

# Ask Dr. Myers

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## Jan Manarite: Patient Advocacy

Posted November 21, 2013

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We recently had the chance to speak with patient advocate Jan Manarite about how she approaches her role as educator and facilitator. The wife of a patient, Jan and her husband Dominic began their prostate cancer journey in March 2000 when he was diagnosed with a PSA of 7,096 with bone metastases to the hips, ribs, spine and skull. Today, Jan is one of three patient advocates who staff the widely popular PCRI Helpline <http://prostate-cancer.org/resources/helpline/>. If you'd like to reach Jan, you can do so by calling her at her home office in Sanibel, Florida at (239) 395-0995 or by emailing her at [jmanarite@pcri.org](mailto:jmanarite@pcri.org). Keep in mind that neither Jan nor the other PCRI Helpline support staff take urgent or emergency calls. If you're in an urgent situation, you need to call your doctor.

### *Facing Fear*

I listen first. Because if I listen first, I'll hear what their fears are. More often than not, I find fear is based on misinformation. "I had a friend with cancer and this happened to them," the caller will say.

So I listen to the situation. I try to meet them where they're at. As advocates, we help you understand your journey, clarify your situation, find your next step, get better information, find resources that you didn't know about, and get you to a place where you feel empowered. I know someone is not feeling empowered if they say they feel helpless, overwhelmed, afraid, or anxious. That's the checklist. If I can start checking those off, I can take people to a place where they feel empowered. That's my goal.

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Everyone has fear going into a cancer diagnosis. Often that is based on misinformation. Yesterday, for example, I was speaking with a gentleman who was asking question after question. He seemed to be all over the place. And he actually sounded like he was doing really well. Eventually, what I heard was a fear of something. I didn't know what it was, but I really thought it was a fear of dying, which is something you have to face in this journey. You have to go there. And you'll come back a better advocate or a better person. I recently wrote an article called "Understanding Survival Statistics" about facing death in your prostate cancer journey. I gave him the article and said, "See if that helps."

### *Medical Records*

I always tell prostate cancer patients to get their medical records. You have your own personal science and it's in your medical records. The more you understand your medical records, the more you're going to be able to develop better questions. And if you develop better questions, you will get better answers.

But there are actually multiple benefits to getting your medical records. When you go for a second opinion or go to see another doctor, bring your medical records, because you have no idea if the facts made it there before you did. Just eliminate confusion and bring your records. Personally hand them to the doctor.

Another reason to have your medical records is that your adult children at some point will need to decide what they should screen for based on their family history. Accurate medical records will help them do that.

Luckily, it's now becoming politically correct to ask for your records. Medical records are also increasingly available online through EMR, or electronic medical record, systems. The change is part of patient-centric health care and shared decision-making. The benefit for patients is that it is now politically correct to ask for your records, which makes it less of a battle or a conflict and much easier to do.

Keep your own records and then every time you see someone ask for a copy of what happened that day. The best time to

ask for your medical records is when you're in your doctor's office. Because your doctor is the only one who has the legal power to give it to you. And you are the only one who has the legal power to ask for it. A new CT scan? A new blood result? I think sometimes there's a tendency for patients to rely on the doctor who ordered the imaging test to interpret it. If an urologist orders a bone scan, you rely on the urologist to interpret the result for you. But the truth is, there's another doctor who reads your bone scan, not the urologist. He is called a radiologist. And he produced a dictated written report for your urologist. So get a copy of the result and take it home. Your cancer is too important to try to make decisions based on verbal information and mental recall. You wouldn't do that for financial decisions, would you? Why for medical decisions?

### *Vocabulary*

Words were intended to communicate. At the very least, they should be communicating to the people who need the information the most. They should be serving them. But there's a big valley between scientific vocabulary and the sick person. My job is to create a bridge over that valley. I talk a lot about the fact that every drug has two names. And science definitely keeps changing words. Hormone refractory became androgen dependent became castrate resistant. Watch and Wait become Medical Management became Active Surveillance. A large part of what I try to do is build a bridge between the science and the people who need the science wherever I can.

The other thing I say this to people about their medical records is that you can google any one term in your records that you don't understand and you'll be surprised at what you can learn. You'll be surprised how much clarity you can get when you're no longer intimidated by a term.

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**MCPOMAACK** on November 21, 2013



As a mentor myself, I have found Jan to have exceptional knowledge regarding understanding prostate cancer and its appropriate treatment. I have exchanged emails with Jan, met her, and consider her a good friend. I would recommend to any and all patients and caregivers to contact Jan regarding prostate cancer issues if having a concern not addressed sufficiently by other means.

Reply

**Ken Alberg** on November 21, 2013



I agree. Coincidentally I just happened to stumbled upon Jan yesterday and what a breath of fresh air she offers patients like me who don't know what why to turn sometimes. Cheers to Jan!

Reply

**Robert Spining** on November 22, 2013



Well written, cudos to Jan as a well informed advocate. As a survivor and having served as Chair of the Prostate Cancer Education / Awareness Committee at University of Tennessee Medical Cancer Institute, the key for patient and family members who share this fight is in fact to be well educated, well read all to gain valued in depth knowledge as to severity of the cancer, treatment options, etc.

I have found that many of our General Practitioners misdiagnose or follow misinformed screening guidelines creating levels of anxiety or false sense of hope in many cases.

PC needs a stronger national advocacy and awareness voice such as the Susan G. Koeman Foundation is to Breast Cancer. ACS 2013 statistics continues to show PC to be the leader in "Estimated New Cancer Cases" of all cancers.

Prostate 238,590

Breast 234,580

American men and their families are in desperate need for more well informed

advocates like Jan.

Reply

**John Kriney** on November 22, 2013



Jan has been my angel who helped bring miracles into my life for the past eight years. Diagnosed with Gleason 9 metastatic cancer at age 59, she helped me better understand my treatment options, verbally held my hand and helped guide me to two doctors who performed their miracles. Now, eight years later I am in “chemical remission”, PSA <0.01 and back living my normal life. Bumps and bruises? Yes. Alive? Most definitely!

Jack Kriney November 22, 2013

Reply

**Ken Almborg** on November 22, 2013



John,

If you don't mind I like to talk with you about your journey. I have a Gleason 8 with metastatic to lymph nodes, periaortic node as well as bilateral pelvic sidewall lymphadenopathy. No bone metastasis.

Reply

**John Kriney** on December 7, 2013



Ken,

Find me at [johnkriney@comcast.net](mailto:johnkriney@comcast.net)

**Stephen Corman** on November 22, 2013



I have met Jan a couple of times. As an 18 year prostate cancer survivor myself (diagnosed with Gleason 9 and positive surgical margins - now metastasized to the spine) who has been a prostate cancer activist and advocate since 1995, both nationally and locally, I echo everything she has said. To counsel properly, you need to listen and the more educated a patient is, the easier it is to help him.

Reply

**Patti** on November 24, 2013



Blessings to you, Jan. We learned to do our own research and be our own advocate. It's exhaustive and exhausting, but it's the only way.

Reply

Anant Kulkarni on November 26, 2013



we all are so thankful for Jan's (and snuffy's) work and advice.

I wish there is a group which will focus on AWARENESS. In other words, I want each man to know BEFORE he is requesting the PSA (soon after he enters the age 50, 40 if one is african american), that any abnormal value should not automatically lead to biopsy, that there are are a few steps to be taken prior to biopsy, that even after biopsy conformation it is by no means a death sentence, that one option may be active surveillance instead of rushing to one of the treatments which can result into some nasty unwanted consequences. That first abnormal PSA value can help you focus on your health, to initiate many lifestyle and food changes and possibly make you more healthy with longer life, especially when we know that many of us will die WITH prostate cancer and not BECAUSE of it.

Reply

Dan Bard on November 27, 2013



I will share your suggestion about medical records with my group: The Villages Prostate Cancer Education and Support Group. We have monthly meetings, with various doctors as guest speakers. We have between 45 -75 men and women attend the meetings. Thanks for sending me the book: Invasion of the Prostate Snatchers. After reading it I suggest at each of our meetings that the attendees purchase the book. Those who read the book thanked me for suggesting it.  
Thanks Jan

Reply

Clark Scarborough on December 5, 2013



I would like to be a mentor, also. I have been studying all of the PCRI Annual Seminar DVD presentations since 2007 (when they started recording them), and many books, CD lecture series, and more. Not only about the disease itself, but also of general health, sleep, and stress. I am a member of my local help group (Tex US TOO) in Houston. I want to continue to learn about this disease to help others, and study the latest in technology, as well as people's reactions (as Jan does so well in listening). What steps do I take to become a mentor?

Reply

[tom orourke](#) on December 5, 2013



I have had robotic prostate surgery in 8/2010 with a gleason 8. since it escaped the capsule they recommended radiation. unfortunately, I was uninformed and relied on sketchy information, I was fortunate to find Dr Myers who accepted me as a patient who with his excellent staff has helped me manage my entire health situation.

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