



PCRI Insights

New Developments in Prostate Cancer Treatment Patient & Physician in Co-Partnership

August 2014 VOL 17: NO 3

**New studies on the use of
Taxotere for high-risk &
advanced cancer: Page 7**

**What to expect at the
2014 Prostate Cancer
Conference: Page 14**

**The importance of participating
in a support group: Page 16**

SHARED DECISION-MAKING

*What is it, and what
does it mean to you?*



Helping Men Know Their Options

Shared Decision Making

By Peter Scholz, PCRI Communications Manager and Insights Editor

Having been involved in an oncology environment for years, I see and hear about many developments in the world of prostate cancer care. There are many exciting advancements in the field of prostate cancer, but as our Executive Director, Mark Scholz, M.D., says, “On its own, the prostate cancer field is resistant to change and in common practice, the disease is being treated the same way it always has been treated. But the medical world needs to embrace the new, advanced ways of treating the disease. Thankfully, knowledge of these advancements is starting to spread through patient channels. As a consequence, the medical world will have to start stepping up its game.” Patient oriented support and education organizations are a key factor in the proliferation of this knowledge. They act as a catalyst that pushes these advancements into common practice.

The upcoming implementation of the Healthcare Reform Act enforces what is called “shared decision making,” the concept that the doctor and patient must dialogue about different treatment options and side effects before arriving at a decision. For years, the PCRI has strongly believed in the importance of patient empowerment since patients aren’t always informed of all of their options in the conversations they have with their doctor. When the patient knows their options their doctors remain accountable, and up-to-date.

Most men only begin looking for information when they are at a crossroads, as Jerry Deans says in his story later in this issue, “Very few people who are diagnosed with prostate cancer have an adequate knowledge base specific to the disease diagnosis, treatment options, side effects, and quality of life.” Once diagnosed, the patient has a lot of “catching up” to do. Thankfully, there are many organizations that provide unbiased and trustworthy information to patients that help with the decision process.

In this issue, we introduce the story of Lloyd Ney, who some have termed “the father of patient empowerment.” His passion for patient empowerment was an integral part of a process that brought about new standards for treatment and challenged old ones. Following that, Dr. Turner will discuss Taxotere and the exciting new ways that it is being used. Callers from our Helpline will also share a success story about overcoming the “old school” way of treating prostate cancer. And Chuck Strand of Us TOO makes a case for participating in a support group, highlighting the importance of the spirit of teamwork that comes from a support group setting. Finally, Paul Nelson will educate us about recapturing quality of life after treatment.

I hope you enjoy this issue of Insights, and that the stories and articles will help solidify the concept of shared decision making, and how it applies to your experience with prostate cancer.

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5

Lloyd Ney: The Father Of Prostate Cancer Advocacy

The PCRI Staff

The inspiring story about how the passion of Lloyd Ney, PAACT's founder, laid the groundwork for today's advocacy organizations.

7

The Use of Early Taxotere for High-Risk and Advanced Patients

Jeffrey Turner M.D., Prostate Oncology Specialists

New studies show that in some patients a combination of hormone therapy with chemotherapy increases survival.

11

Letter to The Helpline: The Importance of Empowering Information

The PCRI Helpline

A couple's inspiring story about their prostate cancer journey.

14

What to Expect at This Year's PCRI Conference

Peter Scholz, PCRI Communications Manager

A brief overview of the annual Prostate Cancer Conference.

16

No, You Don't "Got This"

Chuck Strand, Director of Marketing and Communications, U\$TOO International

Chuck talks about the importance of attending a support group as it is a great resource from trustworthy people.

22

Sex after Treatment: Can An Old Dog Learn New Tricks?

Paul R. Nelson, CCMA, CSE, President, Erectile Dysfunction Foundation and Founder of FrankTalk.org

A Clinical Sexologist talks about how to accept and grow with the inevitable changes that come with PCa.



Lloyd Ney: The Father of Prostate Cancer Advocacy

By The PCRI Staff

When Lloyd was diagnosed with advanced prostate cancer in 1984, an era before PSA screening, hormone therapy and the internet, he became incredibly disturbed by the limited number of treatment options available for prostate cancer patients, and even more so, by the lack of available literature that could educate men about the disease and treatment options. So he founded PAACT, (Patient Advocates for Advanced Cancer Treatments, Inc.). With a passionate belief in patient empowerment, Lloyd set up the presses and began publishing the *Prostate Cancer Communication* newsletter. At that time, prostate cancer educational material for patients was almost non-existent.

Amanda M. Saenz and Chris Meehan of the Grand Rapids Press wrote the following about Lloyd: “Mr. Ney who owned and operated Sports News and Golden Years Senior Citizens Newsletter and who was also a self-employed mechanical engineer, was frustrated with the treatment that doctors offered him. Instead of bowing to the conventional wisdom of the day, he sought help and advice for his prostate cancer elsewhere. He made a trip to Quebec City, Canada to start a special type of hormonal therapy to combat prostate cancer. In Mr. Ney’s case, the hormone therapy helped stop the cancer. When he came back to Grand Rapids, he decided to try to bring the therapy to the United States, by helping to convince the Food and Drug Administration to allow it. After founding PAACT, the organization became the first clearinghouse for prostate cancer treatment.” [2] →

Recently Forbes Magazine published an article titled *When Money Motivates Cancer Treatment Options*. One striking statement was that when a “...physician has a financial investment in the equipment he or she uses, it’s money – as often as science – that often motivates treatment decisions.” [1]

Prostate cancer treatment is no exception. Surgeons are paid to do surgery and radiation therapists to do radiation. Where can a man turn for unbiased advice when a diagnosis of prostate cancer suddenly occurs?

Free support groups and helplines are some of the best resources because they are usually not connected to any center that is in the business of giving a specific treatment. When thinking of patient support, one very unusual man immediately comes to mind, Lloyd Ney, the personification of helpline support for patients. Lloyd originated the first known prostate cancer helpline from the basement of his home which was staffed by himself and other highly educated laymen.

Not many people know that it was complications from radiation that ultimately caused Lloyd’s death in 1998. But that was fourteen years after being given a death sentence with six months to live. After fourteen years of radiation, his bladder and bowel were severely damaged, ultimately leading to multiple bouts of sepsis originating from the super pubic catheter. Dr. Labrie’s hormone therapy is what kept Lloyd alive an additional 14 years, allowing him to create all the resources that are now readily available through PAACT.”

Lloyd helped establish over 140 cryosurgery sites in the U.S. which provided cryosurgical ablation of the prostate as an alternate to radical prostatectomy. PAACT was also instrumental in introducing legislation in some states mandating full disclosure by physicians of all available options for detection, diagnosis, evaluation, and treatment of prostate cancer. Working with other concerned and interested advocacy groups, he supported similar efforts at the national level.

At Lloyd’s memorial service Dr. Stephen Strum, his close friend, was quoted, “Lloyd worked out of his basement, 7 days a week, 20 hours a day directing confused, frightened men and their loved ones – their wives, girlfriends, and children. Lloyd was a one-man powerhouse, as stubborn as a mule, set in his ways, willing to lock horns with anyone, anywhere and anytime. This was the outer crust of Lloyd Ney – tough, irascible. But inside this crust was a soft bread, the uniqueness of Lloyd Ney.”

PAACT’s pioneering effort in prostate cancer advocacy paved the way for many subsequent prostate cancer newsletters, support groups, books, pamphlets, magazines, and information available on the internet.

When thinking of the incredible impact of all the support groups and advocacy organizations and all the good they do, Lloyd Ney - the pioneer, the great trailblazer, has to be given credit as the guy who started it all. □

To Learn More About PAACT – see www.PAACTUSA.org

- 1. <http://www.forbes.com/sites/robertpearl/2014/07/31/when-money-motivates-cancer-treatment-options/>
- 2. <http://www.paactusa.org/about-us/founder>



RESULTS FOR THE 2014 PCRI AND ZERO CANCER RACE IN LOS ANGELES, CA.

Thank you to all who participated!

5K Winners

- 1. Stephen Tippett
- 2. Lacue Kamani
- 3. Ryan Sheperd

15k Winners

- 1. Brianna Calvert
- 2. Sharon Moreno
- 3. Mario Trujillo

Largest Teams:

- 1. King's Hawaiian - 84
- 2. Team Velarde - 32
- 3. Team Jeremy - 18

NEW DEVELOPMENTS IN THE USE OF TAXOTERE

Jeffrey Turner, M.D., Medical Oncologist,
Prostate Oncology Specialists

Taxotere is the most widely-used chemotherapeutic agent for treating prostate cancer. It is also the most widely-used agent for breast and lung cancer. Prostate Oncology Specialists has been using Taxotere since 1998. Two large multicenter studies completed in 2004 demonstrated longer survival for men with hormone resistant prostate cancer (ROYAL) when treated with Taxotere. Recently, another large randomized trial concluded that Taxotere is even more effective when patients with metastases begin Taxotere before hormone resistance develops.

What is Taxotere?

Taxotere is an intravenous chemotherapy which is a “plant alkaloid.” It works by interfering with cell division causing cell death. It also inhibits proangiogenic factors, such as VEGF, (vascular endothelial growth factor) which are necessary for tumor growth. Interestingly enough, Taxotere is synthetically derived from a substance that is extracted from the needles of the European yew tree, Taxus Baccata.

Two Philosophies of Use for Taxotere

Taxotere accomplishes two basic roles in prostate cancer. 1) To treat metastatic disease, with or without other agents, such as Carboplatin, Xeloda or Avastin. 2) As a preventative agent before the cancer becomes metastatic. Testosterone inactivating pharmaceuticals (TIP) are usually the first line of defense for men with high-risk disease (AZURE). However, in some situations TIP alone can prove to be insufficient. Adding Taxotere to TIP is called “adjuvant chemotherapy.” →

Rationale for
Considering
Adjuvant
Taxotere

Adjuvant Taxotere is standard for lung cancer and breast cancer patients. In fact, the failure to administer adjuvant Taxotere to young women with early stage breast cancer is considered malpractice. Numerous studies have proved that adjuvant chemotherapy reduces relapse rates and improves long-term survival.

Studies testing the premise that adjuvant Taxotere in men with prostate cancer who have **newly-diagnosed high-risk disease** (AZURE) are presently ongoing. Because Taxotere is very effective against advanced prostate cancer, we expect these studies will ultimately prove that Taxotere has the same ability to reduce relapse rates and extend survival in men with prostate cancer as it does with lung and breast cancer. Since studies take time to complete, final results may not be tabulated for several years. In the meantime, men with high-risk disease have to decide whether or not to use adjuvant Taxotere without the confidence of a definitive study that proves its effectiveness.

Without any conclusive scientific support, the decision to use adjuvant Taxotere is based on a risk-benefit analysis. On the negative side, 4-6 cycles of 3-week Taxotere has significant side effects (discussed later in this article). Also, there is always the possibility that studies will ultimately show that the benefit is too small to justify adjuvant Taxotere’s routine use. But, on the other hand, presuming that Taxotere does indeed have added anticancer benefits when paired with hormone therapy, it would be a shame for men with high-risk disease to miss out on its benefits. In addition, until studies are completed, the degree of improvement in cure rates is a speculative issue. However, if the breast cancer and colon cancer studies can be used as a metric, a 10% absolute improvement in cure rates might be anticipated with adjuvant Taxotere for men with AZURE.

A New Study
In Men With
Advanced
Disease

One new protocol that does validate the earlier use of Taxotere has been recently reported in a study of 800 men with **hormone-sensitive, metastatic prostate cancer** (ROYAL). [1] All the men in this study were initially treated with TIP, a standard approach. However, half of the men were administered Taxotere at the same time as TIP, rather than waiting until the disease became resistant to TIP. The results of the study showed that the men who received immediate Taxotere had substantially better survival rates. On the basis of this compelling study, most prostate cancer experts have concluded that waiting to start Taxotere until after TIP becomes ineffective represents an outdated and ineffective approach to treating prostate cancer.

Taxotere
Protocols
Can Vary

Taxotere is administered intravenously, most commonly, every three weeks with one large dose of 75 mg/m2. Alternative methods of administration are lower doses 25 mg/m2 weekly or a slightly larger dose of 50 mg/m2 every two weeks. [2,3] There are advantages and disadvantages to the different schedules. A single large dose may result in greater adverse effects including white blood cell suppression and more fatigue. Also for some individuals, weekly infusions may be considered less convenient as they require a greater number of doctor visits. But, some studies suggest that the every three-week protocol may have greater anticancer effects. We typically begin younger men on the every three-week protocol. If tiredness is excessive, the protocol can be changed to the lower dose weekly protocol. Men who are weaker or more elderly usually begin with the weekly protocol at the outset.

Reducing the
Side Effects of
Taxotere

The side-effects of Taxotere vary depending on the treatment schedule. Hair loss, which reverses after treatment is stopped, tends to be more severe using the three-week schedule. Nausea is not very common with either schedule because anti-nausea medicines are quite effective. With either protocol, Taxotere can affect the taste buds making food taste funny. So “icing the tongue” by keeping ice chips in the mouth during the infusion is advisable during each treatment.

Weakening of the fingernails is much more common with once-a-week Taxotere. “Icing” the finger tips during the infusion counteracts this problem. Narrowing of the tear ducts is another potential side-effect that could occur with weekly Taxotere. This effect is usually detected when increased tearing occurs because the ducts are not draining properly. Using artificial tears during and after each treatment to flush the Taxotere from the surface of the eye helps prevent this problem. However, if improper draining persists, a stent in the tear ducts may be necessary to prevent long-term scarring.

Another common side effect of Taxotere is neuropathy. Neuropathy is numbness or tingling in the fingers and toes. Generally neuropathy is mild. It slowly reverses over time after the Taxotere is stopped. Prescription Neurontin, Alpha Lipoic Acid, or high doses of L-Glutamine, an amino acid, can minimize the severity of the neuropathy. Other rare side-effects that can occur fairly uncommonly are rash, liver inflammation or diarrhea. →

Older Men
Tolerate Taxotere

Overall Taxotere is well-tolerated. We published a pilot trial in 2001 evaluating the tolerability of Taxotere in elderly men. The average age of the group was 78. The oldest man was 87. Using the weekly protocol, we found that Taxotere could be tolerated by most anyone. In that study 17 out of 20 men completed a full course of therapy. The three men who decided to stop the treatment before finishing the full course did so because they felt excessively tired. A copy of this published report is posted at www.prostateoncology.com.

Conclusion and
Summary

Taxotere prolongs survival in men with high-risk or advanced disease. Its beneficial effects may be even further enhanced by using it at an earlier stage in men with newly-diagnosed high-risk disease or in men with hormone sensitive, metastatic disease. Taxotere response rates can also be improved by combining it with other agents such as Carboplatin, Xeloda or Avastin. Ultimately, the maximum benefit from Taxotere is achieved by using it at the right time, by selecting an optimal schedule and by combining it with other effective agents. A well-informed patient working with a physician who is an expert in the treatment of prostate cancer will achieve the best results. □

For references and further reading, go to www.PCRI.org

ARE YOU A FEDERAL EMPLOYEE?

Combined Federal Campaign (CFC) season is coming up! Help us continue to provide valuable resources to men with prostate cancer by donating to the Prostate Cancer Research Institute via the Combined Federal Campaign!

PCRI believes that a patient who understands his disease and treatment options will be empowered to communicate more effectively with his physician(s), and will obtain a better outcome. PCRI uses all available communication tools and programs, including a Helpline, a quarterly and a weekly newsletter, website and professional conferences to educate men about prostate cancer.

PCRI undergoes an annual financial audit, and consistently receives a “Best in America” seal of approval from the Independent Charities of America.

The Independent Charities Seal of Excellence is awarded after rigorous independent review. Only charities meeting the highest standards of public accountability, program effectiveness, and cost effectiveness are eligible. These standards include those required by the U.S. government for inclusion in the Combined Federal Campaign, possibly the most exclusive fund drive in the world. Of the 1 million charities operating in the United States today, it is estimated that fewer than 50,000 – or 5 percent – meet or exceed these standards, and, of those, fewer than 2,000 have been awarded the Seal. We appreciate your support!



Use the following information to make a contribution to PCRI as part of CFC:
Tax-ID: 95-4617875
CFC: 10941
California State Employees Charitable Campaign (CSECC) Agency Code: 926

*A story from a couple that called our Helpline.
It details how support and information
helped empower them to become confidently
involved in their treatment decisions*

Letter to the
PCRI Helpline:

*For privacy, the callers requested that
we use the husband's first name only.*




*Ferd Becker, PCRI
Educational Facilitator*

It began in March 2014, my husband Tom went to see a urologist for BPH. When a small nodule was found during the DRE exam, he was told he needed a biopsy *even though is PSA was only 2.1*. We decided to get a second opinion and once again was told a biopsy was required. Because Tom's father died of prostate cancer last year, I started reading everything I could to educate myself. One of the books I read was *Invasion of the Prostate Snatchers*, by Dr. Mark Scholz I found PCRI from that book. Tom insisted that I not tell any family or friends he needed a biopsy and to respect his wishes to keep this private.

Not having anyone to discuss this with made me feel very isolated and alone, so I called PCRI to seek advice and help from people who are going through the same kind of issues we were facing. The very first person I spoke with was a gentleman named David Derris who was very kind and understanding of our situation. What a relief it was to talk to someone who knew what we were going through. He later passed our number on to Ferd Becker who became a great friend to us. →

**The helpline can be reached
at: 800.641.7274**



Tom had the biopsy in April. We requested a MRI to be done prior to the biopsy, but the urologist refused to order one, saying it would not tell us anything. When Tom went in for the biopsy we informed the nurse that we wanted a second opinion on the pathology report and to send the slides to Johns Hopkins when they were done with them. The nurse gave the impression that it was the first time anyone had requested a second opinion. One week after the biopsy, the first report came back negative and we were very relieved and happy. We had to remind them once again to send the slides to Johns Hopkins.

Five weeks later, I received a call from the nurse informed us that the report from Johns Hopkins was back. The first report was wrong, Tom did have prostate cancer. The pathology report found a Gleason score of 3+3=6 involving less than 5% of one core out of 12. The urologist who did the biopsy has never spoken with us, the nurse said he was going out of town and did not have time to call. When my husband came home from work that day, it was me who had to tell him he had cancer. A few days later a different doctor from the same office called and spoke with Tom about his treatment options. Tom told him that active

surveillance was his treatment of choice. The doctor said because of his young age of 54, the fact a nodule was found, along with his family history of prostate cancer, active surveillance was probably not a good option. We did get this doctor to order the MRI that we had requested before the biopsy had been done. Unfortunately it turned out the the MRI was not going to be done with a endorectal coil, so we canceled it.

We made an appointment to see an oncologist, thinking we might get a more objective viewpoint, since we did not feel like we were getting anywhere with the urologist. This turned out to be a huge mistake, everything we asked about concerning active surveillance was shot down. Once again we were told that a MRI was useless and the only way to monitor prostate cancer was having yearly biopsies. He was told because of his young age and the nodule, not getting treatment, was not an option. This doctor was trying to convince us to go with radiation. When asked about all the possible side effects that can occur with treatment and how the quality of life by avoiding treatment would be better, we were once again dismissed, and he told us to "come back when you want treatment." This doctor had me in tears by the time we left. We were now confused more than ever. From all the research

I had been doing on active surveillance we knew that MRI's were being used. I just could not find the right place to get the one we needed. I checked in three major cities near us in the mid-west trying to get the type of MRI needed and got nowhere.

A few days later, we got a call from Ferd Becker from PCRI, his timing was perfect. Without his friendship I'm not sure we could have made it to where we are now. He is the only person we have spoken with during all of this, who actually gave us information we could use. Ferd told us we were correct in thinking Tom might benefit from a multiparametric MRI, and active surveillance would be a viable option according to many current guidelines. He gave us information that helped, including a presentation from Dr. Laurence Klotz, and an article from the NIH. He told us about a doctor in Boston who could do the type of MRI that was needed. We flew to Boston in July and the doctor found no cancer on the MRI; the amount of cancer in Tom's prostate was so small it did not show up on the scan. For the first time in months we felt like we could breathe again. Getting the diagnosis of prostate cancer left us both anxious, sad, scared and confused. I'm glad now that Tom would not let me tell family or friends what was going on. This journey has been difficult enough without the added pressure of loved

ones pushing for treatment. The anxiety that comes with a cancer diagnosis is very difficult to live with at first. I'm very grateful that PCRI sent Ferd Becker to us. He is a wonderful person and has been a great friend to us. The past few months have seemed more like years. A cancer diagnosis knocks you down hard, and getting up is not easy. Tom said he felt like all the joy in life had been sucked right out of him. The choice of active surveillance comes with a price. Anxiety and fear are something you have to come to terms with. Active surveillance means PSA testing, DREs, and followup MRI's. Tom has decided not to get yearly biopsies because he feels they are too intrusive. He thinks poking holes in his prostate is a bad idea unless absolutely necessary. He plans to have a DRE and PSA testing every 6 months and a follow up MRI in a couple of years. We have switched to a vegan diet and he exercises regularly. We have decided to no longer let this diagnosis consume our lives. Things are beginning to get back to normal.

If you or someone you love is diagnosed with low-risk *early-stage prostate cancer* you should know that at least the possibility of active surveillance deserves more attention. I can't help wondering how many other men are being pushed into treatment for something that might not ever be a threat to them. □

2014

PROSTATE CANCER CONFERENCE

SEPTEMBER 5-7
MARRIOTT LAX HOTEL
LOS ANGELES, CA

The #1 Conference for Patients



What to Expect at The Conference

By Peter Scholz,

PCRI Communications Manager

Patient empowerment is the PCRI's theme for the upcoming 2014 Patient Prostate Cancer Conference this September 5th, 6th and 7th. This conference is a unique event for patients to interact closely with experts and leaders in research, and at the same time, connect with other patients who have "been there and done that." This is a weekend to get better informed and empowered to make confident choices.

Cancer care is advancing so rapidly that it takes a team effort between you and your physician to achieve the best care. For the average patient it is overwhelming to try to stay up-to-date with the latest clinical studies, journal articles, and protocols. Often the best place for information is an event like this that specializes in distributing material that patients can understand.

That's where our invited experts come in—specialists from around the world presenting the latest developments in prostate cancer care, but not in the language of doctoral medical jargon. Rather, the lec-

tures and presentations are presented in a way that can be understood by patients, so they can utilize their new information and obtain better care. At the conference you can expect many entertaining and informative presentations and find information you would be hard-pressed to gather and interpret on your own.

Don't miss Friday's afternoon sessions where physicians and advocates will give talks in smaller rooms. There will be ample time for discussion after each session. Like last year, there will be a Q&A Panel Discussion which Jan Manarite will moderate.

This year's program will stress breakthroughs in imaging, immunology, hormone therapy and staging. The Saturday schedule is structured around the PCRI Shades of Blue, a program that simplifies the understanding of prostate cancer by dividing it into five broad categories. For the SKY Shade there will be a presentation on Active Surveillance from Dr. David Krasne; for TEAL and AZURE categories, Dr. Anthony Zietman, Associate Director of Radiation Oncology



at Harvard Medical School will give a presentation about state-of-the-art radiation; for ROYAL we will have a discussion about all the new medications for advanced disease by Dr. Maha Hussain, the Director of Clinical Research from the University of Michigan. Dr. Mark Scholz, the Executive Director of the PCRI and Medical Director of Prostate Oncology Specialists will outline the best approach to managing INDIGO. Dr. Mark Moyad, our moderator, will also be speaking about supplements and diet and how they can lead to increased survival and better quality of life.

The Sunday "breakout" format will enable you to interact directly with the speakers in intimate Q&A sessions and have actual conversations and back and forth dialogue with them. Also, throughout the weekend, the concepts and topics can be further

clarified in support group meetings with knowledgeable patient advocates.

Last year's feedback was glowing with comments like, "Thank you for amassing so many experts in one place!" or "This is one of the most interesting conferences I have ever attended." And, "I wished this information had been available before my husband and I had to make decisions."

The PCRI Conference is for your empowerment. It will give you hope and a new confidence to face the challenging task of making important treatment decisions that will impact you for the rest of your life.

Sign up online:

<http://prostate-cancer.org/events-calendar/conference-2014/>

No, You Don't "Got This"

How Participating in A Support Group Can Empower You for Better Care

By Chuck Strand,
Director of Marketing and Communications,
UsTOO International

Prostate cancer support groups can be an invaluable platform for peers exchanging questions, offering information and sharing their personal experiences with treatment options and related side effects. There is genuine empathy and unmatched credibility from interacting with others who have “been there and done that.” The collaborative format of a support group facilitates conversations among group members who are assembled with the common goal of empowering each other with relevant knowledge and best practices.

There are countless people who credit their quality of life—even their continuation of life—as a direct result of attending a support group. Even so, some guys with prostate cancer may respond to the initial

suggestion of attending a support group with any one or all of the following:

“No, thanks; I’m good” or “It’s probably helpful for some guys but I don’t need a support group” or “I can just go on the internet and get whatever information that I need about prostate cancer,” and “I’ve got this.”

“No, you don’t ‘got this,’” according to Jerry Deans, speaking from his own experience of battling prostate cancer for 16 years. He knows the drill because he was that guy—the one who resisted going to a support group meeting.

Jerry was diagnosed with prostate cancer in 1998 at the age of 50. Two years after having surgery, his PSA began to rise. In response, he started salvage radiation and underwent a series of 38 treatments. His

Us TOO International is a nonprofit organization established in 1990 to serve the prostate cancer community by providing educational materials and resources that include 325 volunteer-led support groups across the U.S. and abroad. Us TOO was founded—and continues to be governed— by people directly affected by prostate cancer. The mission of the 501(c)3 is to be the leading prostate cancer organization helping men and their spouses/partners and their family members make informed decisions about prostate cancer detection and treatment through support, education and advocacy.

Us TOO International Director of Marketing and Communications Chuck Strand develops strategy and content for prostate cancer support services, educational resources and advocacy/awareness initiatives for digital and printed materials including website content and user experience navigation, branding, email development and distribution, fundraising campaigns, events and social media.

PSA continued to rise while the treatments produced severe and persistent proctitis as a side effect, which required six surgeries for bowel obstructions, adhesions and surgical hernias. The radiation impacted Jerry so negatively in part, because of previous bowel surgery for diverticulitis. Immediately following the completion of radiation treatment, and while dealing with proctitis in 2002, his physician advised him to wait for his PSA to rise to a higher level before initiating hormone therapy. The physician advised Jerry that this would allow him to survive for two or three more years once he started treatment.

At that point, Jerry decided to join the Us TOO Richmond VA prostate cancer support group. After listening to the information and advice that he received

from other prostate cancer survivors at the support group, he chose a new oncologist and immediately made nutritional and lifestyle adjustments to slow the inevitable growth of the cancer. In 2006, Jerry learned that the prostate cancer had metastasized to his lungs. With aggressive hormone treatment his lungs were cleared of the cancer in 2008. Although the cancer returned to his lungs one more time, it was again successfully treated with second-line hormonal therapy.

Jerry Deans has managed his prostate cancer for more than 16 years while maintaining his quality of life, which was due in part to his participation as an active member of his local Us TOO prostate cancer support group. And last year, he became a member

of the board of directors for Us TOO International Prostate Cancer Education and Support Network, which includes more than 320 independent support groups led by volunteers across the United States and in several other countries. Support group and chapter meetings are free of charge and open to newly-diagnosed patients, patients currently undergoing treatment, prostate cancer survivors, their spouses/partners, family members and friends, and health care professionals interested in sharing information and learning more about prostate cancer. This objective has been consistent since the nonprofit was founded in

1990 by five prostate cancer survivors who organized the first Us TOO support group meeting.

Jerry's commitment to support groups extends beyond the prostate cancer community. In response to a number of tragic events impacting his family, including the deaths of his teenage daughter, the death of his first grandchild, and the paralysis of his son, Jerry and his wife, Patsi, have reached out to others in their local community. They've been leading a grief support group at their church and retreats in their community for 10 years to help others learn how to deal constructively with loss and trauma.

For more information, visit www.ustoo.org or call 800-80-UsTOO (800-808-7866)

Jerry shares the following thoughts and feelings about his experience specific to managing prostate cancer and his empathy to the initial resistance to joining a prostate cancer support group. Here is his overview on some of the benefits that can be gained from attending a prostate cancer support group:



It wasn't that I didn't value the concept of a support group. I just had the mindset that I would be able to go it alone. I grew up as a self-described survivor and a worst case scenario problem solver. I served as an officer in the U.S. Army and built my career on my leadership skills as warden of Marion Correctional Treatment Center, CEO of Southwestern Virginia Mental Health Institute in Marion, VA, and assistant commissioner of facility management with the Virginia Department of Behavioral Health and Disability Services. Before I retired, I had responsibility for managing 16 facilities throughout the Commonwealth of Virginia with approximately 8,700 employees and an annual budget of a half a billion dollars. I was the guy other people relied on for the answers and solutions to problems.

Cancer, as well as other trials and tragedies in life, teach us that we are not in control. This is a real shock for most of us. We live our lives thinking that we are the "masters of our destinies and controllers of our fate." A diagnosis of cancer robs us of that sense of control. It takes time and work to adjust to a new realization. You don't know what you don't know.

As it has for others, cancer has forced me to face my mortality at ever deeper levels. It has presented

me with a problem for which there are no easy answers. Having been focused on being in control all my life, a diagnosis of cancer forced me into a very uncomfortable psychological and spiritual place, and participation in a support group helped me to navigate my way through it all.

It can be overwhelming to deal with a disease. Trying to do it alone adds the negative impact of isolation. A lot of men have a tough time admitting that they don't have it all together, they don't have control, or they don't know the solution. Most of us are uncomfortable with expressing our emotions. We have been culturally conditioned to hide our feelings and men are taught that feelings are a sign of weakness. We can do anger pretty well; maybe in part because it's the only emotion expressed by men that is supported in our culture. There is real power in hanging out with other people who are going through the same experience. It's about learning and gaining knowledge, which is empowering. Conversely, ignorance breeds insecurity and fear. Dealing with prostate cancer can be scary; partly because a guy cannot be in control of managing his health if he does not know what he is up against; or if he does not know his options for dealing with prostate cancer. →





Fully participating in a support group (not just attending—although that is a start!) can be life-changing – especially for the type of guy who’s been “the boss,” or the “go-to guy” with all of the answers for how to get things done. Depending on the guy’s personality, he may not naturally be open to seeking or accepting help from other guys. But if he can find the courage and confidence to put himself out there, the process of interacting with others at a support group meeting can be a very positive experience. Recognize that nobody is born with prostate cancer. Everyone who attends a prostate cancer support group shares a common bond and a passion for learning about treatment options that are best for their situation. Very few people who are diagnosed with prostate cancer have an existing knowledge base specific to the disease diagnosis, treatment options, side effects and quality of life. A diagnosis of prostate cancer can be overwhelming and crippling. It can be tough to identify

a path or action plan, or even to know basic questions to ask in order to get the answers that are needed for moving forward. Not being sure where you are, where you are able to go, or how to get there is extremely unsettling, uncomfortable and downright scary. But take heart in the Chinese proverb that reassures while counseling, “To know the road ahead, ask those coming back.”

Ironically, some guys who are so intent on not appearing to be weak when hit with a prostate cancer diagnosis fail to ‘man up’ to dealing with reality. They react to their fear by withdrawing or ignoring the problem. They may not be aware that the disease isn’t all about them. Prostate cancer has a direct effect on spouses/partners and family members. Realizing this may result in the guy feeling a sense of guilt or shame for inconveniencing others or for not continuing to fill the role of being the one who others can lean on.

It is so important for a man to bring his wife or partner into the process of dealing with prostate cancer. Common side effects of treatments are erectile dysfunction and incontinence. Depending upon the situation these issues can be non-existent, temporary, or ongoing. There are treatments available that effectively manage both conditions but navigating through the process can take its toll on a relationship. For certain, a best-case outcome can only result from a man and his wife or partner working through these challenges together.

Sometimes the wife of a man with prostate cancer will attend a support group meeting alone. That can be very valuable for her since her life is directly impacted by her husband’s disease. There are break-out sessions at some of the meetings that are exclusively formed for the wives or partners to discuss issues among themselves. But sometimes a wife will attend a meeting to try to work around her husband not acknowledging his diagnosis. By not taking responsibility for managing the problem, his “head in the sand” attitude puts added pressure on his wife to mop up after him. If he is not owning his disease management, it’s impossible for his wife to manage his condition for him. Her attempt of trying to spoon feed information to him hoping to get him to deal with the situation is futile.

The experience of grief and adjustment to a loss like prostate cancer is much more difficult and takes much longer than we expect. This is particularly true of sudden unexpected losses that we have not been able to prepare for. Loss impacts us on all levels: emotionally, psychologically, physically, and spiritually.

We are never prepared for the turbulent emotions, spiritual questioning and personal isolation that are often associated with being diagnosed with a serious disease like prostate cancer. A person’s life has been altered forever and he has to adapt to a “new normal.” Reconciling oneself to this new reality can be much more difficult than initially anticipated. It is common to experience depression or post traumatic stress disorder, which may include intense anger, sadness, anxiety and vulnerability.

We learn that the journey none of us would choose has been thrust upon us. Our only choice is how we respond—constructively or destructively. Loss brings a sense of isolation so it’s important to seek out others who have endured similar losses. This is the power of support groups. Through these groups we realize that we are not alone on the journey. There are traveling companions who are willing to encourage us and show us the way.

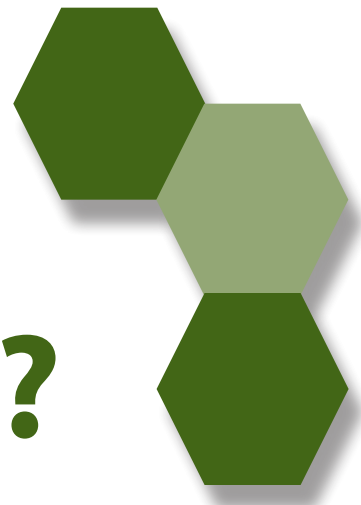
Prostate cancer support group participants benefit from the advice, tips and knowledge of other men who are committed to gaining the knowledge that’s needed to make smart choices for taking control of effectively managing their disease. The sense of sharing life’s lessons and helping others can be infectious. In the spirit of paying it forward, it can be gratifying for a guy who’s been helped by others at a support group to be able to turn around and help someone else down the line. That ability can only come from having accepted help previously. It is a logical, empowering and life-giving process that speaks to the core of positive human interaction—a beautiful thing! □

**"Through these groups
we realize that we are not
alone on the journey."**

A Clinical Sexologist talks about how to accept and grow with the inevitable changes that come with prostate cancer. It's "back to school" for learning a whole new sexuality when it comes to prostate cancer.

Sex after PCa Treatment:

Can An Old Dog Learn New Tricks?



*By Paul R. Nelson, CCMA, CSE, President,
Erectile Dysfunction Foundation and Founder of FrankTalk.org*

John sank heavily into the chair in my office. "I haven't had sex in nine months," he said. "I have gotten to the point where I don't even want to think about it. It's just too painful. Every time I feel anything at all, I am reminded that I'm still damaged goods."

John was your typical post radical prostatectomy patient. His surgery went well, his surgeon was great. The cancer was probably gone. Incontinence was but a memory. The third, and increasing, concern was return of sexual function; the hunt for the elusive erection. But he wasn't having much success.

He had been told to take the usual oral drugs a couple times a week, to no result. His surgeon kept telling him to wait and see. He was tired of waiting and even beginning to regret his choice of cancer treatment. So, he was now moving onto trying injections - which is what brought him to my desk. He was about to have his first lesson.

"Well, you've been having sex, just not intercourse, right?" I asked.

"I'm tired of just the foreplay. I want real sex," he replied.

"OK. So anything other than intercourse is not real sex?" I asked.

He snorted, "What are you gonna do without an erection?"

And so John and I began a conversation which was going to last months about what real sex was. What did sex look like? What did he think sex should be? It took some time, but John eventually stopped focusing on what he could not do, but on what he could do. And best of all, what he could do, ended up being far from second-string sex!

Believe it or not, when I have this conversation with young men, they tend to be thrilled with learning a whole new way of thinking about sex. Many of them are happy to relieve some of the performance pressure they put on themselves when it comes to getting and maintaining an erection. Older men, well entrenched in habits and mindsets, tend to have a more difficult time – "Can't teach an old dog new tricks" is the axiom that comes to mind!

There are dozens of lies that our culture has taught us about sex. But one of the most pervasive un-truths I come across is that no one needs to be taught how to have sex – it will come naturally. To a point, this is true. When we rely on basic instincts, couples do manage to assure the survival of the species quite readily.

But what if you're done procreating? Shouldn't the sexual activity change as well? Alas, for most couples, it does not. Well past child bearing years, most couples are still solely engaged in procreative sex. Sure, it's nice. It's comfortable. It can be the meat and potatoes of sex. But, this kind of sexual expression can be incredibly limiting and often frustrating. It requires a usable, and durable erection and a well-lubricated, flexible vagina – both of which tend to fade with age and health.

I have often said that the unhappiest prostate cancer survivors are the ones who want to have sex just like it always was. The truth is prostate cancer has changed us forever. Many things in life will never be the same again, and sex is just one item on that list. For survivors of prostate cancer, attaining a usable, durable erection becomes the primary focus of their sexual medicine treatment. And frankly, getting men an erection is really pretty easy. I assure our patients that medical science can get most men an erection. But the resurrected erection is not always the answer. →

Paul Nelson is a nationally recognized male sexuality educator and advocate. He is an AASECT Certified Clinical Sexuality Educator as well as a Certified Clinical Medical Assistant (CCMA). He is president of the Erectile Dysfunction Foundation (501c3) and founder of FrankTalk.org, the first non-commercial online community for men with sexual dysfunctions.

He works with Dr. Michael Werner, a men's sexual medicine specialist in New York City, and works as a patient educator at Mt. Sinai Hospital. He oversees a comprehensive penile physical therapy and rehabilitation program which integrates treatment with sexuality retraining. He is currently principal investigator for a study in male pelvic fitness and pelvic floor dysfunction.

A survivor of prostate cancer at the age of 47, Paul began this work after his surgery, when he discovered that there was very little authentic information to help men with sexual issues. The foundation grew out of FrankTalk.org when it became obvious that there was no other patient advocacy or support organization to help men.

Paul puts his years of teaching to use and educates men about every aspect of their reproductive system. He bridges the enormous communication gap between the medical world and the sexuality world and brings an integrated approach to the medical treatment men are receiving. Paul helps men not only restore their lost function, he helps them take advantage of this process by teaching men to look at their sexuality in a way that goes far beyond physical limitations.

He is an instructor at the Institute for Sexuality Education in Hartford, CT, where he teaches male sexuality and function. He is an affiliate with the Men's Health Network, as well as a popular presenter to men's groups across the country. Paul has been featured on ABC News with Diane Sawyer, the New York Times, National Public Radio, the BBC, MTV, Women's Health Magazine and many regional media outlets. He is on the Board of Advisors for the Private Gym and blogs for Betty Dodson, Talking About Men's Health, Prostate Cancer Research Institute, and The Good Men Project.

Just as prostate cancer survivors have to learn new aspects of bladder control, we also have to learn sex in a whole new way. In fact, most of us need to become students of sex. Most of us have found that relying on the old standby of sexual activity is usually going to present quite a challenge. But most men run out of ideas past oral sex or manual stimulation. What else is there?

Betty Dodson, the famous octogenarian sexuality educator once told me, “Paul, tell your boys (my patients) to remember, a vagina is for babies; a clitoris is for sex!” I do tell most of my patients this. It might sound a bit obvious, but most men really do not think of sex this way. And, if all they’ve been practicing is procreative sex, no wonder! Most women do not climax from intercourse without direct clitoral stimulation.

I often tell men that if they asked their female partner what her top ten sexual activities would be, she might well place vaginal intercourse somewhere around number ten! I was talking to one couple in their forties and I made that statement. He looked at his wife and said, “Really?” She shrugged and said “You never asked....” He was shocked. He figured if it felt so good to him, it must feel just as good to her.

The fact is, we all need to be students of anything we care about. We learn about our careers, child rearing, travel and vacations, and even prostate cancer! But the vast majority of people never really become students of sex and sexuality. After dealing with prostate cancer, it is incumbent on us all to learn everything we can about our new sexual reality.

Having fulfilling sex while living with prostate cancer takes dedication, hard work, and, above all, education. I find many couples tend to be afraid of exploring new sexual expressions. This is totally understandable – after 20 - 30 years of sex, it can be hard to change!

So, where to begin to become a student of sexuality? It can be trickier than you might think. Simply gathering information is not the answer. Education is very different than information. A good student gathers information, then synthesizes it through their previous knowledge and value system to come up with their authentic education.

Studying sex can be scary. It can push the envelope of your comfort zone. You might even bump up against some values you are uncomfortable with. Everyone has to learn to navigate the topic in their own safety zone. But don’t let fear stop you. The resulting knowledge is worth the risk!



Don’t rely on:

- Porn. Porn is fantasy; not a documentary. Porn does not resemble good sex in any way.
- Sex Shops. The employees are not trained. The products are often poor.
- Google. Misinformation can outweigh real information.

Do rely on:

- Your Library/Bookstore. Books on sexuality tend to be vetted for quality.
- Professional Organizations. Their resource lists are usually screened.
- Sexuality Professionals. Talk to a sex educator, counselor, or therapist.

Conclusion

Begin by coming up with a better definition of sex. I usually tell our patients that “Sex is any touch with erotic intent,” or “Sex is adult play.” See if you can broaden your definition of sex so that it is not defined by what you do or don’t do.

I encourage couples to put intercourse on the back burner for a few weeks and spend their time relearning each other’s bodies. Massage is the basis for almost all sexual activity. Learn to give sensuous, even erotic, massages. They are far easier than therapeutic massages. Long, gentle, gliding touches are what is required. Refined coconut oil from your local grocery store is the best personal lubricant you can buy. Try it!

Watch some instructional videos on massage, and better sex practices. The Sinclair Institute has some great educational videos. [1]

For some reason in our culture, marital aids, or sex toys, seem to be connected with the pornographic. This is far from the truth. If sex is play, equate play with toys. We often find that when men have a toy in their hand, they do become more playful, relaxed, and less focused on their penis. Buy only quality toys – sadly, they are not inexpensive.

Finally, explore, learn, read, experiment. This journey of sexual exploration will bring you closer than ever. Having prostate cancer definitely changes your life and the lives of those close to you. But take this time to find a new reality and new sexuality that, while different, can be far better, more fulfilling and more connecting than ever! □

[1] <http://sinclairinstitute.org/>

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