Prostate Cancer Uncensored Podcast - Part Two
With Guests: Jay Jay French and Dr. Nilay Gandhi

Jamie Bearse: The podcast is called Prostate Cancer Uncensored because we wanna have real talk. And you've been open to talking about the side effects of prostate cancer and the treatment that comes along with the disease. Tell us, what was life after the diagnosis and treatment?

Jay Jay French: Well, so in terms of the radical prostatectomy, and getting over the operation itself, I got over it pretty quickly. The first week was tough, and wearing a catheter in your penis for a week is probably the worst week of your life. It's just horrible. When they removed that catheter, I kissed that nurse or practitioner and I said 'I love you'. I said, "do you hear that often?", and she said 'every day'.
It's awful. But here's the deal guys. The first question you have to ask yourself is 'do I want to live?' That's the first question. If the answer is, "I want to live" then everything else becomes a matter of decisions you have to make and how well you can adjust and adapt. But you have to say to yourself I'd rather live than die. And that really was the issue.
I had a very healthy sex life. I'm one of these people that had no issues, I didn't need any pills, nothing. My hormone levels were normal.
My brother took seeds and radiation. And when you go that route, they give you Lupron and that destroys your testosterone levels. And you have to hope your testosterone levels return. And in many cases it doesn't return so your sex drive is shot. That's something to keep in mind. Not all people but a lot. My testosterone levels never changed. They are the same today as they were prior, however, depending on how old you are, depends on how much the nerves come back and how much sex can become normal.
So I have friends who have had prostate cancer who are in the early fifties who post-prostatectomy, after six months, came back 100% erectile-wise, and that's great for them. I was 66 and it didn't, so there's a lot of work that has to go into sex, a lot. And you have to be prepared to deal with things you never thought you'd have to deal with. So after three years of thinking nerves will come back, they came back to a

degree, but not enough, so you need things and there's a lot of things out there. There's shots, which are not the most comfortable thing to deal with, but they are injections you make into your penis, there's pills you take along with the shots, there's vacuum pumps you can use. I mean, you have to make an appointment for sex that's the truth. Sex can no longer be spontaneous. That whole idea of spontaneous sex is over. I'm not saying it's over for everybody, but it was over for me. So now it's sex by appointment. And you have to set aside time and you have to prepare. Now what does that say about your spouse? You have to have a spouse that is happy that you are alive and would rather have you here than not here. And that way you can work it out.

But if you don't have a spouse that can deal with it, that's an issue that is unavoidable. When you have a radical prostatectomy the process of connecting your penis to your urethra causes shortening length-wise because they have to connect parts that were not there, they're removing a prostate gland, your prostate. Here's the things that I'll talk about. Women have one sphincter muscle, men have two sphincter muscles. Men have a sphincter muscle in their penis and a sphincter muscle in their anus, and both of them are used to prevent peeing, you know, unless you need to pee you can hold them both. Women have one which is why women can wear undergarments if necessary when they cough, sneeze, getting over pregnancy because everything is open more. They have a single sphincter. Men have two. Prostate cancer removes one, so with one sphincter muscle, you have a lot more control problems. So forgetting sex for a while, you have to talk about premature urination - that becomes an issue. You have to train yourself how not to. You know, none of this, I don't mind talking about any of it, but none of it is easy for people to process when they are told they have prostate cancer.

The idea of prostate cancer allowed me to process all of this for years. So this wasn't like something dropped in my lap on a Monday afternoon with a test result and told you gotta do this, this, this, and this is what's going to happen to you. I already knew all of these things. So you have to deal with all these things and these are difficult things to deal with. So I have a wife who is extremely supportive, no pressure. To begin with, you can't have sex for six months after the operation anyway, just for starters. You can't so that's issue one. Then as far as your ability to return through the nerve connections, that's individual, everybody is different. Now from what I understand, because I react well to shots and to vacuum pumps, that's good. There are people who don't even do that which I guess there's all different levels of coming back from this. Given no problems at all, or absolutely complete inability to ever have sex again, if no problems is a one, and incredibly difficult is a 10, I'm a five. So I can do it. It just takes time and work and effort, but it takes time, work, and effort. That is for sure, so you have to be prepared for that.

Bearse: Do you talk to your friends or others who have been impacted by prostate cancer about their their sex life. You know obviously, guys, we talk about sex with

other men, we talk about sex with other men. We know those conversations can shift with age, with your diagnosis of prostate cancer. Do you have conversations with your friends in this area of your life?

French: A couple of them have been extremely open, extremely helpful, and one of them just did not want to talk about it at all. But two of them who use shots were very open with me and helped me through it for sure. Plus the hospital itself, NYU, has an erectile dysfunction department which is helpful because they deal with erectile dysfunction from a variety of different places, not just prostate cancer. But they handle people getting over prostate cancer, and so meeting with them and talking to them about their issues becomes important too. So if your hospital provides that kind of reinforcement, use it. Of course, don't be shy about it. You're talking to doctors you know. What, what are you doing? You need information and to help you through it. So I've spoken to friends of mine about NYU's erectile dysfunction department and they said, Wow you have an erectile dysfunction department. That's amazing. So they did and I've used it and I've had a lot of consultation with them and it's helped.

Bearse: Hearing about experiences from a couple of friends that you've had has helped you in your journey and your path, right?

French: Yeah I think everybody wants to know where they stand vis-a-vis everybody else. Am I better or worse? Is this normal? Is this not normal? You know that kind of thing you ask yourself all the time. Am I going through what someone else is going through, am I going through similar things or is this just me? A lot of times we internalize this stuff. Oh my God. Oh woe is me. It all happened to me. Woe is me. You know I was in a famous rock band, I still am, but you know for years, and years, and years. So my ability to rationalize this thing, and going, well I had a lot of fun for many, many years, and it's not like I didn't fulfill whatever kind of fantasies I wanted to, without getting too specific about it, because I don't talk about it. But let's just say that it's easier to deal with, I think, if you're not having fantasies about what you never did and now you can't do it. But that's completely separate, I mean, that's a personal statement for me. I have no idea how people process it. All I know is that I used to make a joke that when I'm 90 I'm gonna be sitting on a park bench and a guy's gonna talk about what they did in their youth, and I'll just sit there like a cheshire cat, not having to say anything, because I did everything they could have ever fantasized about.
Look Wilt Chamberlain slept with 20,000 women and Gene Simmons claims that slept with 10,000. Of course, I don't know how you have time to do anything, if that's what you've done. If you think about how long it takes, unless you're the 60-second guy, let's just say that it was a bit easier to deal with it in that sense. And that sounds so, I know, I don't want that to sound as self-serving as it sounds, but here's the point.

Regardless of what that is, everyone's satisfaction or lack thereof is unique to that person, and how you process that ongoing, is unique to you. So regardless of what you've done, what your history could be, once you can't do it, it becomes an issue. Right? So I look at the world and go, "well I didn't have a stroke. I can use my legs, I can walk. I mean there's many things I can do, and don't take that for granted, and everything will work itself out. And again, a supportive spouse is extremely important, or a supportive girlfriend. It's extremely important during this time.

Bearse: You put it all in perspective of what can you do versus what can't you do, or what you're having difficulty with. I was gonna say that, you know, rock stars have a certain image to uphold in terms of sexuality, but it sounds like it didn't come to bear around your prostate cancer diagnosis because I think I hear you saying that.

French: Well a bunch of my rockstar friends died of prostate cancer, too. I mean they're dead so it's not like it helped them at all. Look at the end of the day you go home alone, you go home with your spouse/boyfriend/girlfriend/whatever, your partner, and it's the two of you. And it's how the two of you, for the most part, handle life situations. Whether it's health, finances, it's all the same, so it's all similar how you how you face challenges. It's a challenge. So again, I didn't want to die so I was prepared to accept whatever, whatever hit me. But I also was saying, I'll do whatever I can do to lessen the severity of the side effects of all of it. So luckily there are pathways in which I can do that. Some people can't. It's a tough choice but what are you going to do? I mean are you really going to just die, is that what you're going to do? Just say, hey screw it, I'll just enjoy myself to the end. I don't know anyone who's made that decision yet but there are plenty of guys who've died. Look, I had a friend who died of prostate cancer who didn't know he had it. He was 40 years old. He had severe back pain and he went to the doctor and he was stage four, and he was done. He was gone in two months, okay. He was gone two months, so would he have gladly traded places had he known two years earlier, three years earlier? I'm sure he would have. So you know every day you read a story about a rock star, or a you read a story about some famous person that has some sort of illness. It seems that people are being more honest about their physical issues now and they're talking about it. Ronnie Wood from the Rolling Stones just had a second bout of cancer. Pete Wade from UFO died of prostate cancer. I think Johnny Ramon or Joey Ramone died of it as well. I mean, it's a lot. And then what about all the people that died they didn't want to talk about it? How many of them died of AIDS and didn't want to talk about it. I just had a friend of mine die of ALS last week, 56-year old brain surgeon, okay, 56-year old brain surgeon diagnosed with ALS a year ago and died last week. And you realize how fleeting life is. And as you get older you become more philosophical about what life means to you. If religion is your thing then you put your faith in whomever, but I always tell people you can put your faith in a higher power but you need a good surgeon. I mean if your higher power leads you to a good surgeon then

your higher power did the job, but who's saving you is not the higher power. A good surgeon is saving you, so find a good surgeon, and hopefully that choice you make, with that surgeon, will help you. And by the way, finding a good surgeon is the key in all this. Finding a good hospital, and a good surgeon, and studying it, is really important.
I was on the prostate cancer, there's a Facebook page, sometimes it's disheartening to read it because there are people who are near the end of their life, because for whatever reason, the treatments didn't work, or they got the treatments too late, or whatever, and those are sad stories. And then you hear other stories that are good. I try not to allow myself too much negativity because I don't think it's good for you psychologically to allow that much negativity, so the people that run to the Facebook pages and to the resources, to hearing other people's advice, it can be a double-edged sword. You can read stuff and get really depressed.
In fact you'll probably be more affected by the bad stories than you will about the good stories, so I just choose to kind of focus in on my own situation, my own doctor's information, and deal with my own because it's unique. And everyone's disease is like a snowflake which is unique to them.

Bearse: We have a Facebook page for patients, survivors, and caregivers called ZERO Connect and I was gonna echo what you were saying, is that it really has to be a buffet. Take what's of meaning for you, on what you can take out of it, for advice or positivity, to keep going with your journey and the best way possible.

French: I think what happens is everyone looks at statistics because that's all we have really. You know, how long have I had it? How old am I? What stage is it in? What are the general conditions by which people continue on with their lives given it. So I was at this cuspy age, you know, 66. They said, well you could have an operation or you could have radiation. Like they seem to say that they'd like to have an operation at a younger age and radiation and an older age in general, that's what they say. And I said why is that?And they said because at a younger age your body is more apt to come back from an operation. It takes a lot out of you at an older age. And I said, well what should I do? And they said, you're on the cusp of your choice so you can make both choices. Whereas, if you were 70, we would tell you have radiation in seeds. Okay? So I toughed it out and had the operation. So that was that. It's another issue too. It's how much research have you done, how much have you read, how many conversations with doctors have you had, and have you spoken to your friends, and have they been supportive? Knowledge is power when it comes to this, so I didn't equivocate. This has just been sitting there for years, and so I knew that when it happened, I wasn't going to waste ... you know, like I said to my doctor, how much time do I have to make this decision? So I said to him, and he said, "from what we see, not much. You got like two months to figure this out. You don't have a

year, two years. This isn't watchful waiting bro, this is Gleason nine. You know, liar, liar, pants on fire. You gotta come to terms with this now. So okay so I did.

And now it's time for ZERO's Ask the Doctor segment.

Greg Broy: Hello I'm Greg Broy, Manager of Donor and Fundraising Communications here at ZERO. I'm also a prostate cancer survivor and I want to expand on our conversations with Jay Jay French by talking with Dr. Nilay Gandhi. Dr. Gandhi is a surgeon and urologist for Potomac Urology in the Washington, DC area. He's also a member of ZERO's medical advisory board.
Earlier in the podcast Jay Jay mentioned that his brother chose seeds and radiation to treat his prostate cancer. So my first question for Dr. Gandhi is, tell us more about those options.

Dr. Nilay Gandhi: Seeds is a very common prostate cancer treatment and it's very easy for patients to remember as well. We call it brachytherapy and that's the same as seeds and there's actually two different versions of doing this, where it is done in an operating room. And the traditional form of seeds involves implanting radiation beads into the prostate and these radiation beads will typically radiate from the inside out. So these are beads that do remain in the prostate. So we place them in the operating room and then you go home and they are emitting radiation from within you. And so, that has been the traditional method and that's still somewhat the standard when people describe seeds. For that short time period you are slightly considered radioactive and so, because you are emitting radiation, typically it's recommended that you kind of limit certain activities or limit interactions with people, especially not having, you know, if you have grandchildren, or anyone sitting on your lap, because again, there is a mild degree of radiation exposure.
So there has been a newer form now as well called HDR, high dose rate brachytherapy, and that involves something like a similar procedure in the operating room but this time we're inserting needles into the prostate and radiating the prostate at that time. So that once everything is removed, there are no seeds, there are no radiation devices or implants left in you, and you are not then considered radioactive. So there is a big shift in terms of transitioning towards high dose rate brachytherapy but again the traditional method of seeds is described as the implantation of those radioactive devices into the prostate.

Broy: Jay Jay also mentioned that his brother's treatment was followed up with Lupron. Lupron is a form of hormone therapy. But what exactly does this mean for testosterone levels?
Gandhi: Lupron acts to somewhat lower your testosterone levels. And the way I describe that to men is that it is similar to male menopause. So we understand that menopause in women, due to dropping estrogen levels, and they can have various

side effects related to that. This is very similar in terms of dropping your testosterone levels, then you may experience weight gain, hot flashes, decreased sexual desire and libido. These are all common things that can be attributed to these hormone changes. Now the benefit of it is when we drop your testosterone levels, an easy way to think about it is that testosterone can act as a food supply to the prostate but it also can act as a food supply to the cancer. And so by dropping those levels, we're trying to somewhat starve the prostate and starve the cancer prior to starting radiation therapy, so that you now have a weaker cancer that is more susceptible to the radiation of therapy making that treatment more effective.

Broy: A radical prostatectomy is an operation to remove the prostate and tissues surrounding it. Can you tell us what else this involves physically and why this operation can lead to incontinence and sexual side effects?

Gandhi: So radical prostatectomy is the surgical procedure to remove the entire prostate gland and remove the prostate from the body. That can be done mainly with either an open approach which involves a larger incision and our hands inside to remove the prostate, or more commonly now, it's performed robotically. And those are with small incisions on the belly for us to do this in a minimally invasive fashion. And what it ultimately entails is removal of the prostate. Now the prostate sits below the bladder and there's also the urethra - that's the tube that you urinate through. And so by removing the prostate you have a gap between your bladder and your urethra in terms of for urination. And so because of that, we do have to connect those two together which is why people require a catheter temporarily to allow that area to heal. So once the catheter is removed, you're able to urinate the normal way. Well there are pelvic floor muscles involved in that region that may become a little weaker and that's where, when you think of the external sphincter, when you think of trying to control, if someone says you need to go urinate now and you squeeze those muscles to prevent urination, those muscles can become weak after this surgery. And that's why we have patients practice Kegel exercises to try and strengthen the pelvic floor. But because of that, you could have some, what we call, stress incontinence, when you cough, sneeze, stand up, you may have leakage of urine. And so that's where the incontinence aspect can come from. There are nerves that run alongside the prostate and those nerves typically are dissected off of the prostate, we call that a nerve-sparing prostatectomy. If in the appropriate patient we can do that, then that can help to preserve or improve erectile function after surgery. However there are times that we do have to remove those nerves if there's concern of involvement with cancer, and again that can impact a patient's erection function.

Broy: When a man is diagnosed and it comes down to an operation versus radiation, is a man's age a factor in which treatment he should get?

Gandhi: There's many factors that come into play in terms of if someone should choose either active surveillance, watching the cancer, surgery to remove the prostate, or radiation therapy, and age does play a role in that. I think historically we used to look at it as 70 being a cut off, that if you were below the age of 70, you should have surgery. If you were above the age of 70, you should have radiation. I think as studies have come out showing that the effectiveness of both surgery and radiation for different risk groups for prostate cancer may still be beneficial, I think that age barrier has somewhat decreased and it's really a conversation with patients to assess their risk factors. Mainly if you have someone who is a high surgical risk candidate, so someone who may have had multiple heart attacks, has already had multiple surgeries in the past, may not be the picture of health, that they may not do well with a surgical procedure and may be better served by doing radiation. You can have the opposite though. We've seen, I've seen many patients who are in their 70s and they are extremely fit, in shape, they look like they're in their 50s and they may still be a great surgical candidate. So I think again it's really individualizing that risk in terms of what treatment affords them the best opportunity at a cure, whether it's surgery or radiation, as well as the patient preference. We do have a lot of patients who come and say I've had bad experiences with surgery or radiation, in terms of talking to friends and family, and I would like to do this instead. And having these informed conversations with the patients, I think, are always helpful as well.

Broy: Thank you Dr Gandhi for your time and insight. Again Dr Gandhi is a surgeon and urologist with Potomac Urology in the Washington DC area.