a deep breath and try to mentally take the pressure off of yourself to perform or achieve anything. Try to re-frame your role in sex to something less achievement-oriented – a participant, not a performer. Especially when you’re re-learning and adjusting to changes in your body, internal pressure to achieve can be counterproductive. It can be helpful to give yourself permission just to play -- participate, experiment, and see what feels good to you and your partner, with no particular outcome in mind.

**Start from neutral.** One of the top complaints I hear about prostate cancer treatment is loss of desire for sex. This might be from androgen-deprivation therapy, physical, and psychological effects of surgery or radiation, or just garden-variety stress and fatigue. If you’re not spontaneously desiring sexual activity but know that you want sex back in your life, consider starting from neutral. This means making a conscious choice, based on your own vision for your sex life, that you would like to engage in sexual activity, regardless of how much desire you feel at the outset. For many people, desire can emerge in the process of starting to be sexual and experiencing arousal, even if the desire wasn’t present at the beginning. If you’re accustomed to your sex life being driven by spontaneous desire, this might be new for you. I’d encourage you to give it a try and see what happens.

**Be extremely kind to yourself.** Again, your body and mind have been through a lot. It can be vulnerable to open up sexually to a partner after all of this, and it helps to be on your own team, cheering yourself on through the changes. If you tend to be self-critical, watch out for this tendency during sexual recovery. Try to congratulate yourself instead for small successes, and especially for showing up and trying to get what you want.

**Take good care of yourself.** This goes along with the previous tip, and it’s fundamental. Eat well, sleep, exercise, give yourself downtime when you need it, talk to your support system, do things you enjoy. Sexual recovery is easier with a good foundation of self-care.

**CONCLUSIONS**

Hopefully, this gives you some ideas for how to re-gain and re-create the sex life you want after prostate cancer. If you get stuck, or you and your partner run into problems you can’t solve, remember that a little bit of counseling can go a long way to helping you get past those bumps. Don’t hesitate to seek out a good therapist if you think it could help you create a more enjoyable, satisfying sexual recovery.

“For many people, desire can emerge in the process of starting to be sexual and experiencing arousal, even if desire wasn’t present at the beginning.”

For more information, visit Dr. Erica Marchand’s website at http://www.drericamarchand.com or visit the PCRI website at www.pcri.org or call our helpline at 1.800.641.7274
Helpline Corner: A Letter from a Caller

By “A Faithful Caregiver”

This is a letter that we received from a recent helpline caller. It demonstrates the critical importance of support empowerment and information and how it prepares you for partnership with your medical professionals. This letter was published with permission from its author.

THIS LETTER is long overdue, and words cannot even express my deepest gratitude for your organization that has provided so much help to my husband and me. When my husband was newly diagnosed with prostate cancer in 2012, it left me as a caregiver, devastated. I felt hopeless and afraid with nowhere to turn for support. I remember so distinctly my first call to your Helpline. My anxiety was through the roof, and Silvia Cooper, who is now the most selfless woman I know, assisted me by listening and asking me some tough questions, so that she could provide the best possible resources to us.

That April of 2012, Silvia changed my life. I had nowhere to turn for support. I just wanted someone to really listen, I had so many questions. Would my husband live? If so, how long will he live? These were just some of the anxiety issues I was facing. Mrs. Cooper was there for me every step of the way. Thank you for all the valuable resources! Based upon those resources, we were able to make a wise, informed decision and choose the best treatment options for my husband.

Further, PCRI Helpline educated us as to how to use correct terminology when dealing with the urologists, oncologists, and primary physician. Being able to communicate effectively with the team of doctors made all the difference in the world. We felt like we were heard. In my humble opinion as a caregiver, I don’t think we would have received the quality level of care if we had not been educated about how treatment for this disease can have major impacts on one’s health and well being.

All I wanted at the time was for someone to listen and care about how I was feeling as a caregiver. During this difficult time, my husband had been dealing with his own issues as it relates to this disease. But I often felt like the pressure was on me. I learned to take one day at a time and take care of myself as well. I needed to remain sane and strong through the ups and downs.

I also want to thank Bob Each for cheering my husband up. My husband’s PSA is rising again, 4 years after having a prostatectomy. To see the smile on my husband’s face after he and Bob talked was a whirl of positive energy. Bob’s spirit is positively contagious, as his sense of humor about this disease is breathtaking and refreshing. My husband now calls Bob his ‘go-to man’ for any questions he may have regarding recurrence. Thank you, Bob. My husband said: “I will always remember that guy because his sense of humor about this disease helped me look at things in a different way.” So thank you, Bob, for reducing my husband anxiety when his PSA was starting to rise again. And of course, you reduced my level of anxiety too, which was probably higher than his.

The work that PCRI does is over and beyond our greatest expectations. As a caregiver, I feel much more confident communicating with my husband’s team of doctors and feel like I can stay on top of the current educational resources, so that my husband can receive the best quality care relating to his disease. Thank you for your time. Thank you for your continued dedication, working tirelessly to provide support to all of us caregivers and patients who are living with this disease and may feel as though there is no light at the end of the tunnel.

In closing, please know that the work that you all do at the Prostate Cancer Research Institute is not in vain, and you are making a difference in the lives of many people living with this disease.

Bob Each, PCRI Helpline Facilitator

Need someone to talk to?
Call the PCRI Helpline!
1.800.641.PCRI (7274)
Experienced and trained volunteers can answer any questions you have about prostate cancer
ERERCTIONS LASTING 4 HOURS

and Other Emergencies

By Mark C. Scholz, MD

Since prostate cancer is predominantly a slow growing and asymptomatic disease, emergencies directly caused by prostate cancer are relatively rare. But there are a few conditions that can arise and it is good to be aware of them. Dr. Scholz highlights a few of these emergency conditions.

Mark C. Scholz, MD
Executive Director, PCRI
Medical Director, Prostate Oncology Specialists

All jobs have their pros and cons. Good pay versus bad hours; tough bosses versus a nice work environment; and so on. One thing I really like about specializing in prostate cancer is that emergencies are very rare. My job requires making important decisions about people's health, but the slow pace of prostate cancer gives plenty of time to think and reflect about the advice I render. What I don't like about emergencies is that they demand immediate action. People get rushed by the urgency of the situation, thinking gets clouded and mistakes are made.* In the world of surgery or emergency medicine, for example, mistakes are common. When doctors make mistakes, people suffer.

Managing men with prostate cancer certainly presents many emotional and intellectual challenges. Time pressure, thankfully, is rarely the issue. Recently, however, I got a call and was reminded about the exception to the rule, an emergency that everyone with metastatic prostate cancer needs to know about. A support group leader in Phoenix called me for advice about a mysterious situation faced by a man in his support group. Apparently, this individual had developed unexplained weakness in his legs for the last six weeks. He was also having trouble controlling his urinary function. He was concerned. The doctors seemed mystified as to the cause. He wanted to know if I had any ideas about what might be going on.

Even before he finished speaking a hopeless feeling started to rise in me. He was describing the common symptoms of spinal cord compression. Pressure from progressive cancer in the spine was pushing on the spinal cord choking off its blood supply. Without immediate treatment paralysis usually becomes permanent. He did say a neurologist had been consulted the preceding day though he had not heard yet what the doctor was recommending. I assured him that any competent neurologist would know exactly what to do. Since I did not have all the medical details I refrained from telling him that his friend's symptoms were likely to be irreversible. →
SPINAL CORD COMPRESSION

Spinal cord compression is a disaster. However, knowledgeable patients and doctors who act quickly can prevent it. What are the symptoms that men with metastatic cancer should be aware of?

- New, sudden onset or sharply increased intensity of pain in the spine
- New, sudden onset of weakness or numbness in the legs
- New, sudden loss of urinary control or bowel control

The “suddenness” is related to the progressively enlarging tumor in the spine pressing on the spinal cord, “pinching” the cord against the bony wall of the spinal canal, cutting off the blood supply. Without blood, the cord will die. All nervous control of all the functions of the body below the level of compression will be lost.

Since cord compression is a medical emergency, men with metastatic disease who suddenly develop a new persistent pain in the spine should contact their doctors immediately or go to the emergency room. Whether or not the spine pain is due to cord compression can be determined by performing an MRI scan. If cord compression is confirmed, treatment with high dose cortisone is begun and the tumor is treated with emergency radiation or surgery. If cord compression is diagnosed and treated in a timely fashion the symptoms are 100% reversible.

CHEMOTHERAPY AND THE IMMUNE SYSTEM

In the interest of completeness, let me briefly relate the only other prostate-cancer-related emergency I am aware of. This situation only relates to men who are taking chemotherapy. Chemotherapy causes transient, cyclical suppression of the immune system. A patient’s vulnerable period occurs about one week after the infusion is administered. If men develop a fever during this time period, they need a CBC blood test to measure their white blood cell count. If the white blood cell count is too low, antibiotics should be started. Otherwise, the infection could become life-threatening.

FINAL THOUGHTS

I find the emotions of anxiety and fear unpleasant, clouding thinking and leading to mistakes in judgment. The generally slow-paced world of prostate cancer, therefore suits my personality just fine. A mental alarm needs to go off, however, when men with metastatic disease develop new-onset spine pain or a fever after chemotherapy. If one’s doctor cannot be reached, a trip to the emergency room is needed.

I have also been preparing for many years, ever since the Viagra commercials came out, to intervene on behalf of my patients who develop 4-hour erections. If I ever hear of one, I’ll be sure to write that story as well.

“If cord compression is diagnosed and treated in a timely fashion the symptoms are 100% reversible.”
The Prostate Cancer Research Institute is a 501 (c)(3) charitable not-for-profit organization located in Los Angeles, California. Our mission is to help men research their options. We assist them with their research by disseminating information that educates and empowers. Our programs help them understand their type of prostate cancer and the best way to treat and manage it.