

**JOEL NOWAK – PROSTATE CANCER SURVIVOR, ADVOCATE,
FELLOW MENTOR, FRIEND**



Saved to share by Charles (Chuck) Maack
www.theprostateadvocate.com

Joel Nowak: Advanced PCa Advocate

Posted February 20, 2014

Joel Nowak is a prostate cancer advocate affiliated with Malecare. He runs a popular blog focusing on metastatic prostate cancer called advancedprostatecancer.net. He has also written a free guide to advanced prostate cancer that's been downloaded over 25,000 times. He is a driving force behind startacure.org, Prostate News Flash and the newly launched Malecare advanced prostate cancer newsletter.

Through his work, he has touched the lives of countless men here in the United States and abroad.

Joel recently spoke to us about his prostate cancer journey and how he became an advocate.

Mr. Nowak says: I am a survivor of four primary cancers: thyroid, prostate, kidney and melanoma. I know cancer well. It doesn't really faze me. It's part of living life for me. It's part of the course of events. I get a cold. I have cancer. I'm not going to die of a cold, but I will probably die of cancer.

I always knew that I would eventually develop prostate cancer because I have a strong family history: my father, his brother, my first cousin, and my paternal grandfather. I was pretty religious about getting PSA tests. And then right before 9/11, when I was 49 years old, I was diagnosed with prostate cancer with a Gleason 7 (4 + 3), a 4.1 PSA, 6 samples, 5% cancerous in each sample.

I went through the normal process almost every man goes through in trying to decide on a treatment. Anger. Frustration. I eventually come out of the tunnel and decided to have laparoscopic surgery, which was the precursor to today's robotic surgery, at Massachusetts General Hospital in Boston. It was uneventful.

I have an immune illness and have been on certain drugs for years to control it. I also routinely see my rheumatologist for blood tests and, post-surgery, I saw my urologist for a PSA test. Both routine appointments took time away from my work. I asked the rheumatologist if he would do a PSA test when he did my routine blood-work. He said he would and then I never heard anything. And I never asked. I assumed the PSA test was being done.

I have a house in the Berkshires where I work in the garden. A tick bit me one afternoon. I began to develop a bulls-eye rash, which is one of the warning signs for Lyme's Disease, so I went into a walk-in clinic near my office and asked them to do a blood test to make sure I didn't have the disease. I asked the doctor if he would do a PSA test as well.

A few days later the doctor called and told me my PSA was 88. I thought there had to be some mistake. I called the urologist, whom I hadn't spoken to in two years, and made an appointment. He redid the PSA and confirmed the results. I was having a reoccurrence.

After the diagnosis, we discovered that not only did I have lymph node involvement, but I also had a 10 cm tumor in my kidney. The assumption was that that was part of the prostate cancer recurrence, although a very unusual part of the prostate cancer reoccurrence. Due to the size of the tumor, it was felt that I probably needed to have it removed and while doing so it was discovered that I actually had clear cell kidney cancer. I was diagnosed simultaneously with a prostate cancer reoccurrence and kidney cancer.

Needless to say I was in a total loop. My PSA was doubling in less than four months. I started hormonal therapy while I was still hospitalized for the kidney cancer. Fortunately for me, my cancer was and still is hormone responsive. For the past six or seven years, I've been on intermittent hormonal therapy.

I learned a lot of lessons about taking responsibility for my own disease between the time I was initially diagnosed and the time I got to those reoccurrences. When I was in this funk after the dual diagnosis, I knew I needed to find other people. I searched for support groups looking for other people going through what I had been going through. Keep in mind that at the time I was only 55 years old. I had managed to find one or two other men who had metastatic disease, but they were 80 and I was 55.

And then I stumbled into Malecare. Their support group met weekly, unlike the other groups that met monthly. It was a lot more intense. In the Malecare group, you sat there and talked to other prostate cancer patients for two hours. That said, the first time I went to a Malecare group, I was again the only man with metastatic disease. All of my anger and frustration welled up and after the group I went up to the support group leader. Now, I'm a relatively mild guy. I don't use harsh words a lot. But all of my anger and frustration welled up and I was just verbally abusive. I blamed him for everything. Instead of standing up and cursing back at me, which is what most people would have done, he leaned backed in his chair, folded his arms across his chest, and said "You're right. So why don't you do something about it?"

More four-letter words rolled out of my mouth and I walked out. But I thought about what he has said over the next few days and came to the conclusion that he had a good point. Why didn't I do something about it? Eventually, I called him and said, "I'm prepared to do something about it, but I need help and guidance."

That is how I got launched as an advocate. Out of anger and frustration has come something that is an absolute passion. I'm specifically interested in metastatic disease, although I work with all men from those newly diagnosed on. One of the things I have concluded is that the advocates who are the most successful and make the biggest impact are either survivors or family members of survivors. They bring to the table a passion that a professional doesn't. There's a difference in the type of advocacy because they speak with a passion that doesn't exist unless you've gone through it yourself.

In the breast cancer community, it's the advocate's ability to make other people passionate that really makes her successful. In the prostate cancer community, we're still not at the point where men are willing to be passionate in public—about anything, especially if it involves impotence and incontinence. Unfortunately, they're not willing to discuss that. There are exceptions, obviously, but if anything, I think it's the caretakers—the women—who are more open about these subjects.

We've discovered that the way to get to the man is through his spouse or daughter. We have to find a way to change that. Men have to find a way to talk about prostate cancer.

I started a face-to-face support group for men with metastatic disease in Manhattan. That was my answer to my frustration when I was diagnosed with the reoccurrence. I now have a group of about 20 men that has been meeting for just over 8 months.

I visited a man from that face-to-face group today in the hospital. He is end-stage. I will tell you that having been in the hospital room with him and helping him get out of bed to go to the bathroom makes me look in the mirror. I thought about what it will be like to be in the kind of pain he is in. What am I going to be like when that happens? He still had some sense of humor even though he has mets in his spine and hips. He has two brain mets. A couple of times he was talking to me about a conversation we didn't have and he didn't know who I was. I had to say, "I'm Joel. We're in the hospital." I had to call him back. It's kind of hard to put into perspective because I know someday it's going to be me in that room.

The other men who come to that group have also been visiting him. They actually care about each other and they openly express it. It makes me feel as though maybe we can make a change.

I consider myself to be one lucky guy. As I said, I've got four cancers. One is metastatic. God has sent me on a journey, but he's not killing me in the process. I think about that a lot. Any one of these cancers could kill me, but I'm still alive. I'm not in pain. I'm still healthy. I've got a lot to be thankful for and I have a lot to pay back.