Changes and Challenges in Life after Prostate Cancer with Dr. Anne Katz

For men, the consequences of prostate cancer are often less to do with life and death and more to do with an altered way of looking at certain aspects of their lives and coming to terms with that. There are ramifications of prostate cancer treatment on male psychology due to loss of sexual function, incontinence, and other factors.

Dr. Katz is a specialist nurse who spends much of her time talking to prostate cancer patients and their spouses or partners before their treatment so they understand how treatment will affect their lives.

Full Transcript:

Priya Menon: Good evening, everyone, and welcome to Cure Talk. I am Priya, your host, joining you from India and we are talking about prostate cancer this evening on our 88th episode. Our prostate cancer talks are conducted in association with Prostate Cancer International and Prostate Cancer Foundation. For men, the consequences of prostate cancer are often less to do with life and death and more to do with an altered way of looking at certain aspects of their lives and coming to terms with that. There are ramifications of prostate cancer treatment on male psychology due to loss of sexual function, incontinence, and other factors. We are discussing changes and challenges in life after prostate cancer with a very distinguished guest, Dr. Anne Katz. Dr. Anne is a Certified Sexuality Counselor at CancerCare Manitoba and Clinical Nurse Specialist at the…, at the Manitoba Prostate Center. In these roles, she counsels men and women with a history of cancer who are experiencing sexual and relationship challenges. She also supports couples through recurrence and treatment decisions at that point. She is a Fertility Preservation Counselor for the organization and also runs a sexual rehabilitation program for women after radiation therapy. Welcome to Cure Talk, Dr. Katz.

Dr. Anne Katz: Thank you, Priya.

Priya Menon: My co-host for the show is Mike Scott. Mike is Co-founder and President of Prostate Cancer International, a prostate cancer-specific, not-for-profit educational and informational organization based in Virginia. Mike worked for Calcium, a privately held healthcare communications company based in Philadelphia. He is also member of the Board of Directors of the National Organization for Rare Diseases and the International Myeloma Foundation. Supporting Dr. Katz and Mike on the panel are experienced and knowledgeable prostate cancer survivors and advocates, Tony Crispino, Bill Martin, and Faye Funk. I extend a hearty welcome to the panelists and to all our listeners. I would like to remind our listeners that you can mail your questions to priya@trialx.com or press 1 on your keypad and we will bring you on air to ask them. With that, I now hand over to Mike to begin with the discussion. Mike, you are on.

Mike Scott: Thank you, Priya. Good evening, Dr. Katz. Thank you for joining us this evening.

Dr. Anne Katz: You are welcome, Mike. Nice to hear your voice.

Mike Scott: I…, I actually saw you briefly at ASCO the other day, but you were travelling too fast and I couldn't catch you. After first sort of 15 minutes or so and you could talk to us a little bit about your experience in talking to men at the time they get diagnosed and also to their wives and relevant other family members. I know you wrote, what I consider to be, a very salutary article on that topic a while back in ASCO Connection, and perhaps you could just review some of the things you try to make sure men understand when they do get diagnosed.

Dr. Anne Katz: Sure. So, you know, I…, I think at the time of any cancer diagnosis, the #1 thought for the individual plus their family members is, am I going to die? You know, is…, is this person that I love going to die? And for the most part, prostate cancer, particularly now in what we call the PSA era, so since the 1980s, when the PSA screening has been really popular, we have seen men who are diagnosed with early localized disease. We do see men diagnosed with more advanced disease, but the vast majority are diagnosed with…, with early localized disease, but, you know, we are still saying those words, you have cancer, and after hearing those words, everything changes for the man and his family. What follows is really a…, a time of great trauma and distress for the man and his family and its absolutely imperative, I believe that men get assistance with treatment decision making. This is a process where generally a healthcare provider, who…, who is specialized in understanding not only the treatment for prostate cancer but also the consequences for…, for that man for the rest of his life. The vast majority of men diagnosed with early localized prostate cancer are going to die of something else. They just don't know this at the time when they hear you have…, you have cancer, and when we treat these men generally with radical prostatectomy or radiation, we create lifelong problems for them in the areas of bladder control and sexual dysfunction. So, as a result of surgery, we see men really lose their ability to have erections, sometimes permanently; and with radiation, we…, we generally see the onset of…, of erectile problems generally one to two years after the radiation therapy. So, we treat the…, the cancer. We essentially cure the cancer for many, many men, but they are left with ongoing problems that fundamentally affect their quality of life and men really do need to understand this. Not infrequently, I hear men and/or their partners saying, "You know, sex doesn't matter. We'll…, you know, we…, I just want him to, you know, be around to, you know, mow the grass and…, and…, and be my partner and be the father to our children and the grandfather to our grandchildren" and that's really, I think, a…, an initial response where…, where people think that this is a sex or death decision that has to be made. In reality and this is what I wrote about in the ASCO blog, this isn't about sex or death. Really, I think this is about a treatment decision that's going to affect the man and his partner for the rest of their lives together.

Mike Scott: And do…, do you get the impression that most men and their spouses really grasp this when you talked about it? I mean, I…, I hear a lot of men and spouses after treatment and it only seems to be then that they start to really grasp what's happened.

Dr. Anne Katz: Oh, absolutely! And, you know, I think this is…, this is part of…, of the problem that in that chaos and turmoil of…, of diagnosis, they will do anything. So, one of the things that I do is I tend to see men or I ask to see men about a week after they have…, they have heard the diagnosis because I find by then the dust has really settled and while in many areas of cancer treatment, the focus really is on getting treatment quickly, but the only gift of…, of being diagnosed with early localized prostate cancer is that you do have the gift of time to investigate the treatment options, talk about what the consequences are going to be because all the treatments, surgery, radiation are essentially equivocal or equal in terms of their effectiveness. They just have different side effect profiles. So, take the time to really read, perhaps talk to other men, but you have to be a little bit careful about that. I find that…, that very often men, even if they are experiencing side effects, tend to try and persuade other men to have the same treatment that they had. I call it the misery loves company theory. I am not quite sure why it happens and I would love to study that one day.

Dr. Anne Katz: So…, so, you know, read, speak to healthcare providers, get a second opinion, get a third

opinion until you are really absolutely sure that you have understood the information. I think its very difficult to ask men to imagine what life might be like with poor bladder control. I think its a very difficult thing to ask people. I think its very difficult to ask men to think about what life might be like without spontaneous, reliable, rigid erections. They just can't imagine that, for the most part. I think sometimes there is also magical thinking. I speak to a lot of men and I say to them, "Well, okay, so what are your erections like now" and they say, "Wow, you know, I am in my 60s, they are certainly not what they were when I was in my 20s; in fact, they are not even what they were when I was in my 50s" and somehow, you know, they think that…, that treatment is not going to affect the quality of their erections. Of course, it is! And so, these are really difficult decisions that…, that have to be made, but they have to be made and one of the things that…, that I really want these men to avoid is treatment regret so that…, that feeling of, you know, I shouldn't have…, if I had known x, y, and z, I would have made a…, a different decision. So, I am brutally honest with the men that I counsel. Sometimes they get way more than they expected, but there is no point in me sugarcoating the reality of what life may be like after…, after treatment.

Mike Scott: And that raises a very interesting question because one of the things we hear all the time and of course ones not in the room, so its impossible to know is that men when…, particularly here in America, where usually they do not see anybody other than the person who is going to treat them. They…, they feel that they were not appropriately advised of the potential consequences of the treatment. I am not…, not trying to point fingers here. I know people don't…, also don't hear things that they are told. I…, I…, I have a theory that in fact when people like you who have no interest in the actual treatment have this conversation, it is a different conversation than the conversation they have with the doctor.

Dr. Anne Katz: I absolutely agree with you and that's one of the reasons why I have the…, or the position that I have was created at the Manitoba Prostate Center. We know that after someone hears the word, "You have cancer," they hear about 10% of what they are told. So, it is quite possible that they…, they really aren't not only hearing but understanding, synthesizing what they are told, that's absolutely a possibility. I think the, you know, the other issue and I am also really not pointing fingers at…, at any one particular discipline or specialty, but if a urologist who does surgery doesn't believe that what he or she is doing is the optimal treatment, I think you got a problem. So, I think there is sometimes, you know, a…, a selling job that this is the correct treatment and men don't even realize that they have other options, which I think is disturbing, so, you know, when you are looking for a second opinion, don't go see another urologist, go and see a radiation oncologist. If you first see a radiation oncologist, go and see a urologist. Read widely. If there is a prostate cancer support group near where you live, you know, attend a meeting or two and speak to other people. We know from studies that men do tend to take the treatment of the person who diagnosed them with prostate cancer and…, and then, you know, often decisional regret ensues, which…, which really is a pity.

Mike Scott: Have your conversations changed significantly since active surveillance or active monitoring or whatever you want to call it, has at least become accepted again as opposed to everybody thinking that you had to take out every piece of cancer that anybody had?

Dr. Anne Katz: Umm… It absolutely has changed. As we get more and more information about really the…, the criteria for active surveillance, I think we are able to speak with a…, a little more, perhaps certainty. You know, for example, we know that…, that men with low-volume Gleason 6 disease are ideal candidates for active surveillance and its…, and for me its really important to use the correct terminology. So, when patients come to me and say, "Oh, you know, my doctor said that I could also go for watchful waiting," I…, I explain to them because I think language is important that what we do now is active surveillance, which is actively monitoring the…, the status of the cancer. I get the same thing for men who are prescribed androgen deprivation therapy. They come in and they say, "Well, I am taking hormone therapy," "Oh, I am taking hormones," and I point out to them, no, we are giving you androgen deprivation therapy because the implication of hormone therapy is that they are actually taking hormones and in fact we are doing the exact opposite. So, yes, active surveillance, I think, in some jurisdictions is becoming more acceptable but not in all and, you know, I think the mighty dollar sometimes plays a part in that as well. Physicians are not paid the same for active surveillance as they are for surgery or radiation.

Mike Scott: And…, and is your positioning kind of unusual or…, or, you know, are there other people like you in…, in many Canadian provinces who…, who actually provide this service as a part of the…, the prostate cancer diagnosis experience?

Dr. Anne Katz: Really, I think the only other center that I know where there are people doing similar work is in Vancouver, but it really isn't available and, you know, often men actually go to their primary care provider, their nurse practitioner, or internist, or family physician and they say, "What would you do, doc?" I think that's a really unfair question because their physician or nurse practitioner or…, or physician assistant really, you know, to…, to answer that question is once again hypothetical and until you are walking in that man's shoes, you know, you don't know what…, what its like. Men often say to me, "What would you do" and, you know, I can give them a glib answer. "Hey, I don't have a prostate, so I can't know what I would do." Then, they turn around and they say, "Well, what would you tell your husband to do?" and my answer is, "I wouldn't tell my husband to do anything because he has to live in his body afterwards. You know, I would certainly explore all the options and…, and that's one of the reasons that I wrote my book for the partners of men with prostate cancer and its called Prostate Cancer In The Man You Love, so its for men and women who are partnered with men diagnosed with prostate cancer because the partner plays an important role in supporting the man and often in actually finding that health information and…, and…, and really helping them make that decision. I don't think a partner can make a decision for a man.

Mike Scott: One…, one of the things that was very interesting that I think, you know, sort of ties into this, when…, when they were doing the PROSPECT trial in the UK, they discovered that until they got the doctors out of the way of helping the men to decide whether they wanted to participate in the trial or not, they were having very poor involvement. Once they transferred that to knowledgeable nurses, they became very successful at enrolling patients. It…, it seems to me there is a…, there is a real communication problem here. Though its probably not completely specific to prostate cancer, it is…, is very… It…, it seems to have a particular level of…, of importance in…, in men's understanding of what their options are when they are diagnosed with prostate cancer. Do you find that like in person with diagnosis of other cancers or…, or would that be a misleading idea?

Dr. Anne Katz: Umm... You know, I don't know. I mean I think one of the really, the unique things about prostate cancer is that element for most men of treatment choice. There are not many other cancers where those choices exist. You know, for breast cancer, really its the…, its the mastectomy versus lumpectomy and radiation decision and…, and even there, its not… You know, we know that for early breast cancer, lumpectomy and radiation is…, is as effective in…, in treating the cancer as mastectomy with…, with much less morbidity or…, or, you know, side effects. So, I think really prostate cancer is quite unique and I think the other way that it is so unique is…, is that the side effects affect a fundamental aspect of men's lives, their self-image, their masculine self-image, you know, their erectile functioning, which is really in many instances central to a man's view of himself.

Mike Scott: So, that…, that's kind of interesting and…, and we have Bill Martin on the line, who I know was actually a patient who you talked to originally, but Bill still had a, I think, a considerable period of time before he was able to come to terms with all of the consequences. Bill, would…, do you have questions for Dr…, for Dr. Katz?

Bill Martin: Really, I…, I was Dr. Katz' patient and she answered all of the questions in a very consistent way. Now, would I…, would I ask. I suppose if I had to do it over again, I would…, I would have had a second biopsy because my Gleason score was 8 and as it turned out it was lower of the two 7s, but I don't know and how you get men to talk about this. You know, I was scared silly in…, in panic and thought I was doing okay, but I didn't. You know, I wasn't able to, for instance, ask my surgeon, how many times had he done this, you know, what…, what result did he have? Was there anybody else who in effect who was better than him or in Canada? Did he keep track? He probably did, you know, those kind of things.

Dr. Anne Katz: You know, Bill, you raised a really…, you raised a really important point because sometimes men say to me, you know, "How many…, how many surgeries has Dr. A done" and I say, "Well, you know,

you can ask him or her" and often, you know, they sort of talk about high-volume surgeons being better. I am not sure that that's a 100% accurate. A bad surgeon can be a bad surgeon, no matter how many surgeries he performs. You know, I think… I think that we have oversold this idea of nerve sparing, I think we present that to men in a very black and white way or men understand it in a very black and white way because they are desperate for…, for it to work and in reality, this whole nerve sparing issue, frankly, I think is a little bit of a crapshoot. Works for some, doesn't work for others and…, and that, you know, and that's problematic. Men are upset. They say, I…, you know, I went to this guy because he does nerve sparing and, you know, look what's happened. There are…, are urologists certainly who are older, who didn't learn nerve sparing techniques as part of their training. You know, who kind of figured it out long after. The younger urologists should have learned this as the standard way to do the surgery, but even though there are so many factors, you know, its… First of all, the nerves are not…, are not visible to the naked eye. They do not look like the yellow electrical cords that we see depicted in diagrams in the patient education materials. You can't see them, yes, they run with…, with blood vessels, but the kind of traction and, you know, that…, that happens in the area can put those nerves into shock, which then start the whole cascade of…, of events that…, that the end result of which is no erections.

Dr. Anne Katz: I think sometimes men also are… They are not particularly proactive in trying to get things going again. They are kind of hoping that things will get better by themselves and that's not always the case. However it is for other men, you know, and there are some men who do really well. You have always got to bring the brain into it. So…, so, I think male sexuality is far more complex than we generally give it credit for. We see male sexuality as an on or off…, off switch, that's not the case at all. Men have hopes and fears and dreams. They are concerned about their partner's sexual satisfaction and so, often, you know, their…, their brain gets engaged to the detriment of…, of their penis and they…, they are…, they are concerned, you know, is this going to get rigid enough, is it going to last long enough, am I going to be able to do this, am I going to be able to do that and poop, you know, away goes any hope of an erection because they get performance anxiety and its…, its difficult to quiet that little voice in the head.

Mike Scott: And when you…, when you have spouses there or partners there as well as the…, the patient, are there particular things you try to make sure that they understand?

Dr. Anne Katz: Absolutely! So, the first thing that, you know, spouses tend to say is, "I just want him to live. I don't care about sex." And three months later, six months later, that couple shows up and now sex is really important, you know, and I understand that. So, I ask the partner, you know, to…, to…, to really think about the meaning of the sexual relationship within that couple. Let me give you an example. Some years ago, I saw a couple who fought every single day. One or the other picks an argument, right, and they…, it was…, it wasn't that there was any conflicted relationship. They had a knock-down-drag-out fight every single day. Why? Because at night they made up. (Laughter) This man has a prostatectomy. He no longer can have an erection. So, you know, sort of their usual sexual activity was…, was not happening and yet they were still fighting every single day. They were a couple in trouble because they had no way now to…, to make up. So, that meaning of…, of sexual activity in the relationship is important to consider. So, that's one of the things that I ask the partner to think about and also really to impress upon them that this isn't a sex or death decision and I sometimes feel like a broken record. I have to keep reminding people, right. This is not the choice you are making. The choice you are making is…, is…, is one around quality of life.

Mike Scott: We…, we have…, we have another panelist along with us, Faye Funk, who…, who married a person after he had had surgery for prostate cancer. But, Faye, I am wondering whether there are questions that, you know, you would have thought you would like to ask Dr. Katz if you had been there at the time or subsequently?

Faye Funk: Oh, I think for myself, specifically in our relationship, the communication has been so open and so loving and supportive ever since I came into his life and learned about this and what I have been learning since talking with women and partners on the website is that, you are right, the communication is not there and, Dr. Katz, what can other doctors do to encourage the patients to bring their partners in from day one because you will be surprised or maybe not, how many people I… I spoke to that are not…, their…, their

husbands do not want them going to the doctor appointment. How…, how can we overcome that?

Dr. Anne Katz: Yeah. So, thank you, Faye, for…, for raising the C word, communication. You know, I believe that no matter what the…, the sexual problem, communication is at the root of finding a solution in terms of talking with a healthcare provider, getting a referral for health, and for the couple to talk. I tell patients categorically that they need to bring their partner in because four ears are better than two. Its important to have that other person there, perhaps taking notes or just listening intently because one…, one or both of you are going to have that white noise, you know, that cancer noise going through your head which gets in the way of…, of understanding, hearing, understanding, and sympathizing. I…, I occasionally see a man, not very often, because we really do encourage men to…, to bring their partners with them. In fact, when we send out appointments… So, I will get a referral letter to see someone and we send the appointment out, it says, you know, in upper case letters on the appointment, PLEASE BRING YOUR PARTNER WITH YOU TO THIS APPOINTMENT, but…, but, you know, occasionally I have seen a man who comes in without his partner and one of my opening statements is, so…, so, you are alone here today and…, and sometimes they will say, "Yes, I am single" or they will say, "My wife's at work" or, you know, "My partner couldn't make it today" and there actually have been occasions where I have given the man brief information and then I have said, "Its not fair to do this without your partner. Its not fair to you, its not fair to your partner. You need to bring him or her in" and generally they will come back with their partner once they understand the importance of this. I do not understand any healthcare provider who does not want the man to bring their partner in. The partner is an ally in so many ways and we know that I think…, I think any cancer is a couple's issue, but particularly this one because of the sexual consequences. And I am glad, Faye, I am so glad, you know, I am so glad that…, that…, that you found love in…, in this way. Its, you know, its a blessing.

Faye Funk: It definitely is. Thank you.

Mike Scott: We also have Tony Crispino on the line, who is a patient advocate that works with the Southwest Oncology Group and other groups and runs a…, a support group in Las Vegas. Tony, what do you love researching this area at all?

Tony Crispino: Yeah, as a matter of fact, we are currently working with the NCI in developing nothing so much as a clinical trial base but a survey to get on out there and understand a little bit better about some of the emotions involved in survivorship. I think that one of the keys is, you know, for each of the…, each of the surgeons/doctors and will even go with the medical oncologists who deliver hormonal therapies is understanding the individual just like Dr. Katz just indicated and that would bring me to a question to Dr. Katz. You have mentioned briefly the single man, I just had one walk in the door of our support group the other day and he is going in alone. He has still got a dating life. He still has the desire to go ahead and marry. He has nobody right now towards which he is really closely connected to that is going to get him over the…, over the threshold, if you will, but for these guys, understanding difference sex and intimacy or how to proceed after this and then be able to get back on horse and get out dating again, what do you say to those guys?

Dr. Anne Katz: Yeah, you know, its really difficult and I think these men are.., are really at a…, at a…, at a disadvantage in terms of…, of lacking that primary support. You know, once again, I think its about communication. I do some work and have just actually written two books for and about young adults with cancer, who are often single and, you know, the issue with dating after cancer is a huge one because it requires disclosure of something that is private and scary and…, and when rejection happens, it just adds another layer to the individual's vulnerability. Right? Did the second date not happen because of me or because of the cancer? So, you know, I think everybody has to…, to find a level of comfort around disclosure and a lot of people actually choose to disclose right upfront early so that there is no, you know, implication that there was…, there was not complete honesty and transparency. The other thing that I point out to men is…, is…, and in fact I saw a single man the other day. He was a guy in his late 60s and…, and this was his issue. Right? How am I ever going to find someone, so I say to him, "Okay, so what age group, you know, from which age group are you interested in…, in dating" and he looked at me like I was a little crazy and he said with someone of my own age. So, I said, "You think its possible that any…, this man happened to be

heterosexual…, that any woman your age doesn't perhaps have some of her own issues?" You know, perhaps some body image issues, perhaps some postmenopausal stuff. Is that possible and he just burst out laughing. You know, I think he…, he in his brain was…, was imagining, you know, a scenario where he would…, he would potentially find someone with no baggage, with no problems. As you get older, stuff happens and you know, we have baggage around that. Our breasts aren't where they used to be, we have got cellulite and scars of our's and we are not perfect and…, and are afraid of…, of being…, or know that's about being judged as not perfect. So, you know, we all…, we all come particularly in the fourth, fifth, and sixth decade and beyond, we all come with issues and…, and being vulnerable is difficult.

Mike Scott: I have another question about the ramifications of…, of particularly I think more often surgery than radiation, but it probably happens with radiation too and that is the situation where initially after treatment the relationship seems fine, but gradually thereafter the man starts to withdraw if he discovers that he really doesn't have the capacities that he had before and…, and…, and I frequently speaking with women who, you know, feel that their…, you know, their…, their…, their spouse or husband is…, has literally withdrawn completely into a…, into a…, into couch potato whom they have no relationship with anymore. Do you have particular advice when this sort of thing happens? Are you…, are you familiar with this?

Dr. Anne Katz: Yeah. So, you know, I think there can be a number of issues. Its interesting that you said sort of couch potato. So, is there an element of depression here? I think that, you know, important to…, to…, to identify if the man's being a couch potato and not doing anything and socially withdrawing, you know, what's the issue? If he is having issue with incontinence, you know, it might be that he is embarrassed, afraid to go out in case he has an accident and, you know, the one thing about incontinence is that its public as opposed to sexual problems, which really are private, nobody needs to know about, but if a man has had an accident, you know, people know about it. So, what I commonly see with couples is this scenario. They are past, what we call, sexual script, so their way of being sexual with each other involved, you know, initiation at some point, sometimes earlier in the day, sometimes later in the day. So, they…, and each couple sort of has their way of initiating. So, it might be communication, hey, are you up for it tonight? It might be something nonverbal, you know, perhaps he is more…, he is touching her more whatever… He stops doing that because in their sexual script that was the beginning of the initiation and he doesn't do it anymore because he doesn't want her to think that something is going to happen later because he can no longer have an erection. The partner may stop touching the man because the last time he or she did that, the man interpreted this as the invitation or the initiation of something and because he couldn't follow through and I am making little air quotation marks here that you can't see that because he couldn't follow through, he got very upset. So, the partner stops touching the man because he or she doesn't want that upset to happen again. The net result is a couple who don't touch each other, who are living as college roommates and…, and who are lonely, so lonely because as human beings we need touch. We fundamentally need touch. So, you know, I talk to…, to people about this. I say that, you know, I say to them, "You need to have a conversation with each other around what touch means now in the aftermath of treatment, that it doesn't necessarily mean an initiation. It could just be comfort or skin hunger, right, that need to be touched, but you've got to talk about it because what worked before does not work in the new context of life after prostate cancer or any other cancer for that matter.

Mike Scott: Faye, Tony, Bill, would you like to chip in on that, I mean, obviously, you have got more experience in this than I have.

Bill Martin: Uff… I guess its not so much a question is, just screwing up your courage to figure out what you want and then screwing up even more courage to do that to your partner. I found it incredibly difficult. We all dance. We had a seductive dance and…, and it worked well for years and years and years and all of a sudden that was gone. I had a…, an implant in my penis, so I could have an erection whenever I wanted, but I still wanted more and didn't know how to get it or how to ask for it and I…, I guess if Anne had any thoughts about that, that would be a big…, a lot of interest to me.

Dr. Anne Katz: Bill, you know, I think you really hit the nail on the head here, is that we are human beings and we have the gift of speech, but because things have been automatic, spontaneous, reliable, easy, many

of us have never talked about it, you know, in adult words, using our outside voices. We communicated in grunts and squeaks and facial expressions and…, and over time, you know, you learn what those mean and now lo and behold, you know, that language is gone because…, because, you know, the contexts have changed and you have to ask for what you want and you have to open your mouth and your heart, both of you, right, to talk about what this means and its scary and its difficult because you have never done it before.

Tony Crispino: I…, I cannot relate that to my relationship. My deal with this started at the age of 44 with prostate cancer surgery. I…, I believe that there is a…, a…, a pretty large difference between the younger man and the older man in this particular arena because 44 years old when we were engaging the nest, there were still thoughts of even having maybe another child or so along that. This gave me a little bit of a different concept when coming out of it and with my case, going straight into hormone therapy after…, after surgery. The younger guys and…, they are wanting to continue the family, what would you say to them?

Dr. Anne Katz: Yeah, you know, I have actually seen… I have actually seen men and sometimes actually men into their 50s and 60s, so one of the things that…, that…, that I will ask, you know, and when they bring their spouse or partner in, its a little bit helpful, you know. If I see a woman who is obviously in her 60s, I am not that much concerned about…, about having…, having kids, but I sometimes have a little spiny sense, right, and I say, "Hey, are you… and I…, and I say it in a kind of lighthearted manner because I think sometimes a little bit of gentle humor helps with sensitive topics and I say, "Hey, are you done making babies?" and every now and then I get a little surprised when the man says or the…, or the partner says, "Well, actually no, we are thinking about adding to our family" or, you know, so then, of course, we talk about sperm banking immediately and luckily man has the time to…, to do it or they need to get busy pretty darn quickly, which obviously doesn't…, doesn't always work because, you know, its about the…, the time that needs to be right. I think…, I think things are qualitatively different to younger men, but honestly in the big scheme of things, you know, men are men and…, and…, and this is about pleasure and comfort and…, and male identify and…, and is really important. I have some patients in their 70s and 80s who are so, you know, actively seeking to have erections. Sometimes its because they are…, they are widowed, and…, and there is…, my understanding because I have been told this, is that in order to attract anybody even in a nursing home, you have have to have an erection. It sounds a little bit like high school to me, but…, (laughter) apparently…, apparently the women in…, in these…, in these places are talking about men who can have an erection and that's not a good thing. I think its incredibly cruel with any example, but this has certainly been the…, the perception of…, of some of the…, the older men that I see. You know, I think obviously, you know, adding to a family or creating a…, a family adds an additional level of complexity. That question needs to be asked, particularly of younger man.

Mike Scott: So, in…, in terms of the whole question of male identity, I mean I think this is a very important part of a whole thing and is often something that men themselves, although they know deeply that something about their sex life is incredibly important to them, they don't necessarily really understand why. How do you talk to men about that?

Dr. Anne Katz: I actually think the fact that I am a woman is an advantage. I have…, I have never had a man, after I have spoken to him, say to me, you know, that was not helpful, you don't understand where I am coming from. Because I am a woman, I do not make any assumptions about where the man is coming from, what he thinks or feels. I have to ask those questions, which I think sometimes other men don't ask, right, because they know how they feel, so they kind of transfer that to…, to the man with cancer. You know, I ask questions and I warn men, I am going to ask you lots of questions and some of them, you know, may feel invasive, but there's a reason. I am not just, you know, doing this to be voyeuristic. So, I ask those questions. You know, can you imagine what might it feel like, what is happening, you know, is the issue that you can have an erection standing up but not lying down, you know, how rigid is it, on a scale of 0 to 10, 10 being when you were 17, 0 being, you know, nothing at all. Show me, no, I don't mean show me your penis, not (laughter) at all. That would not be good, you know, and I actually sort of, you know, use my index finger sort of going…, going from curled up to, you know, standing straight up and tell me what is going on and then also, you know, the values, beliefs, and attitudes of that man and that couple are really

important. Is this a couple who are mentally flexible and creative in terms of their sexual script? Those are the couples that manage to create something after treatment. For couples who have a very rigid and ritualized way of being sexual, you know, Saturday night, 10:20, in the dark, missionary position, jammies on, those couples often really flounder because they can't figure out a way to do things differently.

Mike Scott: Well, and I almost feel that men, not only do men not talk, you know, know how to talk about this to a woman, they don't know how to talk about it with a man, they feel so deeply, I don't know, private about it that…, that we are just not good at having those conversations at all.

Dr. Anne Katz: Oh, I think…, I think…, I think in part because you socialize to joke about it. You know, the men joke about it all the time, but I think…

Mike Scott: Oh, sure, that's normal conversation.

Dr. Anne Katz: Exactly. Exactly, but that's the only way you know…, you know how to talk about it. I think the other thing is that it…, it really is about kind of an alpha male kind of thing. I think it is very difficult for a man to admit to another man that he is not able to have an erection because I think in a…, somewhere in the reptilian part of our brains, that is interpreted as that…, that man is weak. I don't believe that for a nanosecond. Right? Because, you know, men and women, we are further more than our sexual organs, but I think, you know, that's a very primal kind of instinct and I think that gets in the way of meaningful conversations often. Perhaps, its just easier for men to actually talk to a woman because, you know, I…, really my…, my reptilian brain doesn't respond to that at all. You know, get me talking to another woman about body image is slightly a little bit different, but I am not a man, right? So…, so…

Bill Martin: I would like to speak to that, Mike, if I may? Before I had the surgery and…, and after I had the surgery, I went to a prostate support group and I wanted to talk about impotence and actually nobody did. The women looked interested in the group and the men didn't say much and that was my experience for quite a while. Then, after a number of years and I had written about it and I had spoken about my experience in painful detail, told how depressed and unhappy and difficult I was and then had my book handy so they could look at it, then it was amazing how many people…, how many men started to talk. You know, once I told my story really explicitly, it was amazing. All sorts of questions came out and…, and I think men need another man to come clean before they can come clean.

Faye Funk: If…, if I could say something to that as well, Mike……this is Faye. We have experienced that first hand, Keith and I. Keith has put himself out there and really has…, has told his story and has been very graphic with other men when they reach out to him and want his story and as soon as he does that, then everyone's guard comes down and he has shared some of the emails that…, that he writes and shares with other men and its…, its quite amazing to see their openness and how they just put themselves out there and make themselves extremely vulnerable, but I…, I do think it takes the…, the man…, the man who has gone through this, I think they need to make the first step to say, "This is what I went through, this is what I have experienced. I am here for you."

Mike Scott: And…, and…, and did that make sense to you, Dr. Katz?

Dr. Anne Katz: Oh, absolutely! I think though that it really does take a special kind of man who is willing to…, to open up and be that vulnerable because I think men are socialized, right, to be big and strong and…, and…, and not to admit to these kind of vulnerability. So, you know, the…, the…, the world is a better place for the Bills and…, and…, and, Fay, sorry, I just already forgot your…, your partner's name….we need more men like…., yeah, Keith. We need more men to be open about it, it will really help.

Mike Scott: So, I think this is…, this is a great conversation and what…, what I would like to do now is hand it back to Priya because we…, we may have some people online who would like to ask questions and we have another 13 minutes or so. So, Priya, if I hand this back to you, do we have any…, any questions from people online?

Priya Menon: Thank you, Mike. I was… I have been receiving some questions via email. Dr. Katz, I will just quickly go through them. Just the latest one says, Dr. Katz, could you please speak about the cases where the doctors tend to say about the radical perennial prostatectomy, which is more likely to leave the patient with erectile dysfunction over the retropubic approach?

Dr. Anne Katz: So…, so, here in Canada and in fact, I think in…, in really North America, the perennial approach has really fallen out of favor for reasons way outside of the erectile problems that it causes. One of the problems with…, with doing the radical prostatectomy that way is that they can't do adequate examination of the lymph nodes and extraction of the lymph nodes. So, I don't… In North America, I don't believe that that approach is even taught to residents anymore. I don't… Certainly, where I live, there is no one who…, who does that and…, and to the best of my knowledge, that really has fallen out of favor. The retropubic approach also causes erectile problems as…, as you have heard, you know, certainly I will talk about on this call.

Priya Menon: Thank you, Dr. Katz. The next question, he writes in saying he had TURP procedure for BPH and has a PSA of 5.4 and this was in 2009 and he has been taking Lupron for quite some time. So, he wants to know, do you have any input on how to deal with current problems due to Lupron and if there are any suggestions for help medically, holistically for side effects? He is a very active 80-year-old man and having met a lady friend would like to…, would be nice…, he says would be nice to have desire and ability for an active sex life?

Dr. Anne Katz: Yeah. So, I am…, I am really not going to speak to the…, you know, the indication for the Lupron. Lupron is one of a class of medications that stops the body's production of testosterone, which has profound impact on sexual desire and erections, particularly when men are…, are, you know, older and certainly someone in their 80s would…, would be regarded as old. There really is very little that can be done while the man is still on the medication, certainly that…, that loss of desire, you know, is…, is very difficult to do anything about that. I sometimes find that men who have no desire are more accepting of their loss of erections and that's about 85…, well 85% of men on these medications actually lose desire. The 15…, 10% to 15% of men who…, who still keep their desire are often extremely…, extremely frustrated by the lack of erections. So, its…, its an unfortunate position to be in, but there really is no medication to treat that or pretty much the other side effects of those medications.

Priya Menon: Thank you, doctor. The next question is from a person who says I have been diagnosed with prostate cancer, and I have been evaluating my treatment options and came across a procedure called MRI-guided laser ablation. He says it seems to me that these ablations would be considered preventive procedure but not having to remove one's prostate radically and he says, personally I would like to retain my organs for as long as possible and maintain a higher quality of life for as long as possible. He is not asking question…

Dr. Anne Katz: Yeah, so…, so, you know, we don't… Laser ablation is…, is…, is really not an approved treatment for prostate cancer. Its approved for the treatment of BPH or benign prostatic hypertrophy, but one of the issues with prostate cancer is that it tends not to be, what we call, multifocal. So, it tends…, there tends to be little bits of prostate cancer scattered throughout the prostate. So, it… You know, when that happens, its very difficult to eradicate the prostate…, the cancer completely, you know, that's really why the…, the radiation is end of the whole prostate and the surgery takes the whole gland out. There is certainly great interest in these, what we call, focal therapies, but that the treatment that this man is considering is really not the…, the gold standard of treatment for prostate cancer.

Mike Scott: Yes, if I may, I think its worth noting that there are several different types of focal therapy that are being investigated at the moment, but they are all either experimental or investigational……and they should probably only be done in the context of a clinical trial if at all possible…, if at all possible.

Dr. Anne Katz: Absolutely. Yeah. Absolutely, Mike. I would agree with you.

Priya Menon: Doctor, I think that's…, that's all that we have from our listeners today. Dr. Katz, would you like to give a message to our listeners regarding emotional aspect of prostate cancer and life after treatment?

Dr. Anne Katz: You know, I think the importance of communication cannot be underestimated and that includes communicating with…, with healthcare providers. I have often seen doctors walk into rooms and say, "You are doing fine, aren't you," and its very difficult to say, "Oh, actually, I am not." So, open communication with healthcare providers and asking for the help that you…, you need or want and certainly open communication with your partner. Let them in. Let them help you or…, or try to find a solution together to the problem. No man involved in…, in a relationship is going to fix this problem by himself. It really does affect the couple and.., and needs to be dealt with on that level.

Priya Menon: Thank you, Dr. Katz. You were saying… You were saying…

Mike Scott: Thank you, Dr. Katz. I really appreciate your time and thank you to the panel, Priya.

Priya Menon: Thank you, Mike, Tony, Bill, and Faye. Thank you for your participation. The talk is recorded, and the talk and the transcript will be made available on Cure Talk's website. Please visit curetalk.com for details on our upcoming talks. Thank you so much. Thank you, everyone.

Dr. Anne Katz: Thank you, everybody.

Mike Scott: Thank you, everyone. Good night!