

Walking Through a New Bladder Cancer Diagnosis: Non-muscle Invasive Bladder Cancer

Guest Presenter:
Ava Saidian, MD



Dr. Saidian:

Okay, some resources and tools.

Resources and Tools

Dr. Saidian:

So, I am biased by this great organization but, hands down, probably one of the best places for resources is the BCAN website. Whether it is finding a urologist, learning more about your treatment, finding other people, support groups, it really has everything you need in one place. All of these webinars are recorded and put up there, it's really got a plethora of information as well as information about local events, our big meetings, things like that.

There are also a lot of other great websites out there, American Cancer Society, the AUA and the American Bladder Cancer Society. I like to emphasize these specific websites because Google can be a very dangerous place, there's a lot of misinformation out there, there's a lot of anecdotal evidence. So, someone's uncle's friend who had this

Great Online Resources:



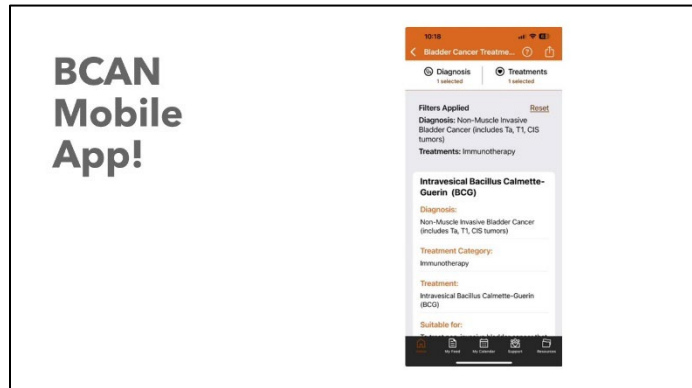
- Bladder Cancer Advocacy Network
- American Cancer Society
- American Urological Association
- American Bladder Cancer Society

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horrible experience which can falsely taint your experience. So, I just want everyone to have accurate information and that's why I always direct my patients to these websites.

Dr. Saidian:

Also, BCAN has a great mobile app. If you just go into the app store and type in bladder cancer, I think this is the first one that pops up. So, it's nice because you can read about different things in the palm of your hand, lots of different resources and then lots of access to support.



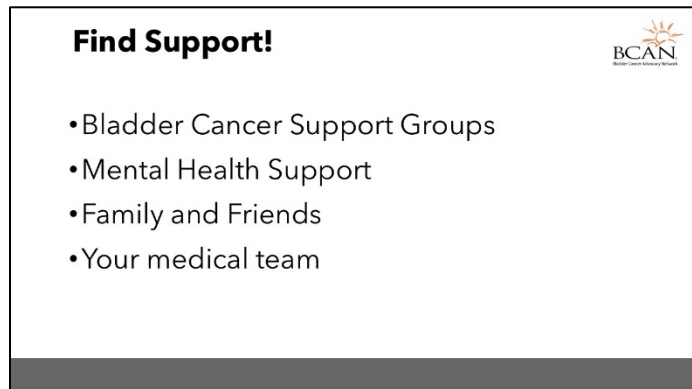
Dr. Saidian:

And then, speaking of support, I think your bladder cancer journey, even though it might not look like what other people's cancer journey looks like, say, people who have muscle-invasive cancer, for example, they have to get their bladder removed, they have to get the chemotherapy that you see in the movies with the IV and losing the hair but, having non-muscle-invasive bladder cancer, it can be a huge burden.

You're seeing your urologist every couple of weeks at minimum, you're getting

chemotherapy instilled into your body once a week for weeks at a time, you're going to and from the doctor, you can have symptoms that are very bothersome every day. So, I think it's really important that you find support for yourself whether that's a bladder cancer support group of other patients going through a similar thing or even mental health support.

I think the mental health aspect of it is just as important as the physical. Sometimes, as urologic oncologists, we focus on the physical because we just want your cancer to get better but your mental health and being healthy in that sense is just as important because, if you feel good about what we're doing, feel confident in us and you feel supported in yourself, then you're really going to have better outcomes that way. So, if that's not a mental health specialist, then your family or friends or church or whatever you need to get you through it. And then last but not least, your medical team. We're here for you to help you find these resources so don't feel like you can't ask your urologist or your nurse or nurse practitioner or PA different resources.

The graphic is titled "Find Support!" in a bold, black font. It lists four bullet points: "Bladder Cancer Support Groups", "Mental Health Support", "Family and Friends", and "Your medical team". The BCAN logo is in the top right corner. The background is white with a dark grey bar at the bottom.

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Dr. Saidian:

And then the most important thing to remember is that, even though we're advocating for you and your family and your friends are as well, that you really are your best advocate. I tell all of my patients to keep a journal or a notebook on their phone or something of a running list of questions to ask me. That is what I am here for, that is what your urologist is there for. We want to know all of your concerns, we want to talk through all of them and make sure that you

understand what's going on and are okay with what's going on and what the next steps are. So, write down your questions because they're going to pop into your head and you're going to forget them when you're in the office and we want to go through those with you.

Another important thing is to speak up, reach out to us if you're having trouble tolerating any part of your treatment. If you're having symptoms, I don't want them to get to the point where they're so bad you can't tolerate your treatment anymore and we have to find something else to do. Sometimes it's better if we know early on that you're having certain side effects because then we can try to stay on top of them. Or, for example, if you can't tolerate the office cystoscopies anymore, let your urologist know. I have lots of patients where, because of the treatment that they had, it's just too painful for them to get it done in the office. No big deal, I take them to the operating room, it's a quick 20 minutes, they go home later that day.

So, really speak up for yourself, let your doctor know what you are and are not comfortable with and ask for clarification. So, I think, if you know what your treatment plan is and what the next steps are, you're going to get the best care. So, ask for clarification, ask why we're doing things, why we're not doing certain things because, like I said, if you're confident in the care that you're getting, I think you're going to have better outcomes. And the other thing I always tell my patient is do not feel like you are bothering me, it is our job to help you. So, advocate for yourself, speak up for yourself and let us help you get the best care that we can give you. So, that is the end of my talk. I hope I covered everything and I'll let Patricia take it back over.

Patricia Rios:

Excellent. Thank you, Dr. Saidian, for such a comprehensive and excellent presentation. As a reminder to our listeners, if you have any questions, please use the Q&A button at the bottom of your screen. And I see we already have some questions, Dr. Saidian, so we're going to go right into the Q&A. First, I want to ask you, there's a question about blue light and white light. Before we address the question, can you explain the difference between the two and their response, if any?

Dr. Saidian:

Yeah, yeah. So, that's a very good question. So, white light is just the light we're using right now, it's the regular light that we plug into our cystoscope. Blue light is where you have a special chemical injected into your bladder and then we use a blue light, it's just using a different spectrum of light and what it does is the tumor cells pick up on ... Or, I'm sorry, the chemical gets picked up by tumor cells that we might not be able to see with our own eye but that the blue light can pick up on. So, this is often used at

You are your best advocate!



- Keep a running list of questions to ask your Urologist
- Speak up! Don't let symptoms get out of hand before asking for help
- Ask for clarification
- IT IS OUR JOB TO HELP YOU!

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usually the re-resection TURBT so it can help us find tumors that we might not be able to see with our naked eye and it's usually used in that re-resection phase.

Some people, for example, our institution doesn't have it in our office, we can use it in the operating room so that's why I use it in re-resection. Some places have it in the office, so your office cystoscopy at just your standard rechecks might use blue light. Basically, it's just a newer technology that can help us identify tumors that we might not be able to see with just the regular cystoscope.

Patricia Rios:

Thank you for explaining that. And is there a benefit on whether there are some advantages in having blue light depending if you're at high risk or intermediate or low risk?

Dr. Saidian:

So, yeah, it's typically used more in the intermediate and high risk because it's better at picking up CIS or high-grade disease, low-grade disease might not take it up as much. So, that's usually in the setting that it's used in higher grade disease but there is a role for it in low grade. But again, it's mostly used for those high risk or intermediate risk patients that are usually getting the re-resections.

Patricia Rios:

Thank you. Now, you talked a little bit about risk factors and genetics, there's some questions about tumor genomic profile. Can you go into explaining what that is, what that entails and explaining its role in decision for treatments in bladder cancer?

Dr. Saidian:

Yeah. So, there are some ... We're using a lot more genomic profiles and different urine testing, cytology testing based on those genomic profiles. A lot of the ongoing trials are currently using those and what they can help do is help us be better at predicting who's going to recur and also who's going to respond to what treatment We don't really have ... The reason those are being used in those trials is because we don't necessarily have the answers yet on a larger scale, a lot of those have been preliminarily studied. But I think in the future what it's going to entail is everyone will get genomic profiling of their tumor and they'll have a more tailored treatment.

Right now, as you can see, it's really broad strokes. If you fall into this risk category, this is the treatment you get. But we will be moving towards a more personalized medicine based on different tumor markers, based on different genomic profiling. I didn't get into that with this talk since this was more of a broad brush stroke talk about it but there is definitely a role for it in diagnosis especially in patients who might have recurrences.

Patricia Rios:

Thank you. Well, there's a question about changes in diet. Do you have any recommendations around the role of nutrition and whether it is affected or what dietary changes people should take?

Dr. Saidian:

Yeah. So, a lot of the dietary stuff is, especially the risk factors, is based on large-scale pattern observations and correlations. We can't say, if you eat bacon every day, you will get bladder cancer. But a lot of it was just found that a diet full of highly processed foods, those patients had a higher risk of bladder cancer. Of course, there might be other things leading to an unhealthy lifestyle that add to it.

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So, I think, once you do have bladder cancer though, what we have been finding is there is evidence of a more, for lack of better terms, a more vegan diet, plant-based foods have been shown to be healthier for all types of cancers and I don't think bladder is excluded from that.

Now, do I think radically changing your diet is going to cure your cancer? No, but I think leading a more healthy lifestyle will probably help in terms of your overall tolerance of things, your overall health and having just a more nutritious diet is going to be better for you overall. But that one-to-one link isn't there, it's just patterns that have been observed.

Patricia Rios:

Thank you. Now, we didn't really go into clinical trials and I was curious to know if you see a role of clinical trials in this space and when should that conversation come up?

Dr. Saidian:

Yeah, absolutely. So, I think you can always bring that up to your urologist. I think it's probably going to be best for patients who have had recurrences or patients who can't tolerate certain treatments. So, if you're not tolerating those treatments but you're not ready to have your bladder out, I think a clinical trial is perfect. I think, if you are having lots of recurrences, clinical trial is good but I think at, any stage of disease, enrolling in a clinical trial is important. Even if you're going to get the standard of care and not necessarily the new treatment or whatever they're testing, enrolling in those clinical trials do help us get a lot of data. But I think, in terms of new treatments, patients who have had recurrences or can't tolerate treatment, those are people that your urologist should really be looking at a clinical trial for you.

Patricia Rios:

And just as a reminder to our listeners, we have on our website a clinical dashboard where you can look for clinical trials that are bladder cancer specific and you can browse through those based on where you live. Now, I know we didn't get into the surgical component of it but there is a question about bladder preservation therapies and whether you could address that and when is that offered and any information you can share with us.

Dr. Saidian:

Yeah. So, in terms of bladder sparing therapies, for the most part, all non-muscle invasive bladder cancer, the standard of care is essentially bladder sparing. The only one that's not is if you have those very high-risk features, in which case, right now, we recommend doing a cystectomy up front. Or, even some of the variant histology, we recommend a cystectomy up front. So, bladder sparing, that terminology is usually spared for or, excuse me, is usually used when we talk about patients who have muscle-invasive bladder cancer where, currently, the gold standard is chemotherapy and then having your bladder removed. The bladder sparing therapies are where you get chemotherapy with the resection and radiation.

So, the bladder sparing comes into play with non-muscle invasive when you've had multiple, multiple recurrences and we're getting to the point of talking about taking out your bladder. And at that point, if you really don't want your bladder out, we can talk about doing radiation along with chemotherapies that boost the power of the radiation.

Patricia Rios:

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Thank you. And what are some of those chemotherapy drugs used typically?

Dr. Saidian:

When or what?

Patricia Rios:

Which ones. Which ones, what?

Dr. Saidian:

So, they're usually platinum-based so cisplatin and gemcitabine but then there are specific chemotherapies like 5-FU that actually work together with the radiation to have a better effect. So, some of them aren't necessarily the ones that you hear about with bladder cancer but gemcitabine and cisplatin are some of the more common ones.

Patricia Rios:

Okay, thank you. And a question was submitted, I know you went over some of the side effects with treatment and is dizziness and lightheadedness, is that a side effect that you normally see after BCG treatment?

Dr. Saidian:

I can't say I see it ... I don't see it often but I have seen it before. So, I don't know if that might be playing into the overall immunological effect, a flu-like symptom, maybe your blood pressure's going down, you just don't feel well. So, I have seen it before, it is more rare. Obviously, if it becomes intolerable, we can't have you dizzy, falling over things like that so that's something I would talk to your urologist about. I have seen it before though.

Patricia Rios:

Well, thanks for addressing that. Well, time has flown by and I see we're almost at the top of the hour. So, the last question that I have for you, Dr. Saidian, and thank you again for joining us today and sharing this very vital information. So, what is the takeaway that you want our listeners to take after today's webinar?

Dr. Saidian:

I would have to say, non-muscle invasive bladder cancer, it can turn into a chronic disease where we want to cure it but we're always going to keep an eye on it. You might not get one treatment, you're going to get a lot of different treatments and, when it comes back, we might change the treatment. And basically, what we're trying to do with non-muscle invasive is to keep it from becoming muscle invasive because, like I said, that changes the paradigm. So, even though you are going to require a lot of treatment, maybe a lot of surgery and lot of different types of treatments, it is something that we can manage for a very long time and hopefully keep from becoming muscle invasive. So, I don't want patients to become discouraged when they do receive the diagnosis because it's something that we can all work together to almost manage a chronic disease.

And the other important thing is I wish we had more time because I see a lot of good questions in the chat and I'm a huge advocate of asking questions, asking your urologist questions and just really trying to understand what is going on with your disease because you are your best advocate. And so, I don't

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ever want anyone to ever stop being curious and asking about what I need to do next, what I need to do next, is a clinical trial right for me. So, yeah, those will be my big takeaways.

Patricia Rios:

Well, those are excellent takeaways and we will certainly invite you back for a part two. Thank you so much for joining us and I want to also thank our sponsors, Merck and UroGen, for making the webinars possible. Thank you to our listeners

