Prostate Cancer Support Association of New Mexico

LIFELINE

Celebrating over 30 years of supporting men and their families

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Issue Highlights

Our website address:
www.pcsanm.org

Email us:
pchelp@pcsanm.org

Support Group Meetings

Meetings are held at
Bear Canyon Senior Center,
4645 Pitt St. NE in Albuquerque,
from 12:30 – 3 p.m.
on the first and third Saturday
of most months.
Meetings may also be accessed virtually.

Please call 505-254-7784 or email pchelp@pcsanm.org for information. Meeting topics and login information may be found at:

https://www.pcsanm.org/meetings/

The Support of PCSANM

By Ray Montano, PCSANM Volunteer

My adventure with prostate cancer began in the spring of 2018. I was going through the process of testing and analysis. I had been in denial during the testing phase and thought I would be the anomaly and be spared. I received my diagnosis in November 2018. After hearing the "C" word, I was devastated, upset, and annoyed beyond belief. I received some guidance from the first urologist and was told about possible treatments. However, after hearing that I had cancer, I don't think I really heard anything else.

How could I get this diagnosis? I thought I was doing everything to keep myself healthy. What was I supposed to do? What would my life be like after this diagnosis? Who was there to talk to besides my wife and medical caregivers? What questions should I ask to get the answers I needed?

There was help, and at first I didn't realize I had it at hand. During one of my early urologist visits, I spotted the PCSANM newsletter on a desk. I took it home where it sat gathering dust. After receiving my diagnosis, I looked at the newsletter again. I saw that there was a contact name and telephone number; I called and was sent a copy of a buddy list.

I hadn't decided on a course of treatment, but I had the buddy list that listed names and treatment procedures each had gone through. I talked to several men on the list. I informed them of my condition, asked questions, and they answered based upon their experiences. I never got the impression that they were advocating a treatment. They talked about their life after diagnosis and treatment. They shared that life does go on and in many cases, it is as active as before the diagnosis. We talked about the major concerns of incontinence and impotence. They shared that these were problems and could often be overcome with the passage of time. They were all willing to stay on the telephone for as long as I needed to talk and had questions. They were empathetic and supportive.

I decided to have a radical laparoscopic prostatectomy based upon talking to my surgeon and wife. The Saturday before my surgery, I attended a PCSANM meeting. I met several men there who had their cancer treated or were weighing their options. The support that I felt in that meeting and the positive outlooks that they had confirmed my decision. I felt confident with my choice of treatment.

I had my surgery in January 2019. After a few days, I was home and the phone rang. My wife answered and told me it was one of the men from the buddy list. I was surprised and wondered what the call was about. Because I had informed my buddy of my pending surgery, he wanted to follow up. I appreciated the fact that he remembered and more than that- he cared enough to check on me.

This feeling of support and compassion is one that I feel each time I am around the men of PCSANM.

PLEASE SUPPORT PCSANM!
Online: www.pcsanm.org/donate
or
By check: PCSANM
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In Memory

With deep sympathy and regret, we list this name:

Herb Trejo

PCSANM *Lifeline*
A quarterly newsletter addressing issues of prostate cancer

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Prostate Cancer Foundation: November 14, 2022

Your Prostate Cancer Diet Questions Answered

By Dr. Stacey Kenfield

Dr. Stacey Kenfield, Associate Professor in the Departments of Urology and Epidemiology & Biostatistics at University of California, San Francisco, was a recent guest on PCF's monthly webinar series hosted by CEO Dr. Charles Ryan. She discussed her research on **Prostate 8**, a collection of lifestyle changes that have been shown to reduce a patient's risk of prostate cancer recurrence or death from prostate cancer, and addressed questions:

I have read and been told that eggs are bad for existing prostate cancer. There seems to be some science behind this finding, but eggs are a major source of protein.

Eggs have come up as being associated with increased risk of lethal prostate cancer in a cohort of men who did not have prostate cancer. A direct link has not been firmly established (for men with prostate cancer) and there is no strong evidence at this point to suggest the need to completely exclude all food sources of choline from the diet. Choline is a required nutrient, and until we know why, it is recommended to limit whole eggs (including yolks) to an average of 2 per week or less. Almost all of the choline in eggs is contained in the yolk, not in the white. You can reduce choline by using egg whites only.

What types of dairy products should be avoided, and which are OK to eat?

Since Prostate 8 was published, more findings have come to light on dairy. Consuming whole milk after prostate cancer diagnosis is linked to increased risk of prostate cancer progression and death from prostate cancer. However, for prostate cancer, dairy products do not need to be avoided entirely. Low-fat and non-fat dairy are not consistently associated with bad prostate cancer outcomes.

Should vitamin and mineral supplements be avoided?

Current data suggest that supplements **do not** help you prevent cancer or prevent cancer growth. In fact, some studies have shown an increased risk of prostate cancer in people on clinical trials who took high doses of Vitamin E or selenium. In an observational study of men with prostate cancer, men taking 140 micrograms per day of selenium were more than two-and-a-half times more likely to die of prostate cancer. There is not much data on effects of other high-dose supplements, but to err on the side of caution, it is recommended to avoid supplements unless recommended by your doctor.

What about taking a multivitamin?

Long-term, regular use of multivitamins have been shown to have neither benefit nor harm related to prostate cancer. There is no increased (or decreased) risk of developing prostate cancer or of death from prostate cancer. Investigators from the Physicians' Health Study II Randomized Controlled Trial comparing a daily multivitamin or placebo reported that daily multivitamin use was associated with a reduction in *total cancer* among the men with a baseline history of cancer.

What about calcium or Vitamin D, especially for people at risk of osteoporosis?

There are certain caveats around the recommendation against supplements, and people should discuss their specific situation with their doctor. For example, many men and women have low Vitamin D levels. Ask your doctor about measuring your Vitamin D level and work with them to see if you need to supplement to get to an adequate level. Some people are deficient in certain nutrients due to cancer treatment or problems digesting certain types of foods and may need supplementation. Regarding bone health, calcium, vitamin D, and exercise are essential. This is especially true for patients taking hormone therapy as part of their treatment of prostate cancer. If you are not getting 1000-1200 mg/day of calcium, you may need a supplement. However, adequate calcium can often be obtained from food sources such as leafy greens (especially collard greens, bok choy, and kale), canned fish with soft bones, beans, tofu, almonds, and fortified products such as soy milk.

How much sugar and artificial sweetener is OK to eat?

Sugar and artificial sweeteners fall under the 'not recommended or limit' category. We know that diets high in added sugar promote weight gain, type 2 diabetes and heart disease. The links between sugar, sugar-sweetened beverages, and highly-processed food and cancer are closely tied to how the foods promote weight gain. Regarding artificial sweeteners, they can help to reduce added sugar intake, though they are not necessarily a better choice. Regular, frequent use of artificial sweeteners may change food tastes with a preference for sweet foods. It's fine to enjoy a sweet treat from time to time, but the goal is to avoid sugar-sweetened beverages, reduce added sugar, and not replace them with artificial sweeteners.

WebMD Health News: November 2, 2022

Mental Distress: Prostate Cancer's "Elephant in the Room"

Howard Wolinsky

Mark Lichty, 73, said it took a decade for him to overcome the anxiety, fear of death, and uncertainty about the future after he was diagnosed with low-grade prostate cancer in 2005.

Lichty, of East Stroudsburg, PA, channeled some of this anxious energy into launching Active Surveillance Patients International (ASPI), which he co-founded in 2017 to help men with low-risk prostate tumors to cope with the worry that their condition may evolve from benign to life-threatening.

Many men have taken to calling this state of limbo "anxious surveillance" – a baseline level of concern that gets worse while they await the results of periodic blood tests that, depending on the results, can signal the need for surgery or radiation therapy to remove a tumor that's become more aggressive.

Ironically, Lichty says, those same tests – which look at levels of a protein called prostate-specific antigen, or PSA – led to an "epidemic of overdiagnosis" of prostate cancer in the 1990s. That in turn led to overtreatment that resulted in erectile dysfunction, incontinence, and other problems for many patients – and now, he says, "the epidemic of anxious surveillance that can result in unnecessary distress in these patients and even in more overtreatment."

Mental distress has been called the "elephant in the room" for patients with prostate cancer that doesn't require treatment right away. For years, these concerns were largely ignored, according to advocates and health professionals. But lately, the prostate cancer community has begun focusing on mental health for this group.

One factor has been the stress caused by COVID-19. "The mental health crisis from the COVID-19 pandemic has brought this issue into focus in prostate cancer," says Rick Davis, of Tucson, AZ, who was diagnosed with the disease in 2007. Davis is the founder of AnCan Foundation, which runs support groups for people with prostate cancer – the most diagnosed cancer in men. According to the American Cancer Society, 268,000 men in the United States will learn they have prostate cancer this year, up about 10,000 from 2021. An estimated 1 in 8 men will be diagnosed with the disease in their lifetime, the group says. For Davis, those figures point to an overwhelming need for more services like those his foundation provides.

"We have attempted to do some programming, but we haven't taken the bull by the horns," he says. "We really saw that it was the elephant in the room, and we needed to identify it and do something about it."

AnCan and ASPI started one of the first virtual support groups for patients with low- and favorable intermediate-risk prostate cancer in 2019. A 2021 survey of 168 people in the support group found that 30% reported symptoms of anxiety.

That's in line with a 2014 study by researchers in the United Kingdom who found that among nearly 4,500 patients with prostate cancer across the treatment spectrum, 17% of men reported depression, and 27% reported anxiety, before they were treated for the disease.

The figure for anxiety is roughly twice that in the general population of men in the United States, says John Oliffe, PhD, founder, and lead investigator of the University of British Columbia's Men's Health Research program. Untreated anxiety can lead to other mental health problems, including depression and suicidal thoughts and behavior, he says. "Anxiety has often been overlooked. The true breadth and gravity of men's anxiety is unknown, which is particularly concerning, given undetected and untreated anxiety predicts future deleterious mental health outcomes," Oliffe says.

In September, the Prostate Cancer Foundation, the largest private funder of research on prostate cancer, held a patient-oriented program. On November 17, 2022, the Prostate Cancer Impact Alliance held a webinar on emotional wellness.

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WebMD Health News: November 2, 2022

Mental Distress: Prostate Cancer's "Elephant in the Room"

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Scott Tagawa, MD, medical director of the Genitourinary Oncology Research Program at Weill Cornell Health in New York City, and a spokesman for the American Society of Clinical Oncology, says, "the world is recognizing mental health issues in cancer more than it did. It was starting to happen before the COVID-19 pandemic, but it was brought up by some issues with the pandemic."

Tagawa says the total number of men in mental distress may be understated. "Men tend to be less communicative and verbal," he says. "They hide things."

Jim C. Hu, MD, a professor of urology at Weill Cornell, said mental health issues are coming into play now because of "a greater emphasis on the whole patient. This goes with patient-centered care. There is a focus on mental health issues in terms of patient care, particularly as it comes to cancer patients."

Corey Lyon, DO, vice chair for clinical affairs in the Department of Family Medicine at the University of Colorado School of Medicine, says primary care doctors are playing a bigger role in providing psychiatric care and can offer emotional support for these patients as part of an emphasis on "whole-person care."

But a lot of clinics may not necessarily be doing this screening because they don't know what to do with the results," says Lyon, who's chair of the American Academy of Family Physicians' guidelines committee. "They don't have the tools or resources if a patient has a high level of distress or higher symptoms of anxiety or depression. If they don't know what to do with the results, they tend not to screen."

Successful Approaches

A few leading clinics, such as Memorial Sloan Kettering Cancer Center in New York City, routinely screen prostate cancer patients for mental health issues.

Andrew J. Roth, MD, a psychiatrist who has devoted his career at the center to mental health issues and patients with prostate cancer and their families, helped develop scales to measure distress in prostate cancer patients, like the Distress Thermometer in 1998. Roth also helped develop the Memorial Anxiety Scale for Prostate Cancer and is working on a scale to identify depression in older cancer patients.

"Screening for distress tries to identify signals that someone is having difficulty dealing with cancer that might interfere with making treatment decisions, managing treatment, improving quality of life, or that a particular patient does not have enough social support," Roth says. "Then there is the opportunity to get them the help they need. If we do not ask, we may not find out, and won't be able to help these men cope better with their prostate cancer and their lives in a timely manner."

But not everyone agrees with the value of such tools. Darryl Mitteldorf, a licensed clinical social worker and founder of the New York City-based Malecare support group for prostate cancer, is among the skeptics. "The [anxiety] scale that Roth came up with and a lot of people use is great for clinical trials," he says. "But in a practical day-to-day sense, it's somewhat irrelevant to helping people with prostate cancer get on with their lives and being as happy and hopeful as they possibly can."

Through the Prostate Cancer Impact Alliance, an advocacy group within the American Urological Association, Davis in September began promoting an effort to screen for mental distress. He says the vision is for medical specialties involved in the care of patients with prostate cancer – urologists, radiation oncologists, genitourinary oncologists, primary care doctors, and even psychiatrists – to develop guidelines as a group. "They all need to come together, and the idea is to monitor, identify, and navigate people to get treatment to deal with these mental health issues and maybe even crises," Davis says. "Right now, we're not even identifying these people."

Harvard Medical School Annual Report on Prostate Diseases: August 26, 2022

How Long Should Hormonal Therapy Last?
Men with high-risk tumors obtain the greatest benefit from long-term treatment

Charlie Schmidt

Hormonal therapy is a cornerstone of prostate cancer treatment, but it has burdensome side effects. Men who take these testosterone-blocking drugs experience fatigue, loss of muscle mass, and a heightened risk of cardiovascular diseases. Doctors and patients alike are therefore highly motivated to use hormonal therapy only for as long as necessary.

But how long is long enough? A recent study provides needed clarity.

Study process and results

Researchers working at 10 hospitals in Spain enrolled 355 men with newly diagnosed prostate cancer that was still confined to the prostate and seminal vesicles (adjoining glands that produce semen). The men were divided into two groups: one group received a short course of hormonal therapy lasting four months, and the other group was treated for a longer duration of 24 months. All the patients were also treated with high-dose radiation.

After 10 years, only men who had been diagnosed initially with high-risk prostate cancer (prostate cancer with biological features that predict aggressive spread) benefited from the long-term treatments. Specifically, 67.2% of these men avoided subsequent increases in prostate-specific antigen (PSA) that signified worsening cancer. By contrast, 53.7% of men with high-risk cancer who received four months of hormonal therapy avoided similar PSA increases. Importantly, 78.5% of high-risk men who had long-term hormonal therapy were still alive after 10 years, compared to 67% of high-risk men treated with hormonal therapy for four months.

Among men with intermediate-risk prostate cancer, the duration of hormonal therapy made little difference. Just four men with intermediate-risk cancer developed worsening cancer that had spread to other sites in the body.

Two came from the short-term treatment group, and two from the group that received hormonal therapy for 24 months. And after 10 years, none of the intermediate-risk patients had died from prostate cancer, regardless of how long the hormonal therapy treatments lasted.

Experts' opinions

"This study settles the question of length of hormonal therapy for most patients with high-risk prostate cancer who are also treated with radiation," says Dr. Nima Aghdam, a radiation oncologist at Harvard-affiliated Beth Israel Deaconess Medical Center in Boston who did not participate in the research. "It provides a robust comparison of options available to our patients, and in my view gives them the opportunity to make an informed decision about the length of hormonal therapy based on high-level evidence.

"In terms of the absolute duration of treatment, I think there is likely a happy medium between four and 24 months for certain patients who have specific high-risk features. I encourage patients to discuss this option with their doctors. However, this study does not answer the question of whether all intermediate-risk patients need four months of hormonal therapy, and we should continue to refine our approach to that very common scenario."

The study did not include men with low-risk prostate cancer, "for whom the current standard is no hormonal therapy at all," added Dr. Anthony Zietman, a professor of radiation oncology at Harvard Medical School who also did not participate in the research.

MedPage Today: November 10, 2022

Reasons to Rename Gleason Score 6 Prostate Cancer to Non-Cancer:
Scott Eggener, MD, a leading proponent, explains the arguments

Jeff Minerd

Experts disagree on whether prostate cancer with a Gleason score of 6 (GS6) should be re-labeled as non-cancerous.

Writing in a commentary in the *Journal of Clinical Oncology*, Scott Eggener, MD, and colleagues argue that GS6 behaves like pre-cancer, not cancer, and that reclassification will thus dramatically reduce overdiagnosis and overtreatment, lessening healthcare costs, and minimizing patient anxiety.

Opponents argue that GS6 is still cancer, histologically and molecularly, and that substantial numbers of patients are found to have higher-grade cancer on subsequent examinations.

In the following interview, Eggener, director of the High Risk and Advanced Prostate Cancer Clinic at the University of Chicago, delves into these arguments and issues.

What is the strongest argument for re-labeling GS6 as non-cancerous, if you had to pick one?

Eggener: Many prostate cancer specialists feel [that with such a change] public health would be significantly improved with far more expected benefit than potential harm. GS6 behaves as non-cancerous as it cannot cause symptoms or metastasize to other parts of the body. As a very common diagnosis, it causes a tremendous amount of anxiety, procedures, cost, and follow-up -- all for questionable benefit. It often leads to treatment with surgery or radiation, each of which have the potential for life-long side effects, all for questionable, if any, benefit.

What do you think is the strongest argument on the other side for not making this change?

Eggener: If it were given a "pre-cancerous" label, the potential that men would be less likely to follow up with their physicians. Counter-point: We have tens of millions of men in the United States who follow up for their elevated PSA, previously negative prostate biopsies, or on active surveillance. Similarly, it would be important for urologists to share the importance of follow-up, and ultimately it is up to the man to follow up, as it is for virtually every other medical situation (high blood pressure, colon polyps, etc).

How does GS6 behave clinically like pre-cancer rather than cancer?

Eggener: Similar to pre-cancerous or benign lesions of the prostate, Gleason 6 is incapable of causing symptoms or spreading to other parts of the body (metastasizing). The Merriam-Webster dictionary definition of benign is "of a mild type or character that does not threaten health or life." Gleason 6 meets that definition.

What else would you like to make sure oncologists understand about this issue?

Eggener: It's an important discussion to have amongst the prostate cancer community, physicians, patients, advocates, etc.

What would it take to settle this issue for good?

Eggener: No clue, but it starts with a discussion, evidence-based argument, and eventually collaborative input between clinicians and pathologists to consider a formal name change.

Prostate Cancer Support Association of New Mexico

PCSANM *Lifeline* Newsletter
Celebrating over 30 years of supporting men and their families

Prostate Cancer Support Association of New Mexico, Inc.
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A Message from the Chairperson

January 2023

Looking back, moving forward

Our 2022 annual conference in November was the first in-person edition since 2019. It was clear folks were eager for the learning and social experience, as evidenced, for instance, by a lively audience Q&A session that followed formal presentations. In-person attendance hit 65, while another 41 chose the Zoom option. That combination topped the 2021 Zoom-only attendance, and attendees represented at least six New Mexico counties. A recording of the half-day event is in the works. Check the website (www.pcsanm.org) for updates.

At the conclusion of a recent support group meeting this question went to the audience: "What presentation topic would you like to see at a future annual conference or at a regular Saturday meeting that hasn't yet been offered?" A response came quickly. "What are the differences between how New Mexico doctors treat prostate cancer from those of other states?" Well, it turns out a presentation at a recent board meeting had addressed just that. The speaker, Michael Forsyth, is a Pfizer oncology health data analytics specialist and pharmacologist. He discussed and illustrated graphically the differences between castrate-resistant prostate treatment approaches in New Mexico and nearby states.

We hope to add that talk, among others, to a support group meeting this year.

Rod Geer
Chairperson of the Board, PCSANM