

# Prostate Cancer Uncensored Podcast - with Guest: Jeff Jones



Jamie Bearse: Hello and welcome to Prostate Cancer Uncensored. A podcast produced by ZERO The End of Prostate Cancer. I'm Jamie Bearse, president and CEO at ZERO and I'd like to welcome today's guest; Jeff Jones who is the head coach of Old Dominion University's Men's Basketball team. He's a husband, a father, and a grandfather, and he's also a prostate cancer survivor. Some, including me, would also call him a cancer warrior. Welcome Jeff and thank you for joining us today.

Jeff Jones: Thanks Jamie, it's great to be with you.

Bearse: So, let me ask you this, you have been battling prostate cancer since 2015, and I understand that it may never have been discovered, unless you had to go through a routine health screening for a new insurance policy, is that right?

Jones: Exactly that is correct. I had applied for some disability insurance and some additional life insurance and as part of the process leading up to acquiring that insurance. They requested that I take several medical tests, which I did, and found out that my PSA level was elevated which kind of kicked in a number of things that eventually led to me finding that I did have prostate cancer.

Bearse: Now, also in 2015 when you were diagnosed, that's the same year that Old Dominion went to the NIT semifinals. Do you think that, the news coming out that of you having prostate cancer, did that help the team sort of rally around you and your story? To reach there? I know that you want to be humble and say that there are a lot of other factors, and I'm sure there are, but do you think that was one of them?

Jones: No. Actually it wasn't because, I mean, I know that because no one else knew. I originally was going through the process and had the PSA done a number of times in the Fall of that year, or of that season I should say. And it took several months before, you know, we finally did a biopsy and it was indeed prostate cancer. You know, initially it was just an elevated PSA. We looked at several possibilities before jumping to the conclusion that it was prostate cancer. Ultimately, in that Spring of 2015, is when I did the biopsy and it came back and said that it actually was prostate cancer. But by that time the season had basically ended. The plan was very methodical I guess, and took our time, and that there wasn't a rush to do anything; even to take the biopsy. And so that wasn't done until after the season. And then once we found out that, it was prostate cancer, then we had some decisions that we had to make, in terms of how to proceed from there.

Bearse: And after the biopsy Coach, what did the doctors recommend?

Jones: Well both my urologists and the folks up at Johns Hopkins that I spoke to, essentially said there was one option and that was surgery. For a number of different reasons, including my age, I guess I was on the younger end of the scope. So there wasn't really a whole lot of discussion about alternative measures and pretty quickly, I was able to schedule surgery at Johns Hopkins.

Bearse: Now for those listening, who don't know, when you go through a biopsy of your prostate and you come back with different cores, that they take prostate cells out, and that they look at under a microscope and see if they determine a presence of cancer. And coming out of that you're given a score, called a Gleason score. Do you remember what yours was, Coach?

Jones: I don't. But that was one of the factors that determined, along with my age, that surgery was the option. That the others weren't practical.

Bearse: So it's after the season ends in 2015, and you get into the summer. It's determined that you have prostate cancer and the doctors are talking about doing surgery. How do you start breaking the news? Particularly to your family, your wife, and your kids? Talk us through that.

Jones: With my wife, when I first started taking the PSA and everything, I talked with her about it. We weren't anticipating the worst-case scenario, I guess. But telling her the first time, you know that was difficult. And I think, quite honestly, when you find out you've got cancer or a recurrence of cancer, talking to your loved ones is maybe the hardest part. It wasn't great when the doctors called up and said 'well you got prostate cancer'. That was a little bit of a shock to the system but I really do believe that telling my wife, telling my kids and family about the cancer, particularly the first time, was probably one of the toughest things about this ordeal. With the surgery set up, I needed to inform a lot of people because everyone was going to know, so I did that as quickly and as simply as possible. Obviously talking with my team, like many they simply hear the word cancer and that's a scary thing. The biggest thing that I tried to do was, to assure them that I was going to be fine and after a little bit of a recovery period I was going to be back as good as new. Not a hard thing but something you want to get past you, and move forward, to start trying to get healthy.

Bearse: Now, telling others about the news, we were chatting offline and you were telling me your daughters were pregnant at the time. You waited until after they gave birth to let them know?

Jones: Yes. At that time, I didn't want to. (This was the re-occurrence) We were in observation mode and there wasn't any real urgency, so I kept as long as I could, the circle of folks that knew of the cancer, pretty small. After my daughters (one in August and one in October) had their babies, the next time that we were all going to be together as a family was going to be at Christmas. So, I waited for Christmas to tell my daughters and son. Which, put a little bit of damper on the Christmas celebration for a couple of hours (chuckles). But after that, we were able to go through it and do everything I could to quell their fears. And let them know that everything was going to be okay, but we had to go through this period.

Bearse: Well I guess on the positive side, it draws everybody a bit closer knowing how precious the time that you all have together is, am I right?

Jones: Well absolutely. I think one of the things for anyone who has cancer is understanding that you are not alone. There's other people in your shoes. Having your family and your friends (the people closest to you) as a support group I think is really, really important for trying to go about your life as normally as you possibly can. The other factor, whether it's prostate cancer or anything else, it's not always easy on the family members as well. Having other families that they can lean on, because they need the support as well, is really important. One of the things that I found out after the original diagnosis and the surgery, and subsequent radiation, that having prostate cancer is not a very exclusive club. I was able to talk to some people that I knew, but didn't know that they had prostate cancer. Some people that were either strangers or mere acquaintances, informed me that they had prostate cancer and they had been living with it for 'x' number of years. Being able to hear their stories, I thought was good for me from a psychological standpoint. And anytime you are able to talk and meet with men that have, kind of walked in your shoes, can help you attack your disease and make you not feel isolated.

Bearse: Well you're right about that. Prostate cancer is definitely a family disease that affects everybody within the family. And I think you are spot on saying that our caregivers and the ones who hold us up need support too. As you grew your support network and as you said 'talking to others who have been impacted by the disease maybe through their own journey' looking outside of your family, who was sort of there for you and served as a mentor? Anybody?

Jones: As I said there were a few men in this community that I guess served as mentors or certainly sounding boards. It wasn't something that I talked about a lot but simply knowing that there were others and that I could reach out to them was big. My wife through everything was my caretaker. I don't know that I need a caretaker but she was the one who could actually tell you my Gleason score and everything else. She has studied this stuff and I learned that I kind of need to do what she says. She is on top of everything and she's in contact with the physicians and a great resource and support.

Bearse: Those are wise words Coach, (chuckles) do what your wife says.

Jones: I remember this as being a pointed moment for me. I had talked to a lot of people and being in a public 'kind of' position a lot of people approached me when they found out that the initial announcement about having prostate cancer. There were two women in our community that I met at a couple social events and they introduced themselves, and informed me that they were widows and their husbands had passed away from prostate cancer. And that was very sobering. I talked to so many men that had prostate cancer and were living with prostate cancer. And I think there can almost be a letdown that this isn't that big a deal, and meeting and having those conversations with those women who lost their husbands to prostate cancer. It kind of reinforced that this is the real deal. This isn't anything to play with, you take it seriously, you do what your doctors or your wife tells you to do. That there are a lot of people who are living pretty much normal lives with prostate cancer, but you have to take it seriously and you have to follow through with whatever the treatments or doctors advise because if you don't then your wife or

significant others will be without you. I thought that was a really good wake up call for me, through that process early on.

Bearse: Well let's go back, in 2015 you had prostate cancer surgery. So you had your prostate removed. Then you had to go through a battery of daily radiation treatments for some period of time. But then after that it all seemed fine for a couple of years, is that right?

Jones: Yeah I had at the end of the summer. I believe I started in August. I had 8 weeks of radiation 5 days a week. They found in my surgery that the cancer had spread outside the margins, was the term that they said, so outside of the actual prostate. The radiation looked to be successful and I was at a level that didn't show up (my PSA) so that was certainly good news. I quite honestly, the radiation, I had very little side effects or anything negative from the radiation. For a year and a half, I was cancer free. And with my regular (checkups), first it was every month, one of my normal 3-month checks of the PSA, my cancer had come back and within a very short period the numbers had doubled. Which obviously was an indicator that the cancer was growing. And at that point it was really surprising, and was again very difficult. I remember, I found out on my birthday, I forget which birthday it was. I got a call from the doctor and said that the numbers had doubled and that we needed to begin monitoring it and start treatment right away. My wife was with me that morning and she was listening and I told her what the numbers were and she said 'no, no, no, you mean this..' and I said no that's not it. I guess we were in a little bit of denial. But again, it was a slap in the face and let us know that we needed to keep an eye on it and get ready to face the next step.

Bearse: And what was the next step? What did you do after monitoring it?

Jones: For about the next year we just watched and observed. Kept a close eye on it. And ultimately, we had to begin treatment and the treatment that was decided on was hormone therapy. Prior to that point when we were just observing, there was no reason to let anyone know. It's not like it was obvious, or that there was anything really going on. I just had to periodically do blood tests, making sure we kept a close eye on the PSA, and once I started the treatment, there were going to be side effects and things folks outside the small circle would need to know. That's when I made a public announcement after letting my bosses here at Old Dominion know, I let the team know, I made a public announcement that my cancer had come back and that drew a lot of attention around here.

Bearse: And how did the team and the University and the fans take it? What was the response, were they shocked too? What was that like?

Jones: I think so. I think so. Certainly the team and the people in the ODU community were extremely supportive. A lot of folks were reaching out, and again I tried to assure my players, and my assistant coaches also, but my players especially that 'I'm going to be okay', 'I'm going to get through this', 'I'm going to fight,' 'I don't want you to have to worry about anything'. And I was determined. There are side effects with any treatment. There's unpleasant side effects to hormone therapy. I was bound and determined that the players weren't going to see that, that they weren't going to see me feeling bad for myself or whatever. That I was going to continue coaching the same way I always had. And giving them absolutely everything

that I had. The people here at ODU kinda rallied around, and my wife and I, we actually looked at it and talked about it. Thought that this was an opportunity maybe. I'm a fairly private person, it's not like I was relishing the opportunity, given my platform, that I advocate for men in the fight against prostate cancer. One of the things, through the whole transformation there, my oncologist had recommended and really wanted to do. Again, he advocated, 'hey it would be nice if we could get this scan'. He thought it was really important. But the insurance companies turned down the scan. And that was really frustrating with my wife and I. But it really wasn't about money, for us. I had the scan, we paid for it out of pocket. We are, I am, fortunate enough that I could afford, I think \$13,000 for that scan. Something called Axumin.

Bearse: So a scan to be able to determine where the cancer is spreading to, so they can make sure that it is being treated properly. So important these days Coach, sorry to jump in there. You are right on the money there. So many breakthroughs going on right now to be able to determine what's aggressive disease and what's indolent disease and even what treatments might work on a patient or what treatments probably will not work on a patient to take out some of that guessing game. It's so important to get some of these tools around precision medicine to be covered, so every guy has an opportunity to have a fighting chance against this disease. Absolutely, thanks for raising that.

Jones: That really got my wife, especially, and I up in arms thinking about those folks, prostate cancer or not, fighting this fight. She wrote an editorial in the newspaper and started a fundraiser to raise money to fight against cancer. Try to raise awareness that there are a lot of folks out there that might not even have the insurance, or the money, the disposable cash, to be able to pay for these things out of pocket. The fight against cancer is an unfair fight. Cancer doesn't discriminate along racial lines, rich or poor, it is indiscriminate. We just wanted to do something at that time and be very visible doing it, to raise money. But just as importantly to raise awareness. Again, whether it's prostate cancer or any other kind of cancer, it's so important that everyone has the resources to try and make it as fair a fight it possibly can be.

Bearse: That's right. We talked offline a bit, and we have a program called ZERO360 that's absolutely free to patients to call in. That if their going through something, a fight with insurance companies, a treatment that had been turned down, or just trying to make ends meet and having to deal with that financial stress, that comes with a cancer diagnosis, a cancer battle, they can call in and a nurse navigator is able to help them out and try to get some of these insurance decisions overturned or be able to get coverage for things like the Axumin scan. Now you mentioned the ODU family, Your ODU family members are huge prostate cancer advocates and you all had a prostate cancer awareness night, recently. A few people showed up in the stands with blue shirts, the team wore throwback uniforms. That had to feel pretty amazing, didn't it?

Jones: I was appreciative. There was a video of some of my colleagues here at Old Dominion, that they showed on the big screen during the game. There was a fundraising effort along with recognizing the fight against prostate cancer. I was very humbled and appreciative, and very proud of this tidewater community, but especially the ODU community. The way they supported me, but they supported the cause which I think is even more important. It was a special night and something that was really good and something certainly I'll remember for a long, long, time.

Bearse: And ODU athletics put down the razors and they participated in our Grow and Give campaign, so they grew the facial hair. You do that too?

Jones: I did. We got the message and the request and I've never really been able to grow much of a beard to be quite honest. But obviously for the cause I talked to some folks in the athletic department, my entire staff, our radio guys, our sports information. Once we started, there were even some fans who joined in. We had a lot of support with that. As soon as I was able to though, or November ended, I got that beard off. That was something that wasn't something that was very much fun (chuckles). But it was something that was fun to do together. The simple act of not shaving, but trying to make a statement, a bonding experience with the men on the staff and the men from the athletic department that joined in as well. I'm guessing that will become an annual occurrence for those of us here at Old Dominion in the Athletic Department, specifically, in the men's basketball office.

Bearse: That's great. Got to feel great to feel appreciated and feel the love through your prostate cancer journey.

Jones: That support network means so much to anyone that is on this journey with prostate cancer.

Bearse: Now what has been the lowest and the highest points of your prostate cancer journey thus far, Coach?

Jones: The lowest I think after I had my surgery. I bounced back pretty quickly. Maybe I was a little bit too eager to get back to normalcy. I was trying to do everything that the doctor said. I was walking a lot. And it was actually on Father's Day, I forget which year it was, 2016 maybe, that we had a basketball camp. I went, in a limited capacity, and was visible in our basketball camp, and I didn't feel quite right. And one of the things that the doctors had said, this was after the surgery, if it felt like there was pressure in the abdomen, that just walking, and it wasn't making anything go away. Long story short I had to be taken to the emergency room at four in the morning. I never in my life experienced the kind of pain that I experienced that evening. I was shaking, the pain was so bad. I couldn't even take pain pills to alleviate the pain. Ultimately I found out that I had a tear and a buildup of fluid in my abdomen. I can remember saying to my wife in the emergency room, 'I don't want to be sick' and I think that ultimately was a side effect of the surgery, but that was the low point I think because there was nothing I could do. The amount of pain was something I had never experienced.

Bearse: How are you doing now, Coach? Give us an update on how things are going.

Jones: I'm doing great. The treatment has worked, in fact it's been several months, since I've even had to do the treatment. I'm feeling good, I'm feeling healthy. We are in the middle of our basketball season. I think anybody around me would tell you, if I hadn't come out, they would have never known that I had prostate cancer. I feel strong, I feel good, and I'm really optimistic. If at some point in the future I have to continue with treatment, we'll cross that bridge when it comes.

Bearse: So off treatment now? And PSA is close to undetectable? Where are we with that?

Jones: Yes. The PSA has been undetectable for several months. Anything to put off that treatment is a good thing in my book.

Bearse: Sounds fantastic. Feeling strong ready to get on the court and throw up a couple shots or what?

Jones: No. Those days are over (chuckles). That has nothing to do with prostate cancer or anything else. That has to do with bad knees and two artificial hips from playing too much basketball many years ago.

Bearse: Understood (laughs). Now for everybody who's listening Coach, what message, or advice would you give? What's something that you learned along the way in your prostate cancer journey that you'd like to share with others so they don't have to go through it themselves? Does anything come to mind?

Jones: Well I think quite honestly, there might not be anything that someone can do to ward off prostate cancer, but I think early detection is so important and gives you a much better chance of treating it. And attack it aggressively before it becomes a life changing event. I would just say, make sure you see your physicians during that recommended period. I know the age range changes, from here and there. I don't know what the recommendation is. If you're of a certain age you should be getting that PSA checked. Hopefully for many years it will be 'there's nothing to see here' but if it were to happen that you had an elevated PSA, having the doctor recognize it and be on top of it, I think that's probably the best way to treat prostate cancer. To not let it progress and to detect it and identify it early on.

Bearse: Thanks Coach. Any message to those who already have it and are in their prostate cancer journeys, right now?

Jones: What I found is that oftentimes, there are men that are hesitant to talk about it. There's lots of us out there. I've had, let's say that there are a lot of people that have reached out through the mail or email, because I did speak up, not that I'm necessarily looking to be any kind of a spokesman. There are resources out there. We can get through this. It's not always ideal. It might not all the time be life threatening, but I do think prostate cancer is life altering. But we can have very healthy, productive lives and hopefully those men out there that do have prostate cancer understand that, and understand that we are a fraternity of sorts. We can all support each other through this journey that we're on.

Bearse: Thanks Coach. Those are great words. Great wisdom. As we bring this podcast to a close, I'd like to thank you and everyone again at ODU athletics for their support in [ZERO's Grow and Give campaign](#) last fall. It was tremendous! It was all to generate a lot of awareness and funds towards ending prostate cancer and being able to help out with our programs and to advocate for access to care issues and increasing prostate cancer research funding. I appreciate it immensely. And with that Coach, thank you for being with us today and making time during a busy basketball season. And thanks to all of our listeners and be sure to check out [other podcasts](#) at [zerocancer.org](http://zerocancer.org). I'm Jamie Bearse and you've been listening to [Prostate Cancer Uncensored](#).