

In this issue....

Most issues of Prostatepedia focus on improving prostate cancer control. All treatments for prostate cancer, however, adversely impact quality of life. In fact, fear of side effects can lead patients to select a treatment that is less effective at cancer control or even to select no treatment at all. There are also patients who appear to be cured-but who must now face the life-long loss of sexual or urinary function. This month, we're focusing on research aimed at helping patients cope with the emotional impact of a prostate cancer diagnosis and its treatment.

As many of you know, I have personally struggled with these issues. In February 1999, I was diagnosed with prostate cancer and received aggressive radiation therapy. I also had hormonal therapy for 18 months. I had to learn how best to deal with the side effects of these treatments and then how to recover. It has now been 18 years since I was diagnosed: I have also, therefore, had to deal with the long-term consequences of those treatments.

In my own case, exercise has had a huge impact on my quality of life. Both aerobic exercise and weight lifting proved very effective in helping me recover from both radiation and hormonal therapy. They have remained key to my survivorship program.

I also found meditation very useful in reducing the stress of the initial diagnosis and of the treatment side effects. I even found it an important tool for pain control.

In my clinical practice, I found that attention to survivorship issues increased the odds of having happy, optimistic patients rather than depressed, pessimistic patients.

I hope you find this month's *Prostatepedia* as useful as I did.

Charles E. Myers, Jr., MD





Contents:

Contributors:

P4 Guest Commentary
Stephen Freedland, MD

P6 Arash Asher, MD

The Psychology
of Cancer Survivorship

P10 Alicia Morgans, MD

Cognitive Impairment

+ Prostate Cancer Treatment

P14 John Peteet, MD

Anxiety, Depression

+ Prostate Cancer

P18 Nina Priebe
Fear + Prostate Cancer

P20 Clinical Trial:
David E. Victorson, PhD

Meditation +
Active Surveillance

P24 Patients Speak:
Roger G
Anxiety, Depression
+ Prostate Cancer

P26 Chuck Strand:

Anxiety, Depression

+ Prostate Cancer

Editor-in-Chief
Charles E. Myers, Jr., MD

Publisher
Jessica Myers-Schecter

Copyeditors
Grier McCain
Lito Velazquez

*Proofreader*Robert M. Protz, MS

*Transcriptionist*Sarah Mason

Designer
Verity Burgess

Community Outreach
Corinne Halada

Sales Consultant
Rod Schecter

Business Consultant
Rose Sgarlat Myers, PT, PhD

Editorial + Billing Offices 274 Redwood Shores, #739 Redwood City, CA 94065 (800) 975 6238

Administrative Offices
PO Box 655, Earlysville, VA 22936

Guest Commentary Stephen Freedland, MD



Historically, the goal was to cure cancer. We don't really cure other major medical problems like heart disease, diabetes, high blood pressure, or high cholesterol: we manage them. Cancer, in general, and prostate cancer, in particular, are becoming chronic diseases. Occasionally, we need to do something more aggressive, but we really just need a management strategy so that people can live normal, healthy lives even after being diagnosed with cancer.

With this shift from quantity of life to *quality* of life comes an opportunity for us to have conversations about how prostate cancer and its treatments affect daily life. People are now younger at diagnosis than ever before. They're still active. They're still working. They're still productive members of their families and of society.

How do we help them maintain that while providing the best cancer care? The challenge is how to marry those two. It's not enough to focus on Gleason score, PSA, and stage. The focus is on the patient. On the person. It's not just about the numbers.

I applaud *Prostatepedia* for delving into this subject matter with some very engaging conversations with

some of the world leaders on the topic. I work very closely with Dr. Arash Asher at Cedars-Sinai Medical Center. We focus now on nutrition, exercise, and psychosocial health. It's really spectacular to see. Men are able to maintain much of their quality of life and sometimes feel better than ever.

"It's an exciting time. When people die within months of diagnosis, you never get a chance to sit and talk about how you will live your life. You have cancer now, but how are you going to live the rest of your life? That's a very powerful thing. It's very exciting as a doctor to see this change.'

At the same time, we're realizing that what works for one patient will not necessarily work for another. There is no shortcut to sitting down with a patient, understanding his needs,

goals, and desires, and then working together to come up with a care plan that manages his cancer and his side effects. We want to keep you psychologically strong and able to fight your cancer-but also to live your lives. Pp1



Arash Asher, MD The Psychology of Cancer Survivorship



Dr. Arash Asher is the Director of the Cancer Rehabilitation and Survivorship program at Cedars-Sinai Medical Center in Los Angeles, California.

Prostatepedia spoke with him about the issues cancer patients often face.

Why did you become a doctor?

Dr. Arash Asher: One of the things I loved about medical school was the spectrum of personalities in a medical school class. At my school, there were a hundred people in each class with a hundred different personalities. By year four, each person found the right match for their strengths, weaknesses, and personality type. It's rewarding to be in a field where you have to understand not only anatomy and physiology, but also the human psyche. Issues related to existential and emotional distress go along with the physical domains of pain, fatigue, nausea, and things of that sort. Being in this niche and combining all that was the perfect draw for me.

How did you come to focus on cancer survivorship?

Dr. Asher: I'm a physical medicine and rehabilitation doctor, which basically means I was trained to support people

"Fatigue tends to be the most distressing symptom."

who have had a traumatic brain injury, stroke, amputation, or some kind of chronic pain syndrome. I always knew I wanted to be involved in the cancer arena, but my primary interest wasn't in figuring out the right chemo drug or the right radiation regimen. I was really interested in helping put lives back together. I discovered this emerging field of cancer rehabilitation, or cancer survivorship. That was the perfect match of trying to help put someone's life back together while integrating all those rehabilitation tools.

What are some of the issues that come up for cancer patients after treatment?

Dr. Asher: There are physical issues and then there are psychological, emotional, and spiritual issues. In the physical domain, the most common complaint by far is fatigue, which may not seem very significant, but it often has a psychological component. It is consistently a major issue in cancer quality-of-life

studies. Fatigue tends to be the most distressing symptom of all of the different symptoms that cancer patients go through.

Not pain?

Dr. Asher: We generally do a much better job of managing pain. And not everyone has pain. For example, of those with metastatic prostate cancer all over their bones, only 22% or so have pain, whereas fatique is ubiquitous. Whether you're going through chemo for breast cancer, prostate cancer, pancreatic cancer, or any other type of cancer, it is almost impossible not to experience some fatigue. Fatigue is what really keeps people from doing things that are meaningful and important to them, so it tends to be the most distressing symptom, perhaps because it's so common.

Is fatigue always directly associated with a treatment, or is that fatigue due to treatment plus any stress, anxiety, or depression the person may be having about the fact that they have cancer?

Dr. Asher: This is why I find this a fascinating problem: it may involve all of these facets together. It could be just the cancer itself, so you could have fatigue before you even start any treatment. Clearly, chemo and

radiation cause fatigue. And it could also be the emotional stress—not sleeping well, nutrition changes, and being in pain all the time. It's exhausting. Depression and fatigue have a lot of overlap, and the challenge is teasing apart all of these different factors and coming up with a plan once you sort them out.

Are there any other issues common to multiple cancers?

Dr. Asher: Everyone has fear of something, though fears may be different. For some, it just may be the fear of death, fear of the unknown, or fear of becoming dependent. Many fear losing independence and having to rely on or burdening their loved ones. This kind of fear is quite common.

In the cancer world, you hear a lot of talk about stress, but you very rarely hear people talk directly about fear. Is stress a code word for fear? Or is it different?

Dr. Asher: Stress is a complicated issue. Stress can be a good thing. There's a good TED Talk about the science of stress. (See https://www.ted.com/talks/kelly_mcgonigal_how_to_make_stress_your_friend?utm_campaign=tedspread-b&utm_medium=referral&utm_source=tedcomshare).

More and more studies show that stress doesn't really hurt us or kill us, but our perception of stress is more impactful. Studies show that people who perceive stress as something that allows them to rise to the occasion, perform better, or overcome a challenge tend to have higher survival rates. If someone views stress as something that's going to hurt and negatively impact them, that perspective tends to have a spiral effect and is associated with higher mortality rates.

Over and over, studies show that chronic loneliness is associated with a poorer cancer prognosis. Chronic loneliness is a more negative risk factor than this loose idea of stress, which is so dependent upon one's personal interpretation of the phenomenon.

I guess you could tease out stress to be both fear and loneliness, though.

Dr. Asher: It could be fear. It could be loneliness. It could be a sense of poor self-efficacy.

What is poor self-efficacy?

Dr. Asher: Self-efficacy is the idea that we're capable and able to accomplish something. Again, that sounds like a mundane idea, but many people going through a cancer process have to meet with surgeons, oncologists, radiation doctors, and previous doctors, and they just totally get lost. Many people feel like they're not capable of succeeding in this environment. Low self-efficacy, a belief that one is not capable psychologically to rise to a certain challenge, is a common issue. In general, lack of self-efficacy is associated with poor resilience, poor well-being, not being connected, and higher rates of loneliness.

There are a lot of moving parts to being a cancer patient.

Dr. Asher: It's very complicated.
Oftentimes, doctors don't talk to each other. Insurance barriers and financial concerns are too common. It is a very complicated process. This sets the stage for fear, loneliness, depression, and a lack of a sense of self-efficacy.

A great support team, whether that means family, friends, or the center where you're being cared for, can make a huge difference in how you get through this whole process.



There is nothing I feel worse about than seeing someone going through this all on their own, with no family members, friends, advocates, or caregivers. My heart sinks for these folks.

"Meditation is a type of mindfulness, but there are many ways of being mindful."

What recommendations would you make to someone like that? If you don't have those kinds of support networks, how can you find them? How can you get the help you need?

Dr. Asher: Awareness is the first step. Our psychology may change our biology.

But I should mention, for clarity's sake, that loneliness is not defined by a certain threshold or a certain number of friends. It's not that if you have seven or more friends, you're not lonely, and if it's less than seven, you're lonely. Loneliness is a subjective phenomenon. Some people can have 10 friends around them and still feel lonely while some people can have one or two really close friends whom they can count on and not feel lonely at all. It really is subjective. It's the quality that seems to matter rather than the quantity.

It's so important to understand and communicate this.

There are organizations that can help. In the United States, we have the Cancer Support Community (cancersupportcommunity.org). Many cancer centers also have support programs. They may have

a buddy program that teams you up with someone who has gone through a similar cancer diagnosis.

We first need to recognize that this is an important issue, do our best to reach out to our family and friends, and invest in those relationships. That's where we, as a society, need to put more effort.

You can't really address a problem until you acknowledge that it's actually a problem.

Dr. Asher: Exactly. Acknowledging this is the first step, for sure.

Do you have any specific recommendations or techniques—meditation, therapy; or support groups?

Dr.Asher: Here at Cedars-Sinai we run a six-week program where we try to help people navigate the psychological and existential distress of a cancer diagnosis. There are a number of pragmatic practices we teach.

The first is learning to cultivate an attitude of gratitude. I know the first response is often, "Well, I have cancer, so what is there to be grateful for?" The idea is not to be grateful for the medical condition necessarily, but to learn to be grateful for the things in our lives that we can still experience, whether it's having a loved one by our side, having health insurance, or whatever it may be. We need to spend a little time each day cultivating that gratitude skill because, if we don't, it's really easy to be overwhelmed with stress, distress, fear, and the unknown. People who are generally grateful tend to have better support, connect with others, and are more resilient than people who don't have a sense of gratitude.

We also talk about mindfulness approaches. People assume that being mindful requires meditation. Meditation is a type of mindfulness,

but there are many ways of being mindful. Mindful means developing a process of self-awareness and just really being present in each moment. There can be mindful eating, mindful listening, being in nature mindfully, or just mindfully being present in a conversation without being on a smartphone and distracted. There are many ways to get there, but if we're not having mindful moments, we're usually spending time thinking about what's going to happen with the next CT scan, tumor marker test. or MRI. If all of our attention is on either the future or the past, fear, anxiety, and depression may follow.

By mindfulness do we really just mean paying attention?

Dr. Asher: Absolutely. It could be laughing with a friend and being mindful with that. Or it could be mindful eating. There's a Mindful Eating Institute that teaches people to really taste, smell, and appreciate the texture of whatever they eat. Certainly, mindfulness-based stress-reduction and meditation programs are well-studied, viable ways of getting there, but these are by no means the only way to achieve mindfulness.

In addition to gratitude and mindfulness, what else do you teach patients during your program?

Dr. Asher: Finding some sense of meaning or purpose in what you're going through is another element. We try to communicate this in a way that is authentic to each person.

In Viktor Frankl's book Man's Search for Meaning, he noticed anecdotally that maybe one in 10 or 20 people in Holocaust concentration camps survived. A big part of that was just luck: luck, whether you went into this line or that line or whatever lucky circumstances you may have

had. But besides luck, he noticed that those individuals who survived seemed to have had some profound sense of meaning and purpose in what they were going through rather than just viewing their experience as pointless suffering. That seemed to be a critical piece to survival. He argued that if you can find meaning in suffering and in what you're going through, you can get through almost anything.

We draw attention to this idea of purpose in suffering, that we still have an opportunity to do something purposeful and meaningful, and that we can rise above our trials to cultivate courage.

Some men become support group leaders and advocates after their own prostate cancer experience. I wonder if that drive is part of this search for meaning in suffering?

Dr. Asher: That's the same idea. Someone says to himself, "I'm going to get through this, and once I get through this, I'm going to help someone else get through his experience." It doesn't have to be about the cancer, though. Someone can say, "I'm going to get through this, and I'm going to get back to my important writing, or my art or, whatever it is I care about." But having some sense of meaning or purpose rather than just suffering for no purpose at all makes it almost tolerable.

Distraction is another tool. Distraction and denial, in healthy doses, are not bad coping tools. I know it gets overlooked or dismissed, but sometimes when there is a lot going on, a good comedy, a nice, warm bath, or a great meal can take your mind off things.

You don't always have to focus so much on your cancer. You can take a psychological break.

Dr. Asher: Yes. There can be an obsession with having to do

a mindfulness program or some psychologically profound act when sometimes we just need to be distracted, to have a break.

How does physical well-being affect psychological well-being?

Dr. Asher: Every cancer survivor, whether he is in early or late stage and anything in between, should try to find an exercise program that works for him.

The benefits of exercise are unequivocal. Exercise is probably the best antidote for fatigue. We know that exercise can reduce stress. In terms of prostate cancer survival, more emerging studies show that exercise has anticancer effects because of the way it activates the immune system. Exercise reduces inflammation.

Exercise also improves self-efficacy. This has been well established in the exercise physiology literature. When you are in an exercise program, you're mastering a new experience, you're modeling other people, and another person, as in a trainer, is persuading you to persist. All of these things help one gain self-efficacy. From physical, emotional, and psychological perspectives—all fronts—exercise is helpful. The science is just so compelling that we really need to make exercise a part of medicine.

Do you have any thoughts about solo versus small group exercise?

Dr. Asher: It depends on the person. Some people do fine and know how to go about their own exercise regimen, but when you are tired because of the fatigue that we talked about or you have bone metastases or low blood counts, a supervised program with a trainer who can guide you is important.

Small group exercise programs can also become a kind of social support group. Obviously, I'm biased, because we created this kind of program here at Cedars-Sinai, and I've seen that it both helps physically and is a social support. I just think that combination can be so powerful.

It becomes a form of personal connection.

Dr. Asher: Exactly. You're not going through this alone. We know from psychology studies that social persuasion and social modeling are important.

What is social modeling?

Dr. Asher: Some get this idea that they can't exercise because they have cancer. They're exhausted. But when they see another patient with the same cancer exercising, they can model themselves after that other patient. Just going to a local gym and joining some class with a bunch of adults who don't have cancer may not help as much. Those people aren't going through what you're going through. In a small group program for cancer patients, you model yourself after a peer.

You might feel more isolated in the typical gym setting because you're the one with cancer.

Dr. Asher: Exactly. You might even feel more isolated, generally. Everyone reacts to these things differently, but social modeling is one way to promote self-efficacy.

All of these tools can help cancer patients navigate the stress, depression, and anxiety that often come with a diagnosis.

Alicia Morgans, MD Cognitive Impairment + Prostate Cancer Treatment



Dr. Alicia Morgans is a medical oncologist at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University in Chicago, Illinois. She specializes in treating advanced prostate cancer and is particularly interested in addressing treatment side effects.

Prostatepedia spoke with her about cognitive impairment, stress, and prostate cancer treatment.

Have you had any patients whose stories have impacted how you approach patient care or how you think about your role?

Dr. Alicia Morgans: The most poignant in my mind right now is my grandfather who recently passed away from advanced prostate cancer. I know we have spoken about him before. His passing really brought home to me how important it is to have a good medical oncologist, and how privileged we are as medical oncologists to share in this journey with our patients and their families. He was diagnosed at a late age with prostate cancer, but throughout his entire life, he had been averse to doctors and medical care. It was challenging for our family, and for me in particular, because by that time, I was already a prostate cancer

+

"No one wants to feel weak. No one wants to admit that he's not feeling like he did 10 years ago."

+

specialist. We tried to help him understand that his doctors made recommendations to help him.

During his entire treatment history, I really felt very strongly and personally how important it is to balance quality of life with length of life for men with prostate cancer and their families. Living longer doesn't mean living better for a lot of people. It's really important for physicians to recognize that we can't put our own beliefs about what is most important onto someone else. We have to listen to our patients so that we hear what is most important to them. That is the thing that is most clear in my mind right now.

As my grandfather approached the end of his life, we had to make difficult decisions for him that walked a fine line between length of life and quality of life. He made decisions that some people may not make. He chose not to undergo further therapy at a certain point, even though those therapies existed, because it didn't make sense for him given his goals and preferences. That is what I think about as being most impactful when I meet with patients.

Do you think patients are often reluctant to have those kinds of conversations with their doctors?

Dr. Morgans: Absolutely. Those are not easy conversations to have. I would say that we were lucky in my grandfather's situation. We were lucky because I'm persistent and just kept pushing him to speak his mind and let us know what was important to him. In many conversations with patients, I find it's really important to wait and just be quiet. Let some space fill the room so that men who may be reluctant can take that next step and answer.

As physicians, many of us are so pressed for time that we are almost pressured in the way that we ask those kinds of questions.

Just letting some space sit in the room can give men an opportunity to speak.

The other thing that is important to do for men with prostate cancer is engage with their caregivers and loved ones, as long as the patients feel comfortable with this interaction.

Sometimes caregivers will share things that men themselves don't feel comfortable sharing. But once it's out, the men can open up. They feel able to continue that conversation.

I guess some patients might not know how they feel or might have a difficult time expressing how they're feeling.

Dr. Morgans: Absolutely. No one wants to feel weak. No one wants to admit that he's not feeling like he did 10 years ago. Optimism is a huge part of feeling well too, and for some, admitting that we don't feel as well as we did before can stand in the way of optimism.

I think it's important for us as physicians and as caregivers to make it clear to people that it's okay to express those feelings. A lot of times we have ways of making those symptoms better. If you're able to express it, maybe there's something we can do about it.

I know many prostate cancer treatments, like hormonal therapy, can impact cognitive function and therefore lead to depression, stress, and anxiety:

Can you talk a bit about that?

Dr. Morgans: The clinical trials associating cognitive decline and hormonal therapy are still being performed and still being validated. There is a good signal in the data available that there is some association between cognitive change and hormonal therapy. That is what a lot of my research focuses on.

Some of the men I have treated have not necessarily had measurable cognitive changes, but they feel that they are not as sharp. We wouldn't have been able to diagnose them with dementia, for example, but they

subjectively felt when they were trying to perform integral tasks in their jobs as lawyers or pharmacists or architects, that they weren't as able to complete these meticulous tasks in the way that they had been previously.

A lot of times family members also report a change, not only in cognitive function but also in other areas, like lacking the drive or motivation to do the things they used to do, or becoming somewhat depressed and perhaps moody, or not as engaged in family conversations.

"This is something that patients are living with day to day."

An effect on cognitive function or on these other related aspects of life can have profound effects both in an individual's working environment as well as his home life.

Any impact on memory?

Dr. Morgans: Absolutely. These are just case reports, but I have patients who certainly will say, "I can no longer remember where my keys are," and those kinds of things. The complex functioning that people do every day —perhaps remembering steps in a series or forgetting which task they were in the process of completing after being interrupted—are impacted. Their minds are engaged elsewhere and when they return to that task, they can't remember what it was they were trying to do in the first place. I've heard patients talk more about this set-shifting, or executive function loss, than simple memory issues.

I imagine that might cause a lot of stress and anxiety if you're experiencing those kinds of changes at your job.

Dr. Morgans: Definitely, and it can be an issue at home, too. Spouses, children, and other people in your life don't expect you to experience those kinds of issues when you look generally the same as you did before you were treated. Certainly, as men age and approach retirement, there can be a lot a pressure to maintain a certain standard of work product. If you feel like you're not quite living up to what you could do a few months ago and your family depends on your income, there can be a lot of personal pressure as well.

These are all changes we see with hormonal therapy, but what about some of the other treatments prostate cancer patients undergo? Are there similar cognitive changes in men on radiation therapy or chemotherapy?

Dr. Morgans: Radiation can definitely cause fatigue, and that can make you have a little bit of cognitive slowness if you're just really exhausted.
Usually, that wears off after your radiation is over.

What role do you think medical oncologists traditionally play in anticipating that patients might have these kinds of struggles? What role do you think the medical oncologist should play?

Dr. Morgans: That is a tricky question. I think, in general, medical oncologists have a lot of things on their plates. They're trying to balance all of the side effects of therapy, the reason for doing a particular therapy, the complications that a therapy can cause that are medically dangerous, as well as where we go next if this treatment fails. I don't know that they always take the time to dig deeply into questions about cognitive function,

depression, or anxiety unless those things are very clear because a patient is complaining about them himself or a caregiver says it is a huge issue. Medical oncologists have very short

"If you aren't talking about it, then there is no way for anyone to make you feel better."

patient visits, especially for followups, and have many things going on that they're trying to work through with patients. These cognitive changes are not always at the top of their list.

However, it's a critical part of our job and something that I take the time to do because of both my personal experiences and the way that I think medical oncologists should practice. That is not to say anyone else is wrong, but it is a really important part of my practice. This is something that patients are living with day to day. It's something that needs to be addressed and can negatively impact their quality of life.

A patient's experience of his quality of life is what really matters at the end of the day. Length of life and quality of life, to me, are both critically important. If you are not thinking clearly or you're severely depressed or anxious—about your job, financial toxicity, or dying—you can't live your best life.

Helping optimize quality of life during treatment for cancer is a pivotal part of what we do. That being said, I don't criticize any of my colleagues for missing discussions on this or myself when I'm having a day and

running an hour and a half late, but it is something we should strive to do.

Are there ways to circumvent these problems, or is it just a matter of identifying them early on and getting patients the help they need?

Dr. Morgans: I don't know if there's necessarily a way to completely avoid them, but we might, with some of the research being done, identify patient populations or individual patients who might be most susceptible to some of these side effects based on their genetics or based on the way they metabolize certain drugs.

If we can identify who may be most sensitive, we might be able to steer those men away from certain treatments and toward other treatments or delay treatment if that's in their best interest and is a clinically reasonable choice. Our goal is to provide men with a balance of best quality of life and longest length of life.

What we can do now is ask questions of our patients to diagnose these issues.

We can ask, "How's your mood? Are you feeling depressed? Are you feeling down?" We can figure out if they're depressed or anxious. If we talk to men and their caregivers about their daily life, we can treat these problems whether it is through pharmacologic therapy or counseling with a social worker, a psychologist, or a psychiatrist.

We can treat depression and anxiety. Loss in cognitive function is a little more challenging. I have referred patients to behavioral or cognitive therapy (similar to what is recommended for patients post-stroke) to give them strategies for dealing with memory loss or thinking problems. I've had some success with that approach, but I would say the standard approach





to managing cognitive decline is still being defined. This is the work that I am trying to do, because we still need to confirm which tools are best for measuring cognitive change, and then we need methods to prevent or reverse these issues.

The name of the game is identifying the problem as early as possible?

Dr. Morgans: It is. Then doing what we can to make it better, knowing that we can't fix everything—like cognitive change. We might be able to provide men with strategies to overcome the cognitive changes they're experiencing, or potentially we can switch therapies. We can't necessarily turn back time in terms of cognitive function. We haven't devised that strategy yet.

Do you have any advice for men about to start treatment who are worried about developing cognitive deficits?

Dr. Morgans: Feel confident and comfortable talking to your doctor about these concerns, especially if you haven't yet started therapy. In some clinical situations, hormonal therapy might not be the only option. Sometimes deferring systemic treatment is an option. If that's the case, voice your concerns to your doctors and have that conversation; maybe you can delay starting therapy until a later time.

If you are already experiencing these problems, it's important to talk about it. Even if there's not a perfect solution, sometimes talking about it and dealing with potentially associated symptoms like depression can help you feel better. If you aren't talking about it, then there is no way for anyone to make you feel better. Giving your physician and clinical team the opportunity to intervene, even if they can't make everything perfect, is really the first step in living a better life.

Do you think that as more patients start to report symptoms through mobile apps or desktop portals that they'll be able to tell their doctors about more sensitive side effects like depression and loss of cognitive function?

Dr. Morgans: I hope so. Last June, data came out that suggests that reporting these symptoms between visits and then acting on them when they reach a threshold can actually prolong survival in addition to preventing hospitalizations and preventing emergency room visits. (See *Prostatepedia* November 2017 for a discussion with Dr. Ethan Basch about that trial.)

I look forward to providing these newer reporting options to caregivers as well, because I think they are an underused resource. If caregivers have the opportunity to report side effects, we might be able to identify problems and intervene even earlier.

I suppose caregivers know a lot more than we give them credit for: they are observing and may see a difference before the patient even notices.

Dr. Morgans: Yes. They are also driven by different motivations. They sometimes want to share more, while patients feel either less comfortable in admitting their own deficits or don't want to admit them even to themselves. Caregivers are sometimes able to share those things before the situation becomes catastrophic.

John Peteet, MD Anxiety, Depression + Prostate Cancer



Dr. John Peteet is a staff psychiatrist at Brigham and Women's Hospital, and Dana-Farber Cancer Institute, and an Associate Professor of Psychiatry at Harvard Medical School.

Prostatepedia spoke with him about the anxiety and depression many prostate cancer patients face.

Why did you become a doctor? Why psychiatry?

Dr. John Peteet: I was always interested in science and in helping people. Then, in the first year of medical school, I had a very good exposure to psychiatry and started seeing patients as part of a course. I've always had an interest in the challenges and opportunities that psychiatry offers. I can hear people's stories and to talk with them about the larger issues in their lives rather than focus solely on the technical, medical aspects.

How did you come to focus on cancer patients?

Dr. Peteet: After my psychiatry residency, I spent a fellowship year at the Peter Bent Brigham Hospital, connected with Dana-Farber Cancer Institute. During that year, I began seeing some cancer patients in consultation. As no staff person

was on site to help with this, at the end of that year, I was offered the chance to become the primary consultant to cancer inpatients. Although in some ways, I fell into the role, I've also enjoyed the intensity, the teamwork, and the challenges of working with that population. I've continued to spend roughly half of my time at Dana-Farber and half at Brigham.

Do you see patients who have a variety of cancers or only prostate cancer?

Dr. Peteet: A variety. As our program has grown so that I'm now one of several psychiatrists seeing cancer patients, I have tended to focus more on genitourinary oncology.

It's a bit unusual, isn't it?
I've not heard of a lot of psychiatrists
or even social workers dealing with
genitourinary cancers specifically.
It tends to be more of a generalized
approach to psychiatric care.

Dr. Peteet: Yes, it is.

Are there common themes or issues that many cancer patients face?

Dr. Peteet: Anxiety around the time of diagnosis is a common theme. It tends to diminish when patients receive a treatment plan,

especially if the treatment starts to have some effect. A treatment response provides time for patients to stabilize their functioning and their expectations.

Recurrence, is, of course, distressing, but when a treatment works for the recurrence, this typically decreases anxiety and distress.

Then, if treatments ultimately fail, it's stressful to face discussions about goals of care and what to do with one's limited time.

In general, when patients lose their ability to function in ways that have been central to their identity—for example, becoming unable to work—they tend to need more help.

Are there issues specific to prostate cancer? There is a fair amount of uncertainty about what the appropriate treatment path might be for certain groups of prostate cancer patients. Does that create a special challenge in prostate cancer?

Dr. Peteet: Some decisions about course of treatment for breast cancer make women anxious, but anxiety about course of treatment is a particular issue in prostate cancer because patients can get so many differing opinions: radiation versus surgery versus watchful waiting.

There's also considerable apprehension on the part of many men about the potential side effects of some of those treatments—especially sexual dysfunction and incontinence.

After treatment, it is anxietyprovoking every time a man returns to see what his PSA indicates that his cancer is doing.

Making decisions about systemic treatment after a recurrence can be difficult because of the concern about side effects. For example, there is sometimes a risk of depression with hormone deprivation therapies, such as Lupron (leuprolide). If a man has a history of depression, he might be particularly vulnerable to depression, or a worsening mood disorder.



I know for many men it can be frightening to see their PSA go up a little bit after treatment: What does it mean? Is my cancer coming back? Is it a temporary bump? What would you say to men who are experiencing that kind of anxiety about PSA testing after treatment? Are there any techniques you would recommend to manage PSA anxiety?

It's important for men to talk to somebody they trust, who follows the PSA along with them, whether that's an oncologist, a radiation oncologist, or a urologist. Those doctors would be the ones most involved. Sometimes support groups are helpful for men to just share what the experience is like with other guys.

Do these kinds of issues impact the kind of choices men make? We have another conversation this month in which we talk about how many people come off active surveillance because they're nervous about whether the cancer is progressing or not.

Dr. Peteet: I have seen a few men unwilling, or very reluctant, to have hormone deprivation treatment because they were concerned about what it would do to their bodies. For example, weightlifters, bodybuilders, or men who are very invested in their sexual functioning, might turn that therapy down.

There are also occasionally men who don't want to get tested in the first place, don't want to have a surgery they think will impair their functioning in those ways, or put off treatment. Usually, there are other choices like radiation that are more palatable to them.

So yes, I think it does impact treatment. Their values about what is most important to them do influence the treatment choices they make.

Some men don't care about side effects. They want to get the cancer out. They might be more apt to choose surgery while somebody else who is more concerned about those other issues might go in a different direction.

Do you think, in general, doctors who treat prostate cancer patients are addressing these issues?

Dr. Peteet: I think most physicians—urologists, oncologists, and radiation oncologists—who concentrate on prostate cancer have a lot of experience with these issues. Most of them are sensitive to the anxieties men have and where they're coming from.



"There is sometimes a risk of depression with hormone deprivation therapies."

There are probably some who are less sensitive and just want to push whatever they think is the best treatment without really exploring the concerns so much. I've heard stories like that. My experience here is that most of the people who see patients are aware that patients are likely to be anxious and get other opinions. They're respectful of the need to let that happen.

Do you have any other thoughts on how men can manage some of these issues that may come up before or after treatment?

Dr. Peteet: I've seen support groups be pretty helpful. When a man has a history of being very vulnerable to depression or anxiety, there may be a need to see someone with more specialized expertise and have some individual time to talk through these issues. Those are the kinds of people I end up seeing: those whose anxiety is getting in the way of their functioning and it's obvious to the rest of the medical team.

Sometimes the spouse is helpful, but sometimes there is tension with the spouse, so we need to include that other person in our discussions. Some data shows that spouses are as distressed as patients about some of these issues. They may not always communicate as well as they could about that anxiety. Some support groups include partners as well. There have been some attempts





to look at educational interventions that help in decision-making so that people can have things written out when they go for a consultation and have ways to remind them of what they were told. We give them choices so they can feel somewhat proactive. That seems to be helpful.

What do you think about online support groups?

Dr. Peteet: I don't have much experience with those actually. There are probably some people who make use of them.

"It's important for men to talk to somebody they trust."

What about religious or spiritual communities? Do you think those could be forms of support?

Dr. Peteet: That's a good question.
One of the prostate support groups here at Dana-Farber, the Prostate
Health Education Network (PHEN), has done a lot of work in African
American churches trying to raise awareness about PSA screening.
They explicitly try to reach out to churches. That's been pretty helpful from what I can see in terms of marshaling support within those religious communities.

In general, the more men can talk about what they're going through with other men who have been through it too, the more they can feel like they're making the best decisions for themselves. Support groups are one way to do that.

But sometimes just informally networking and making it more legitimate to talk about your cancer, not just an embarrassing thing that men shouldn't be talking about, is a good thing.

Do you think that part of the stigma around prostate cancer is due to its association with erectile dysfunction?

Dr. Peteet: I think so. It's probably a macho thing.

It cuts to the core of what it means to be a man, I suppose.

Dr. Peteet: That's right, especially for a lot of men.

I had a patient this week whose wife died last year. He's lonely. We talked about whether or not he would go online to find another partner. He's a retired attorney. He has a lot going for him. He said, "I can't function sexually anymore. I'm not sure anybody would want me."

It's a major barrier for a lot of men. We have a few psychologists who specialize in sexual health, and sometimes they talk with men about what they can do given the limitations. There are urologists who are particularly interested in talking about erectile dysfunction; patients can be referred to them. Men don't have to feel like they have to settle.

Pp

Nina Priebe Fear + Prostate Cancer



Ms. Nina Priebe is a social worker at the Cedars-Sinai Cancer Center in Los Angeles, California.

She works with prostate cancer patients and their caregivers to manage some of the emotions sparked by the cancer journey.

Prostatepedia spoke with her about stress, depression, and prostate cancer.

"A man who always took care of the finances does not have time now because he's in treatment."

Why did you become a social worker?

Ms. Nina Priebe: I've been in the social work field for about 38 years. When I was nine years old, my sister was diagnosed with autism. We were part of a program owned by Cedars-Sinai that was multidisciplinary and helped us work as a family with my sister's behaviors. One of the most instrumental people on that team was the social worker. Because he

made such a difference in our lives, it became an interest of mine to help people through difficult times in their lives.

You saw firsthand the impact a social worker can have.

Ms. Priebe: Exactly.

How did that morph into helping cancer patients?

Ms. Priebe: My mother was a nurse, so I was always interested in science and medicine. But I wanted to apply my social work skills, so I've always been in medical social work. I spent 28 years in intensive care, and in the last year, I did palliative care with people who have very serious illnesses. I was part of the decision-making processes that they ultimately made considering quality of life and all of that.

I came to work at the Cancer Center because I wanted to do more of the palliative kind of social work. I was assigned the areas of prostate and pancreatic cancers, which was ironic because, six years ago, I had a personal experience. My fiancé was diagnosed with both breast and prostate cancer at the same time. Then it was personal. You really understood what these men were going through.

Ms. Priebe: Absolutely.

Are there common themes that come up in your work with cancer patients? Are some specific to prostate cancer?

Ms. Priebe: All cancer patients deal with the shock and disbelief of their diagnosis. They also go through feelings of lack of control, identity issues, sometimes role changes, changes in their family, and changes in communication.

Many things in their lives often have to be rearranged in terms of priorities. Side effects can have all kinds of impacts, both on emotions and psychological body image.

Many people have kind of an existential crisis: What does this mean? How did this happen? Why did this happen to me now? They're meaning-making. They're trying to make meaning of what happened. The caregiver experience parallels it in many ways.

In prostate cancer, men experience issues related to erectile dysfunction and incontinence. Some experience mood swings from the treatment. They may cry for no apparent reason

whereas, in the past, they may have had a good sense of control over their emotions. That's confusing and can be very overwhelming.

How does the caregiver experience parallel some of the issues that prostate cancer patients may find themselves facing that, say, caregivers of pancreatic cancer might not?

Ms. Priebe: A caregiver is anyone who helps. That help can range from practical kinds of help to emotional support. But the caregiver is also shocked by the diagnosis. Sometimes there were no symptoms. It was just a check-up. They too can have some denial or just some shocking disbelief.

Caregivers should be part of the treatment team. Because they're not the patient, sometimes they put aside their own needs, which isn't good in the long run. Some of them have their own medical problems, or they have the demands of elderly parents, young children, or special needs children, and the changing roles that may occur.

A typical change is that a man who always took care of the finances does not have time now because he's in treatment or doesn't have the energy. Role changes may occur and then change back again, but the caregiver balances his or her own work with caregiving.

Some issues that come up for prostate cancer patients and caregivers are related to stress and fear. What role do you think fear plays?

Ms. Priebe: Fear changes, depending on the process. At the time of diagnosis, depending on the man's history, fear can play a large role. My fiancé's father had died of prostate cancer, so he was initially very fearful of death.

After that, the primary focus of his fears related to impotence. But my focus as a caregiver was on his survival.

You're gathering information, going for second and even third opinions. I think the fear can be about making the right treatment decisions. Sometimes you have two and three differing opinions about what to do.

After treatment, there are fears about recovery for both the patient and the caregiver. Following that, people fear the cancer will come back. And then there is the anxiety around scans and blood tests every year or every six months.

Do you think the fact that there's a fair amount of controversy over how to best treat prostate cancer adds to that sense of fear?

Ms. Priebe: Absolutely. In his case, my fiancé regrets his decision, but that's because he had some adverse effects some years later. We see in hindsight. We didn't know. He made the best decision he could at the time given what we knew.

What do you say to men and their caregivers? Do you have any advice about coping strategies or ways to deal with these emotions?

Ms. Priebe: As much as both of them can, I strongly advise them to maintain some part of a routine in their lives. I tell them to practice relaxation, which means different things for different people. There are all kinds of relaxation techniques, including hypnotherapy. But distraction, inducing relaxation as much as possible, and keeping some part of a routine are most important.

I have lots of patients who've gotten into adult coloring books. I have people that use guided imagery,

which many of us use here at the Cedars-Sinai Cancer Center. Those kinds of things are very important.

What about support groups? Do you find them useful for men and caregivers?

Ms. Priebe: Some men who don't have a good support system find it really useful. It varies. We have them, but many men just want to go on with their lives and they don't want to focus on what they've been through with a group.

What about caregiver support groups?

Ms. Priebe: I think they end up being useful. People think that when they join a support group, they have to stay indefinitely. Sometimes, it might just be a certain stressful time in the process. Finding out that their feelings are normal—that other people have felt that way—can just be the reassurance needed to feel that they're really okay.

What should patients and caregivers be aware of as they go into treatment or monitor themselves for recurrence?

Ms. Priebe: Being as generous with yourself as possible and allowing yourself to mourn are important. Until you mourn, you can't go on to see: What did this bring to my life that might be positive? Have I now decided that different things are important to me? Whether something as simple as getting up and watching the sunrise or as complicated as a relationship that needed some repair, allowing yourself to mourn is the first step in being able to improve, adjust, and accept whatever has occurred.

You can't really deal with anything until you acknowledge that you're mourning.

Ms. Priebe: That's right. You lost something. You grieve.

Clinical Trial: David E. Victorson, PhD Meditation + Active Surveillance

Dr. David E. Victorson is a clinical psychologist and Associate Professor at Northwestern University's Feinberg School of Medicine in Chicago, Illinois.

Prostatepedia spoke with him about a trial he's running on mindfulness meditation and active surveillance for prostate cancer.

Why did you become a clinical psychologist? How did you end up working with cancer patients?

Dr. David E. Victorson: My training was in clinical health psychology and behavioral medicine. A lot of my early training experiences were in cancer, and in some of those, I had the opportunity to work with men with prostate cancer and their spouses in a clinical capacity.

The reasons why I went into this area are multifaceted, but I would say one of the primary reasons is that there is so much that we can do with our own behaviors and lifestyle practices. There is so much good that we can do for our own health by ourselves without needing any heavy equipment or extreme intervention. A lot of times, it just takes a little nudge in a different direction to get people going on a path that will be incrementally better for them.

How do you usually work with patients?

Dr. Victorson: I don't work with patients in a clinical therapeutic capacity today. I do 100% research. In 85-95% of our research studies, however, we deliver psychosocial and behavioral clinical interventions. Sometimes you might call them selfmanagement interventions. A lot of them are prostate cancer-focused. Usually, we involve spouses. We help men and their spouses learn skills that can support their health and well-being in different ways.

Most of those studies are groupbased, bringing groups of men and their spouses together for classroom skills

I'm sure that the skills you teach are useful beyond a cancer diagnosis.

Dr. Victorson: They are. A lot of the things we do are applicable across a whole range of different diseases and conditions. People who don't have a disease can still benefit. But when you get a prostate cancer diagnosis, modifiable health behavior comes into the picture quickly in terms of diet and exercise.

What we're trying to do with our meditation study is along the lines of mood management, which can



be really important in the context of cancer. There's nothing like a cancer diagnosis to motivate a person to make that kind of lifestyle change.

I've heard that before, especially when it comes to exercise and prostate cancer. Dr. Rob Newton told me that cancer patients tend to be more motivated than cardiovascular disease patients, for example. (See Prostatepedia December 2017.)

Dr. Victorson: Right.

What will you be doing in this particular trial? Why mindfulness education in an active surveillance population?

Dr. Victorson: We are comparing our eight-week mindfulness intervention with a matched attention control program. We anticipate that the attention control program is also going to lead to positive health changes, but we hypothesize it will be different than the mindfulness program.

This is a blinded trial, and men and their partners won't know what group they'll be put into outside of the fact that it's a health promotion intervention. This can be challenging for recruitment when you don't know what you're signing up for. All the men will know is that we are testing

two different health promotion and wellness interventions that have been shown to be good for men with prostate cancer. That's about as far as we go. Most people who sign up really like it, but they don't even know that they're signing up for a mindfulness intervention. We're not trying to deceive anyone, but we need it to be blinded like this to increase the rigor of our results.

Why mindfulness? As we're doing a better job of prostate cancer screening, we're finding more indolent or lower grade prostate cancers. Many of these cancers don't need to be surgically removed or radiated. Active surveillance is becoming a more possible management paradigm. We know that trend is only going to continue.

Many patients are happy with active surveillance. But there are others who, because of how they grew up or because of what cancer means to them, equate cancer with death. When they're told they have a tumor, they just want it out.

We're dealing a specific demographic. Older men might be used to the idea of just wanting to get the situation fixed. That's how they may cope. We're also dealing with a treatment culture in which active surveillance hasn't totally caught on. There are still quite a few urologists who recommend what they were trained to recommend: surgery or radiation even for a very low-grade tumor.

There is a certain type of man who will leave active surveillance after one to three years for definitive therapy even when it may not be medically warranted. This shift may be more connected to them wanting peace of mind and just wanting the cancer out.

I always try to say to patients, "If that's what it's going to take for you to get peace of mind, more power to you. You know better than me. I don't have prostate cancer." But at the same time, as a health psychologist involved in behavioral medicine, I know that there are other ways to help men manage their anxiety than through surgery.

Therefore, we're exploring which behavioral approaches can be delivered to keep men on active surveillance longer when it is medically warranted. If their physicians say that they can stay on active surveillance longer, we try to support that.

You're hoping that with mindfulness meditation you'll be able to help men stay on active surveillance longer.
Could mindfulness ultimately be a routine part of active surveillance programs?

Dr. Victorson: Yes. That is the 30-year career goal. We're not going to be able to answer that question from this five-year trial, though.

One of the biggest indicators of peace-of-mind-related departure from active surveillance is uncertainty intolerance and fear of progression. Those two things can form a powerful cocktail that might drive a man to leave active surveillance prematurely. Some men are able to tolerate uncertainty and fear of progression more than others.

We know that mindfulness training can be very useful in helping someone learn to tolerate uncertainty to a greater extent. We can help build that muscle, if you will, in tolerating uncertainties and with sitting with the discomfort of not having your tumor taken out. We are looking at mindfulness training to help reduce fear of progression and increase tolerance to uncertainty. We think those are two important mechanisms toward this goal.

The psycho-educational health promotion group of men and their partners will learn how to integrate positive health behaviors into their lifestyles—things like eating more vegetables, getting more physical activity, and being more aware of their patterns and behaviors. The program doesn't have anything to do with mindfulness, regulating emotion, or tolerating uncertainty.

What kind of patients are you looking for? Men who are just starting on active surveillance or those who have been on active surveillance for a number of years?

Dr. Victorson: They have to have been placed on active surveillance within a year. We are looking for men who are somewhat new to the protocol. The eligibility criteria are quite broad: if your urologist has placed you on an active surveillance protocol within the last year, you're eligible. We also invite spouses to participate as well, but that's not a requirement.

What's involved in the program?

Dr. Victorson: It is an intensive eight-week, face-to-face, group-based course that meets for about two to two and a half hours a session. It is skills-based. We try to assuage concerns about there being too much kumbaya support group emotional processing going on. Every now and then someone might talk about their stress, but the class is really designed to teach practical skills in mindfulness and how to bring mindfulness skills to your life. It's intensive, though, and it can be tough.

Again, in this age group, many are snowbirding in Florida in the winter and vacationing with family in the summer. Trying to find time to come to eight sessions doesn't work for

everybody. We find that the men who are able to come to most of the sessions really benefit a lot.

Usually, the sessions occur in the evenings after work. We provide a healthy, delicious dinner, and then we spend a lot of time practicing the skills: we learn, we practice, we go home. There are daily homework assignments, which involve listening to a 20- to 30-minute recording of the meditation they're practicing that week.

We have them fill out questionnaires before they start, after they finish, and again at six months and 12 months. There is a monetary stipend after each assessment period.

I'm assuming patients would need to live near one of the study locations?

Dr. Victorson: Yes. A challenge right now at one of our study sites is that they tend to draw men from much further away than some of our other locations, which makes it tougher for men to participate because of the drive. You don't want to drive two hours to a session and then drive two hours back home. Our next study after this one is likely going to be either a completely online, video-conference-delivered intervention or a hybrid where most sessions are online coupled with a few in-person booster sessions. The program is impactful, but right now it's not scalable the way we would like it to be.

Do you have any other studies looking at mindfulness in any other patient populations or are you just focusing on active surveillance?

Dr. Victorson: We do. We've finished several randomized controlled studies on mindfulness in prostate cancer. I also work with young

adults with cancer. But by and large, most of our studies are in prostate cancer. Not just active surveillance, though: we're also looking at men with advanced disease. That study is a randomized controlled trial in which we are comparing a four-week face-to-face version of the program with a four-week video conferencing version. We want to see if there is some level of equivalence between doing it in the center versus online Brady Bunch style in which your face is on a screen, and you're looking at somebody. That study is in the Chicago area.

We've got another study in which men getting radiation treatment listen to mindfulness recordings or to relaxing music during their daily treatment. In that study, we're also seeing if meditation can help decrease fatigue and increase sleep quality.

Is there anything else that you think patients should know either about this particular trial or about accompanying studies that you're running?

Dr. Victorson: Whether or not you do mindfulness training to promote health and well-being, staying engaged and activated is critical. Mindfulness might be great for some people, but it is not for everybody. But being activated and proactive is really important.

How To Get Involved...

For more information, email Dr. David E. Victorson at d-victorson@northwestern.edu to find out about future trials on mindfulness in prostate cancer.





Patients Speak: Roger G Anxiety, Depression + Prostate Cancer



Roger G. is an Australian man with prostate cancer.

He spoke with *Prostatepedia* about how he dealt with anxiety and depression during his prostate cancer journey.

How did you find out that you had prostate cancer?

Roger: My general practitioner had been checking my PSA since 1999. I'd had some issues with urination. He wasn't too concerned because my PSA hadn't changed much.

In 2003 it had risen to 3.8. In 2004, he said I should get another PSA test but said to leave it until early December, which I did. By that time it was up to 5.6. He referred me to a urologist who said, "We'll do a biopsy. No hurry. Come back after Christmas."

I went back to see him in January. The cancer looked pretty well contained. My Gleason score was 3+4=7. He said we'd have to operate, but there was no rush. At that stage, I was a little bit anxious about it all. I thought: Here we go. Just my luck to have cancer, but let's get on with it.

The urologist said, "If it has spread, which I don't think it has, you can go on hormone treatments. Lots of people get 12 more years with that. Don't worry."

I had the bone scan to check if it had spread. Nothing was found in my bones. I had them book me for surgery as soon as they could. The surgery went well.

Three months later, I went back to see him. My PSA was 4. He said, "Surgery failed."

A week later I had another PSA test. It was 5. I started to feel a little bit anxious, but he told me not to worry. He sent me off for a PET scan, which took a little bit of organizing. This was back in 2005 when the PET scan machines were new. They didn't even know which PET scan to give me. I now know that the PET scans I had were part of a study to determine which was best for prostate cancer.

I had one scan and then another. It lit me up like a Christmas tree. There were three big red dots well apart and away from where my prostate was. I was pretty anxious about it all.

How did you deal with that feeling of anxiety?

Roger: I asked, "How long have I got?" They estimated two to five years. I asked about surgery? "No," they said, "That's like weeding a garden." What about radiation? They said they'd have to burn my guts out. I asked what to do. They just told me to "Keep fit and come back in three months." I was 59.

My experience with cancer in my family was pretty grim. My dad was diagnosed with cancer and died three weeks later. It wasn't prostate cancer, though. My aunt died from lung cancer. One of my sisters said it was breast cancer, but I didn't know that at the time. She died pretty soon after her diagnosis. My dad's brother was 72 when he told us he had lung cancer on Boxing Day in 1995. He was dead by Easter.

I was a mess. I would see healthy people and say to myself, "How come you are okay and I have only a few years?" The black dog was giving me a hard time.

But that's when I organized myself to see the psychologist at the hospital. I had a breakdown. I saw her every week and just talked about how things were going.

She suggested I obtain the Guided Mindfulness Meditation CDs by Jon Kabat-Zinn and start with body scan meditations. I bought the discs. These helped a quite a lot, and I felt as though I was doing something to cure the cancer.

Then, by chance, I went to a support group meeting in one of the Melbourne suburbs—pure chance. I couldn't find anybody at the meeting who was in the same boat as me. Everybody I met had either had surgery and was all clear, or they were just waiting and watching. But also at that meeting was a motivational speaker. He was fantastic. He talked about how it was mind over matter and about self-talk. He mentioned Lance Armstrong's book: *It's Not About The Bike*.

It's about turning things around with this self-talk stuff. It all gets to you. I've only got a few years to live. I want to really enjoy the rest of my life. Now, I say to myself, "You're going to be okay."

Anxiety had me looking at the dark side. Everything on the TV was death. It wouldn't matter what it was. It was all death to me. It was all why me? A good friend invited me around to his place for a drink and we enjoyed a bottle of red wine. For the first time in two months my nerves settled, and I knew that I could put the black dog in his kennel.

Things took a dramatic turn. My boss, who was very understanding, told me of his brush with cancer and how he was given the all clear. A work colleague told me about his 80-year-old father who had been told he only had a year to live when he was 40. When I took my first PSA test in 3 months, my general practitioner said it might be down. And it was: 3.4!

Cancer is tough. I'm sure most people wonder why me at some point.

Roger: I went through a period when I had a tough time. I was on a hormone-suppressing drug when my PSA went back up to about 20.

I got a little bit depressed once I started on that. I went back to the meditation tapes. There were other issues, too, with loss of libido and putting on a bit of weight.

I use the meditation CDs and self-talk. I keep myself fit. I do a good bit of resistance training and stretching. In June 2016 I had another serious mental breakdown. My general practitioner put me on a moodenhancing drug. Now I'm feeling terrific and energized.

And you lead a support group, don't you?

Roger: I'm the secretary there. That keeps me busy. I play golf three days a week. I walk around the golf course, dragging my clubs around behind me.

Even though I was depressed, I still played golf and worked out at the gym.

Do you have any advice for other men facing similar circumstances?

Roger: Prostate cancer is a chronic disease. If you get a black mood, use self-talk. Talk to yourself inside your ear: "You won't have any symptoms. They don't happen. If you do get a bit of pain, well, you can just let them do a bit of radiation."

You've got to keep in touch with your oncologist, just to see if you are eligible for one of the new effective treatments.

Work out because your bones degrade when you're on hormone treatments. Exercise is medicine. Get your heart beating and get your muscles working. This will give you a sense of control over your destiny. If you are anxious or depressed, see your general practitioner. The medication my general practitioner prescribed sorted that out (and decreased the intensity of the hot flushes).

I enjoy my grandkids. Two of my daughters are married. I've got four grandkids. It makes me see the joy. I am really looking forward to all the joys of old age. I had a friend who is about 12 years older than me and he has dementia. I think prostate cancer is a better route.

Chuck Strand: Anxiety, Depression + Prostate Cancer



Mr. Chuck Strand is the CEO of Us TOO International Prostate Cancer Education and Support Network (http://www.ustoo.org/). He discusses the anxiety and depression often associated with prostate cancer.

A cancer diagnosis of any type triggers a wide range of initial reactions and emotions. While in some instances it might provide a sense of resolution, a more typical response may include sadness, loss, fear, guilt, stigmatization, embarrassment, anger, or disappointment.

Many aspects of living with a prostate cancer diagnosis can be sources of anxiety and depression— everything from anticipating the next PSA (prostate-specific antigen) blood test results to dealing with the post-treatment impact of common side effects like incontinence and erectile dysfunction (ED).

Unfortunately, men and their partners are not always fully informed about the likely side effects when selecting a treatment. In addition to managing the anxiety resulting from ED and/ or incontinence, an unexpected decrease in a man's sexual virility can lead to a sense of betrayal or reduced trust in his medical provider or in the medical community

in general. Recognizing and learning to cope with anxiety and depression can be critically important for effectively managing life with prostate cancer.

In a recent collaborative survey conducted by Us TOO International and Cancer Care, 94 percent of men who were diagnosed with prostate cancer indicated that experiencing anxiety and/or depression is to be expected. Anxiety and depression can interfere with a person's day-to-day activities, responsibilities, and relationships and can impact not only the person with cancer, but also the caregiver. Helping family members manage their distress may have a beneficial effect on the distress level of the person with cancer.

The stress and anxiety associated with a prostate cancer diagnosis can be significant enough to influence a man on active surveillance to opt for treatment earlier than necessary, resulting in what is often referred to as over-treatment.

Treatment decisions must address whatever aspect of disease management is a priority for each man, after he has sufficient information on all treatment options, possible or probable side effects, and management of side effects.

One man's priority could be to do everything he can to minimize the possibility that prostate cancer will metastasize, while another man's priority could be to do everything possible to maintain and maximize his quality of life. It is important for a man to recognize that once diagnosed with prostate cancer, the disease will unfortunately be a perpetual issue of concern and a potential source of anxiety due to ongoing monitoring of PSA test results at a minimum, regardless of the course of action he takes. While active surveillance can be emotionally exhausting, over-treatment can result in decreased quality of life with ED, incontinence, and the potential emotional and psychological impact of having second thoughts about his treatment choice.

Symptoms of Anxiety and Depression

Anxiety and depression not only affect the quality of a man's life, but can also keep the body's immune system from functioning at its full capacity. Additionally, it can have a negative impact on adherence to treatment regimens. Therefore, it's important to recognize these conditions and attempt to address them accordingly.

Anxiety is a feeling of nervousness, fear, apprehension, and worrying—

typically about an imminent event or something with an uncertain outcome. Symptoms include: feelings of fatigue or weakness, sweating (for no reason), chest pains, headaches, gastrointestinal problems, or inability to rest.

Depression is a feeling of severe despondency and dejection.

Symptoms include: sleeping more or less (as compared with regular sleeping habits), loss of interest in daily activities, an unusual increase or decrease in energy, changes in appetite (eating either more or less as compared with regular eating habits), increased irritability or impatience, or difficulty concentrating.

Action Items to Help

Take action rather than passively accepting anxiety and depression as a given. Begin by acknowledging the very real relationship between anxiety, depression, and prostate cancer. Take stock of your own emotions. Talk to your doctor about your concerns. Make sure your diet is heart-healthy/prostate-healthy. Exercise even if you do not feel like it. Especially if you do not feel like it! Exercise releases endorphins and neurotransmitters that promote relaxation and eliminate excess cortisol, a hormone released during stress and associated with anxiety. Get mindful and try to incorporate yoga, meditation, acupuncture, or other holistic practices into your life. These lift the body, mind, and spirit. Try to keep a positive attitude when possible, but understand that ups and downs are normal and expected during prostate cancer treatment.

If appropriate, your doctor might be able to provide a referral to a counselor who can help. Some common techniques to effectively manage anxiety include talk therapy (especially Cognitive Behavioral Therapy [CBT]) and anti-

anxiety medications. Depression can be managed though lifestyle changes to establish more connections and support, psychotherapy (including Cognitive Behavioral Therapy), pharmacological treatment and, in advanced situations, Electroconvulsive Therapy (ECT).

Reach Out!

If you are dealing with prostate cancer and experiencing anxiety and/ or depression, know that you're not alone. Educational resources and support services are available to help cope with anxiety and/or depression.

Many men with prostate cancer and their wives/partners have dealt with anxiety and depression. It can be helpful to attend an Us TOO prostate cancer support group to share experiences and gather information and strength from those who have successfully managed these challenges.

To find an Us TOO prostate cancer support group near you, visit www. ustoo.org/Support-Group-Near-You, call 800-808-7866, or email ustoo@ ustoo.org.

To join a prostate cancer support group via telephone, visit www. ancan.org/support-calls.

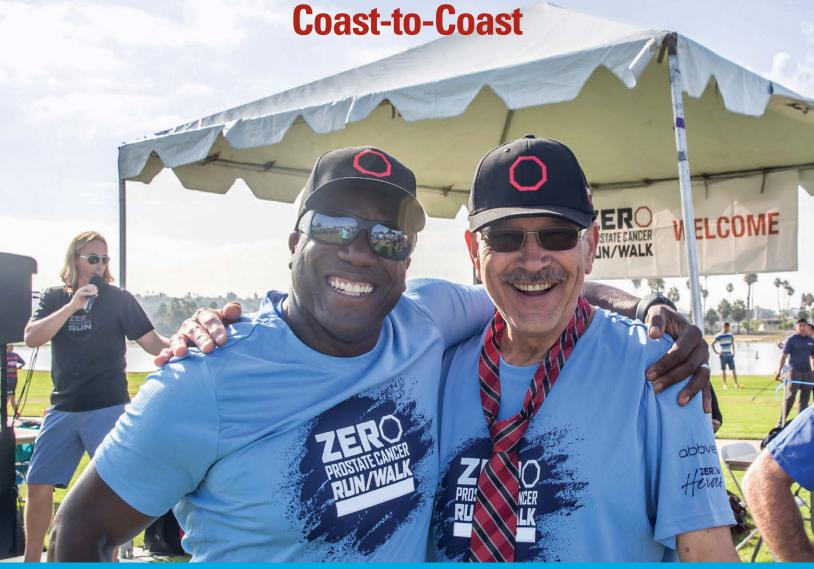
For individual counseling on anxiety or depression by telephone and online group counseling, contact Cancer *Care* at 800-813-4673 or www.cancercare.org.





You can join the fight against prostate cancer!

2018 ZERO Prostate Cancer Run/Walk Events



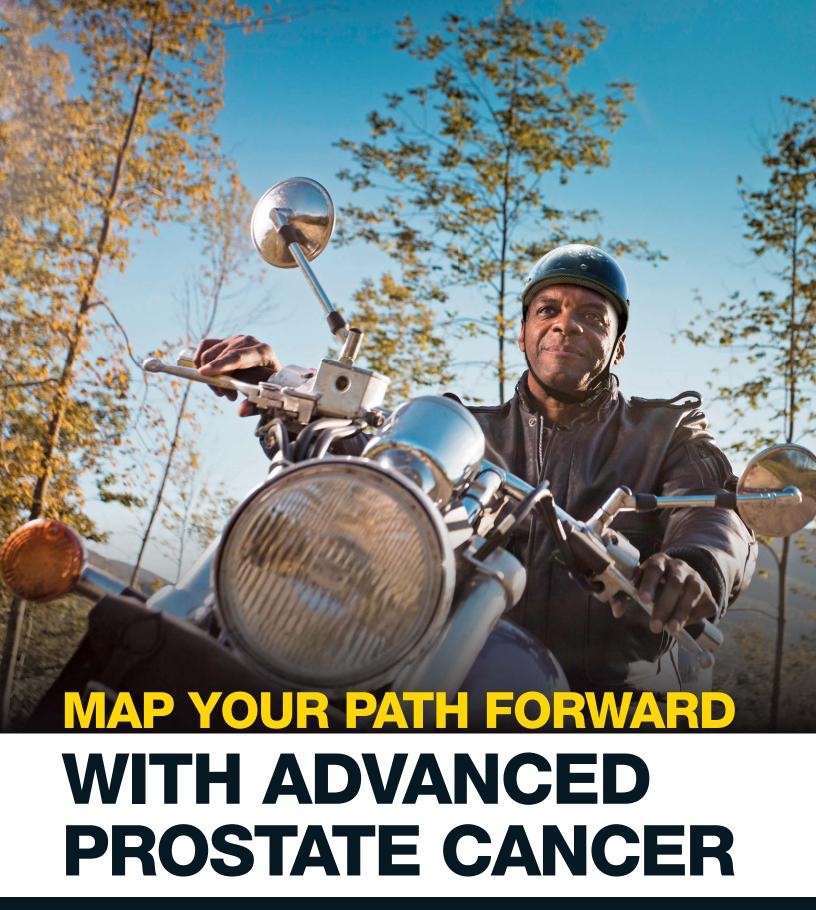
Coming to a city near you. ZEROPROSTATECANCERRUN.ORG





Prostatepedia¹ expert insight + advice Subscribe to Prostatepedia ☐ \$85.00 for 1-year email subscription (organizational) □ \$55.00 for 1-year email subscription (individual) □ \$30.00 for 6-month email subscription □ \$15.00 for 3-month email subscription Please enclose a check made payable to Rivanna Health Publications or order online at www.prostatepedia.net. Name: Address: Email: Phone: Please return to: Rivanna Health Publications 274 Redwood Shores Pkwy, #739 Redwood City, CA 94065

Conversations with Prostate Cancer Experts www.prostatepedia.net





MyProstateCancerRoadmap.com is an online resource that can help patients and caregivers navigate through advanced prostate cancer topics such as:



UNDERSTANDING YOUR ROAD

You already know about prostate cancer. What is advanced prostate cancer?



CHOOSING YOUR ROAD

Explore your treatment options so you can partner with your doctor to decide what is best for you.



FINDING YOUR WAY

Learn how to adapt to changing relationships and begin to navigate other changes in your life.



VIEWPOINTS FROM THE ROAD

Educate and empower yourself with educational articles and real stories about people facing prostate cancer.

Visit www.MyProstateCancerRoadmap.com/start to stay in the know and subscribe to our newsletter.



274 Redwood Shores, #739 Redwood City, CA 94065 (800) 975 6238 info@prostatepedia.net www.prostatepedia.net

Coming Up!

March:
When Your Cancer Recurs

April: Genomics + Prostate Cancer

May: Joining Clinical Trials