Your Guide To Active Surveillance In Prostate Cancer Transcript

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Welcome and Howard Wolinsky Introduction

All right, everyone, welcome again to the Prostate Cancer Summit. I am your host, Doctor Geo Espinosa, and it is my pleasure to have Howard Wolinsky. Howard, this is one of the few cases where we don't have an actual physician speaking, being interviewed, but we have a patient and a patient that's been a patient for, I want to say, about 14 years.

And he's been on active surveillance for 14 years. Active surveillance is something that probably started about 15, 20 years ago. So many people, even 15 years ago, 14 years ago, were still getting their prostate treated with, you know, prostate removal, prostatectomy, radiation, probably when they did not need to get it treated because they had low risk disease.

And that's my conversation today with Howard Wolinsky. Howard, thank you for being on today. Well, Geo, it's always good to see you. We haven't seen each other since you were in Chicago.

That's right. But, you know, you were too generous to the medical profession. In the introduction, when you said maybe they were having unnecessary surgery and radiation.

They definitely were. And they definitely still are, right? Back when I got diagnosed, only 6 to 10% of us went on active surveillance, which is close monitoring of the cancer with, PSA tests, biopsies.

And these days now with MRI's and, and also, genetic markers. Right. But back in the bad old days, when, you know, when we barely had a choice, most people didn't make a choice, even though they had low risk cancer.

And so back then, something like, 94% of the men with low risk prostate cancer, and that's the majority of men who get diagnosed, by the way.

Why Active Surveillance Matters

That's almost 300,000 men will be diagnosed with prostate cancer this year in more than half was going to have low risk to immediate risk, maybe even higher 60%, which means even low rate immediate risk means they don't need aggressive treatment.

It depends. Right? Yeah. Okay. They call it, Gleason six three plus three or Gleason three plus four for intermediate. And there's a new system. For Gleason, six is called, grade Group one.

That's right. Because if you call it Gleason six, it sounds like you're halfway off the plane and falling into the abyss. Right? Or you're thinking, I mean, I'm not kidding.

Many people who said, did Jackie Gleason have prostate cancer? And that's what they, you know, many, many, many people have said that to me, that it's well, you know, last year where I started a couple of different support groups for men with low risk prostate cancer.

Because they're not necessarily a good fit to be in with the guys with advanced prostate cancer, which is far more, rigorous treatment, horrible side effects, and a lot of the low risk men assume that's going to happen to them.

Right? When the ads are very much against that. But what I gotta tell you is, we start Doctor Donald Gleason. Yep. Invented the system that pathologists use to identify the pattern of prostate cancer.

You know, like, from 1 to 10, or at least the condition of prostate. And used to be a Gleason five was considered prostate cancer. They dismissed that.

Now there's debate and whether even Gleason six is prostate cancer. Yeah. Scott, ignore, doctor Scott ignored by you over there in, in Chicago is one of the leading voices in that, isn't he?

Well, yeah, I was actually, I was on a team again. I was, I was like the Maytag repairman. It was just me as a patient with five, high profile physicians, including doctor Ignore, suggesting that, Gleason six be, redefined is, is a non cancer, right.

But we wrote an article together that was in 2022, in the Journal of Clinical Oncology. Yeah, it was the most read article in the journal. And I can go on and, but I gotta tell you, my Gleason story.

So I created, Comedy Award because there's tons of jokes about prostate, enlarged prostate, prostate exams. Sure. All that. And so we we had various categories.

The funniest doctor. I hope you will enter. Yeah. Yeah. And and so we, we one of the posters that we had for it, he had a picture of Doctor Gleason with Jackie Gleason and, and and the what we call the the contest is putting the Gli back into Gleason.

Oh, that's so funny. And, and so we've been giving out these awards, during the year, but Jackie Gleason did that. Hey. Prostate cancer. Right? Not that we know if he died of other things.

So for sure, I, I, I'm going to be taking a guess at this, but I think I'm right. I think he, he had, colon cancer, but other issues too. That's what I remember. Yeah.

He was a big, heavy smoker. Yeah. How many members of your audience even know who the Great one was?

Gleason Scores and Reframing Low-Risk Disease

That's a I think when we're talking about prostate cancer, I, I would hope that many do. We're not talking you know, we're not yet appealing to millennials.

Although they're getting older. We're appealing to, you know, generations, you baby boomers and and I think it's a yeah, we're we're the not so great generation or the great generation.

We're we're our fathers and mothers. That's right, that's right. So, Howard, where? Take us back to your diagnosis. We were talking 14 years ago, and they were ready to, they were ready to remove your prostate.

So take us back when you were diagnosed. And what? At the time, I think Doctor Klotz had already, published a little bit on active surveillance at that time.

There was some research already on that. Yeah, well, he he does fit into the story, actually. Doctor classes, a urologist, and by the way, he calls me a force of nature.

So, yeah, you know, I think he's a force of nature. That's right. Doctor Geo is too, but. Oh, I appreciate that. Thank you. Class name this approach, active surveillance in he and Doctor Carroll at the University of California, San Francisco.

Yeah. And Doctor Carter at Johns Hopkins were the lead figures in the late 90s. Yeah. Who were proposing this idea of of the prostate cancer, even Gleason six. Yeah.

And probably Gleason three plus four. Or Gleason seven. Intermediate cancer and low risk cancer that they probably didn't need to be treated. Yeah, they could be watched.

It's different than watch for waiting. And I don't want to go down that rabbit hole right now. Why don't you let's talk about that a little bit. Because still to this day, Howard, people are still mixing up to to active surveillance versus watchful waiting.

I'm going to give it a brief description, because I don't want to get too caught up on that. And then you just, you know, fix it if you have to. So watchful, waiting for those listening, it's very important you understand the difference in watchful waiting means, you're diagnosed with prostate cancer, but we're not going to monitor you until things get worse.

When things get worse, then we'll do either aggressive treatment or palliative care. Active surveillance is exactly what the word implies. Actively surveilling meaning you come back for PSA is over.

You know, whether it's every six months for a period of time until you you can go a little longer, maybe 12 months. And they do follow up biopsies. That has changed a little bit.

However, and have you know how because some people are saying, look, I'd rather get my prostate treated, if I'm going to have eight biopsies, you know, one every year for, you know, for forever.

And that's not comfortable. So even that has changed how how we do things now. So your experience in that regard. Yeah, it's changed dramatically. But you brought up the I was trying to avoid the issue, but you brought it up with, watchful waiting.

Yeah. True. True. As recently as yesterday, I was talking to, man who I call the poet laureate of the prostate. He's actually a Welsh poet who wrote a book of poetry, about being in the trial.

Right. And he he brought up the word watchful waiting. Watchful waiting. Used to be an approach. It was mainly. It's still was an approach, I guess. It was mainly for older man. Yeah.

Howard's Diagnosis and Early Surveillance

So who's an older man? Well, depends. I mean, it depends. 80. I mean. Well, I'm, you know, some 80 year old guys who are still, surfing, so. Oh, yeah.

So, but, so they, you know, they kind of let those guys go, and a lot of them died. And it was a bearded beard experiment. And, and so with, with these that other doctors apparently decided that they with watchful waiting, there was too much waiting and not enough watching.

Right. And so they came up with the active surveillance, you know, it's like the Pepsi generation or something, right? Right. We're not we're not going to be passive.

We're going to be active. Right. And so it was mainly the approach was mainly adopted in the academic world. And but over time it's changed. And in the early days, and I guess I'm part of the early days in 2010, we had annual biopsies and and coordinated with that.

I was in the first cohort that had MRIs in the MRI. And that was in 2011, actually. And, I, we can get lost in any of these topics. And I'm trying how many biopsies did you get in total before they say, okay, we're going to leave this guy alone?

Well, all right, I had five, five. But it was over a period of four years at that point, doctor, ignoring who you mentioned, who was my doctor? At that point, he said, you know, at this moment, we kind of know how your prostate works.

I think it's enough with with the biopsies. So he put me on a biopsy. Vacation or holidays? After four years and five biopsies, somewhere in there, I switched to another doctor.

I switched to doctor, Brian Health saying it. North Shore University health system. Okay. Outside Chicago. He gave me baseline MRI. They didn't see anything on the MRI.

Then anyway, then he gave me a a random biopsy. You know, where they looked at, like, six different areas in the

prostate? Yeah. Fishing for cancer, if you will.

They didn't find anything. Right. And that was eight years ago. You know, I haven't had a biopsy or an MRI since then, and I'm monitored with a type of PSA test.

And what what what has your PSA been? As of late, it's been stable. It's been, between 4.8 and 5.2. So that's a very important point because, still a lot of people are saying, oh my God, is above four, right?

That has to mean something, right? That the 0 to 4 range that some people still get stuck on. It's not the PSA for the audience, those watching. It's not that the PSA, you know, if it's within range, you don't have prostate cancer above range, you have prostate cancer.

A lot of it is age dependent. And in a situation like this with Howard, we know the history. So it seems like it was stable. You know, at about four point between 4.8 and 5.2 for the last several years, which is good, right?

I mean, at one point when I was seeing the my second doctor, I fired the first one. I guess I started the second one too, but for different reasons. My PSA had grown as high as almost nine, and, Doctor Agnew said not to worry.

We know your prostate pretty well by now. It's going to come down. And it did. I mean, it could have gone up for a variety of reasons, maybe undetected.

Infection. Or maybe I had inflammation. Yeah, he had prostatitis or or a check down a tree the day before, or I went bicycle riding or whatever. So. But it's been stable and, you know, gee.

Or is, you know, is as men get older, it tends to go higher. Yeah. Maybe for benign noncancerous reasons. Mine has been stable. I'm due to have another one soon, so we'll see.

But you've been on active surveillance for about 14 years, and I look at your newsletter, it's phenomenal. It's called active surveillance on active surveillance.

When did you start active surveillance and why? Well, technically, I have the word, but on there. And so I wanted more, active surveillance. S u r v e l or that.

Well, one of my sons is a journalist, and he said you know, you're nothing without a newsletter. So that Substack newsletter. So I it's going to be three years now and I started playing around with it.

Next thing you know, I had a newsletter and, you know, I followed all the prostate cancer news, and so why not write it up? I was the, medical editor at the Chicago Sun-Times for about 25 years.

Wow. Okay, so I, I was used to, you know, writing up medical news. I knew the terminology I wrote for Doctor audiences. I wrote for the general public.

So he started doing it, and so steadily, the, subscriptions have increased. And, I still have a long way to go before, Doctor Geo, but my audience is is mainly men and and their caregivers, mainly men with low risk prostate cancer.

A lot of doctors are subscribers a have, column in their columns in there by some some leading doctors maybe I can talk you into one. I'm, I'm, I am putting one together on dietary supplements. I'm still working it through because I want to be very it's a very important topic.

So you asked me to do that and I'm working on it, so bear with me. It's very controversial. Yeah, yeah. It's misunderstood. More than controversial. I think it's just misunderstood.

And with good reasons. Honestly. Is misunderstood for good reasons. Because it could be a little bit of the wild, wild West sometimes with dietary supplements.

So we'll talk more about that. And in this summit, there going to be the thought leaders on talking about this. So stay tuned for that. So, you know, I want to take you back.

We were sort of tracing my history, so I got sent to this doctor. He is well, my family doctor said, oh, your PSA is up in him. Quite reach for it was 3.95.

And actually, by the time I saw the urologist, it was already back down to 3.6. It varies, you know. But. So the doctor did a biopsy.

PSA Monitoring and Biopsy Follow-Up

They found what in those days was about to be a precursor to cancer. Yeah. And that's you know, to your point so many things have changed in the last 14, 15 years.

In the last five years. It's a it's a moving target and it's you know keep up. You don't stay lost. So yeah. And so yeah you cannot it seems to hover like it's, it's a bit unfortunate.

This is why I like to empower patients with information. It seems like the patient has to be well-informed. They cannot just go, willy nilly. Not knowing to their doctor because there's inherent bias in, in medicine and with each physician.

So they have to go in and ask the right questions so that they can, you know, not get overly treated. Right. Well, you know, that's part of the reason that I started the newsletter was, give the audience the questions they need to ask their own doctors.

I don't pretend, I don't pretend to be a doctor, but I do know a lot of the leading doctors. Yeah, and they'll talk to me and give me some latest thinking on it.

But, you know, latest thinking is a moving target for some of this, 100%. Yeah, 100%. Yeah. I don't pretend to be a doctor online either. Because I get a lot of questions where people want me to diagnose them online and and so forth.

But, but, but, but it's very important to, disseminate important information that people can gather and just be engaged in there, be proactive in, in the decision making.

Right. There's a lot of talk on shared decision making out there, even amongst physicians. Well, that talk is also, for the patient to be well informed so they can be part of that shared decision making process.

Right. Well, so they have first start. After said to me, you know, Mr. Lewinsky, you have cancer, you know, just very serious. You didn't say low risk cancer.

You have cancer, period. I have good news. They I have good news and bad news. I said, well, give me the bad news. And he said, Will you have cancer? Okay. What's the good news?

The good news is I have a cure for you waiting in my operating room if you come in next Tuesday. But now realize, of course, I. I had been the medical editor of one of the country's biggest newspapers at the time, and so I had already done my homework.

And I said, well, what about active surveillance? And he just kind of huffed. He said, I don't support that modality, by the way, these days he does 14 years later because his patients probably started, you know, voting with their feet.

He had to try. I get a second opinion from Doctor Ignorant at the University of Chicago, and he's one of the leading figures in this. And he you mentioned doctor quite well.

He showed me some of the doctor classes, research in classes. Research showed, you know, three, three major choices for somebody like me with even, low risk prostate cancer.

One was to do active surveillance and just follow it. One was to treat it aggressively with radiation. The third was to treat it aggressively with with the prostate.

To me and, what's his research? And also I mentioned the Protect trial in England all came to the same conclusion, essentially, whatever choice you make, the death rates the same.

So I'm thinking to myself was the death rate is the same? Why would I want to do anything? You know, the death rate was very small. It's 5 or 10 or even now, 15 years.

Yeah. So why would I do anything so ignorant? Was generous to my first doctor. He said, well, you know, he's right. You could cure it, but I don't think you need to have the surgery.

Building Patient Support and Education Groups

You're you're you're the, poster child or poster boy for active surveillance and so, you know, when I realized how close I was to having surgery, if I can, use the French, I was pissed off.

And, it happened, say, of a cousin, in California who was going through the same thing, a few months earlier. And he went on active surveillance. He sent me a book, The invasion of the prostate, Dr.

Mark Schultz. Yeah. And and that kind of gave me the courage, in part to go ahead. The science also gave me the courage. Schultz is there to, And so I went on it and eventually I initially it was I was invited.

Okay, here's what happened. I was an early adopter of Facebook. I missed the college campuses, although I was teaching at northwestern, and my students were all afraid I was going to spy on them.

But I was an early adopter, and and I started describing my experiences as a urology patient, and I started to get flooded with phone calls and emails and comments from the brothers and sons and uncles and grandfathers and, and, and aunts, even, of of people who were my Facebook friends and they were looking for, you know, what was this active surveillance thing?

And so inadvertently, you know, I just said, all I can tell you is my story. I can't tell you what's the right thing is for you. But here's what happened to me.

Just like I'm telling you now, Geo, this is what happened to me. And so I. Hey, the next thing I know, in 2016, I was at a medical journalist meeting in, in Cleveland, and I had a friend there who was, founding editor of, Medpage today.

And she said, you know, would you like to do a blog for us or a column for us and share your experiences as a patient? I said, you know, what am I going to tell the doctors?

She said, you'd be surprised. And, so I still do that blog, four times a year. And, and so as a result of I was originally I did the blog monthly. And so as a result of that, I got invited to a major medical meeting, American Society of Clinical Oncology.

That's 2 or 3000 people in the audience. And, doctor was saying aforementioned Doctor Klotz was on stage with me, along with other leading lights in the field.

And so I, you know, I was invited to tell my story, but we're a half hour into the program. They change moderators, and I was forgotten. And so I'm sitting there and it's almost an hour into the program, and I'm thinking, you know, if I don't make a move, you know, why did I make this trip?

And, you know, you know, I didn't. All I had for them up to that point was a pat on the back for inviting me. So finally I said, do you mind if I speak?

And they said, oh, no. So in essence, they grabbed the microphone and went on a seven minute rant. And what was wrong with this picture? Oh, they invited a patient and then they ignored the patient and they said, that's what's wrong with you guys and gals.

You know, listening to it. And, you know, it had an explosive effect. Some doctors in the audience wrote about it. I wrote about it for, for, medpage today, I see.

And then I became sort of, like Martin Luther nailing the thesis that theses theses. And the church door. Because there, there was a big meeting of patients, I wasn't there, it was Prostate Cancer Research Institute from Doctor Schultz and people were talking about me.

Did you hear about that guy? And so a guy, Howard Walensky, you know, you know, stirring up stirring things up over here. Yeah. And so I, you know, I was teaching at northwestern and I heard they checked my mail email there because I was with students all day, literally from like eight in the morning till 6 or 7 at night, working one on one with them.

The these are budding, medical writers, and and I happen to check my email, and I downloaded and I got a note from a guy named Tom Thorvaldsen from Iceland.

He started the first support group as far as he knew in the world, that was for men on active surveillance. So he asked me, was there anything like this in the U. S.?

And I discovered there was. And so I got involved in starting an education and support group called, yeah, I am, I, I hope you can get rid of, brain. So I started active surveillance International.

Yeah. Active surveillance patients. International. Yeah. Aspi yeah. That's me, I started that helped start that group. And then, as a result of that work with the and Khan Foundation to start, it started off as a monthly support group for guys on active surveillance, and it became twice.

Then it became three times, and now it's almost weekly support group with and cam and I hope you can share the, the the. Yeah for sure. Aspi and also active the active surveiller.com.

Yeah. And also, and can that org and active SB is actually as patients.org as patients. Okay. Good. Yeah. So I, I started working with them and you know, as a journalist, I was always the guy sitting in the back of the room taking notes furiously.

Suddenly I found that I had the skills to organize meetings to get just about anybody I wanted as a free speaker. And, and so we started to do, webinars.

And it's been, you know, it's been successful. We did a series of programs that are available and s patients that are we call it's one on one. And we we talked to some of the leaders in the field.

We have a couple, from New Mexico, man with prostate cancer. And his wife is super researcher. And they're interviewing the top people in the field. So so that's S 101.

So there's a little bit of plug overlap but that's that's okay. And so these are like this is like an online patient support group for for for for men on active surveillance for prostate cancer I think that's important.

Yeah. Yeah. And you know it really came in handy during Covid for sure.

Patient Advocacy and Ongoing Active Surveillance Debate

We were already online and ASP has reached thousands and thousands of men in 40 different countries. We've we've had, people from course, Canada and the US, but Brazil and, England and Belgium and Italy and and Israel.

Good. So it's a global it has a global audience. Great. Howard, thank you. So I really appreciate because I don't think I still don't think that patients know a lot about active surveillance.

Believe it or not, though, it's been a thing for close to 20 years to protect, study, and recent trial, they did their 20 year follow up show that, you know, for the most part, it makes no difference between active surveillance, radiation and surgery in terms of survival from prostate cancer.

And people are still confused about that. So I think you shared some good information on it, particularly from a patient perspective, who you're not a typical patient, you're well informed, I think, and you can talk the lingo with any physician on prostate cancer.

So I think you're a unique, a unique case. Your unicorn in the prostate cancer world, I would say. So what's better, a unicorn or a black swan, I don't know.

Oh. That's interesting. I will have to look that up. I like a black swan. Would be. It's nice to. At least it sounds better, but, you know. Great. And I should point out, and you're sort of hinting at it, that this is still an issue.

Yeah. I mean, the US 60% of men with low risk prostate cancer choose active surveillance, but flip it 40%, don't you? And if the state of Michigan is an exception, 90% choose active surveillance in Michigan.

And that compares to the best rates in the United Kingdom in Sweden. So there's a in you know, it doesn't just have to do with, money incentives. It has to do with tradition and the way things have been done and the need to change the way things have been done.

And so how it not everybody will end on this, not everybody. Let's flip it. Because I think that, for, for, for the, for a large part is blamed on doctors.

They, they just trigger happy. They, you know, if you have a hammer, everything looks like a nail. The patient also with Gleason six even after they know they're a candidate for active surveillance, maybe they're doctors.

If they're not doing it, they're not capable of being on active surveillance psychologically, knowing that they have the C-word in their in their body.

Well, we've been told since we were little that if you have a cancer, you need to get it out. Yeah. And so it's a counterintuitive idea to think about active surveillance, to live with the cancer.

You know, I, I, I go to the Dexter show and I call this, my dark passenger. Right. And, no, it's not going to kill me. The odds are it's not going to kill me.

It's not going to progress. It hasn't been seen in 14 years, right? Just about 14 years. But it it you're right. We did a survey of 150 patients, and over half of them had serious emotional distress issues.

10% really serious. Yeah. And so it's hard in a significant percentage of these men, even if their Gleason score hasn't gone, within five years to ten years, we'll switch to treatment because it's hard for some of these guys to live not only with the side, but the reality of cancer in their bodies.

It's unless you go by the definition of Scott Agnew, which is, hey, let's not call it cancer. And I guess that's why that movement is so important. Good point Geo, you're the boss.

Hey, Howard, thank you so much for being on. We'll make sure to connect the audience, to, the activesurveiller.com, and aspipatient.com. Is that right? It's a patient.

Yes. Patients.org. As patients I talk you can double check me on there and we'll put we'll make sure that patients and people find out I think is a very important, website, an organization you guys have.

Hey, Howard, thank you so much for being on. I really appreciate you coming on. Yeah, it is a thrill, and it's always good to see you. Thanks, Howard.

See you soon. Thanks, everyone, for tuning in to the Prostate cancer Summit. We'll see you at the next episode of the Prostate Cancer Summit with our next guest.

Thank you so much. Have a great day.