

# Patient Etiquette: How to manage your bladder cancer treatment

Becci Hannigan, RN



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## Patricia Rios:

First, I would like to ask Becci, again, thank you for that presentation. You went over so many great points and particularly I was trying to keep a list of the insurance, the different tests we have to get done and all of that requires being organized and so I was wondering if you could share some tips with us on how we can get organized because we have things that are in paper, things that are electronic. What is the best way that we can have all that stuff handy and be ready when we need them?

## Nurse Becci Hannigan:

So, having a cancer diagnosis, any diagnosis to be honest with you, can be very overwhelming and adults, when they're being taught, really only retain about 30% of what they're being taught. So, if you imagine you're going in and your doctor tells you you have an ingrown toenail and you're being taught how to take care of it, you're going to retain about 30% of that, but when you get the C-word diagnosis, that cancer diagnosis, it's like you have earmuffs on. It's difficult to process anything that is being said to you. It can be such a challenge and I watch the patients as I'm talking to them, and I can tell they're not getting anything I'm telling them.

So, I always recommend, first of all, if you have an inkling that you have cancer, if you're being referred to a doctor because you think you have cancer, the first thing you need to do is get a notebook because when you go to that doctor's office, in that notebook should already be at least five questions, at least five questions that you're going to ask. You should have somebody with you at least for that first appointment, an advocate who is able... Now, if your husband or wife is twice as anxious as you are, they may not be the best choice. You need to have a really sound mind an objective person who is going to be able to go in there and listen and truly hear the words that that team is telling you and somebody who can write notes.

I have some really incredible patients that are just tough as nails and they're in there and you can just see that they're just, "I'm going to fight this cancer. I'm going to win," and they're just intent and they're writing everything down and you could tell that they're really getting it, but that's very rare. That is really very rare. Cancer diagnosis is incredibly overwhelming. So, have an advocate with you. Have questions prepared before you go to your appointment, and almost every appointment there should be

a question. Write those questions down. Have a little book. Anywhere I go, I have this... I was in the army for six years and we had these little green books that we kept in our breast pockets. We called them CYA books. You can imagine what that means and it was just something that you always had with you in case you needed to write something down and I do that even to this day.

### **Nurse Becci Hannigan:**

I'm a sticky note fiend. Sticky notes everywhere all over my desk because when I think of something, I have to write it down so I can remember later. Always have something available in your pocket or in your purse or whatever. So, if you think of something, "Oh my gosh," because as soon as you leave the doctor's office, invariably the question is going to pop in your head. Write it down. This is where the portal comes into play. Patient portals, you can go, "Hey, I just saw you guys today." Type in your little question. "Can you answer this question for me really quickly?" And then it can be answered back. So, having a book and then even using that book as a journaling opportunity.

So, it can be used by your advocate who's writing down the answers to your questions or dates of your next appointment, but it's also someplace where you can write down, "Becci was really sweet to me today," remembering the valet guy, his name, so that the next time you've come, you can let him know. "Thank you, but you took really good care of me last time and I really appreciate it." Those types of things. It's good to have that information because like I said, 10, 12 years, we're going to be best friends. So, having that book to go back on. Definitely getting medic alert is really important. Let me pull something up really quickly if I can find it. I can't find it.

So, having organization is important. Having a book, writing notes, having an advocate is going to be really helpful throughout your journey. Lots of appointments to keep up with. Make sure with your portals that you do assign your phone to get notifications from it. That's very, very important. All you need is a random three-year-old and they can help you set up the portal. These kids these days are really, really good at the technology. So, setting up your portal properly is very helpful as well.

### **Patricia Rios:**

That is very true. So, there's definitely tools available to us as simple as a notebook as well as something more advanced like the portals. So, we have a question from our audience, and this person says, "Since bladder cancer is a geriatric disease, how does one manage the ageism that you're going to be confronted with and the older you are, the worse this is?"

### **Nurse Becci Hannigan:**

So, interesting...interesting enough, I don't necessarily see that unless you have significant comorbidities. I had, I think my youngest bladder cancer patient, 32. Now, this poor guy already had... He had a heart attack. He had bladder cancer. He ended up in kidney failure, got bladder cancer again, and then had another heart attack. So, I think he was way worse off than some of my 80-year old people who have had their bladder taken out and they're still playing golf. As far as ageism is concerned, I don't necessarily think it applies with bladder cancer, at least not in my practice in the sense that the oldest patient we took to surgery was 94 with an expectation that she's absolutely not going to die from bladder cancer or even her surgery. So, it's really the cardiac clearance that is going to factor in as far as your care with bladder cancer.

I have a 92-year-old lady who comes in for her bladder cancer treatments weekly. So, I don't see it. Like I said, I don't see it in my practice. We have a very, very broad spectrum of ages and they all do very well wherever it is that they start in. At which age? 50 or 60, 70, 80 or 90.

**Patricia Rios:**

Well, thank you for answering that. Now, another question. This is related to conversations with the doctor. So, this person has non-muscle invasive bladder cancer, and the only time this person gets to see and ask her doctor questions is when she's on the exam table during cysto and this is obviously very awkward in a rushed environment and wants to know if there's a better way to communicate.

**Nurse Becci Hannigan:**

So, one of the ways is the portal. So, if there are things that you want to get across, you have questions, would be the portal. The other thing is to simply tell them, "Hey, I have questions for you. Can you put me in a room and talk about this?" We do this very frequently in our practices. After we're done the cysto, we can put them in the room and discuss things about maybe what we've seen in the cysto or even ask, "Hey, before I go in for my cystoscopy, can I have a few minutes with you?" That is not unreasonable to ask. Even somebody as busy as Dr. Lerner, he would be more than happy to answer your questions.

Another resource is always the staff. So, as the staff brings you into the room, you could ask them the questions. The medical assistants here are so incredible. My entire career I worked hospitals so 20 some years in critical care, I worked in the hospital. I didn't know what a medical assistant was as compared to anybody else. I just knew that they took my vital signs at the doctor's office and then I come here and these medical assistants are functioning as nurses, incredibly, incredibly high functioning nurses, very knowledgeable. I mean, medical assistants, very, very knowledgeable. So, don't hesitate to ask the staff that's bringing you into the cystoscopy room, "Hey, I have a couple questions for the doctor. Let me run them by you and see if you can help me." If not, at least the staff can convey, "Hey, Dr. Lerner, Ms. Smith said that she was concerned about this. Can you address this after the cysto is over?" Because we are very comfortable having conversations with strange people's penises in our hands.

We understand also that it might not be as comfortable for you to have that conversation with your penis in our hand. So, that's something that you can always ask for a little more time and maybe even get a virtual visit. Ask if, "Hey, after this, can I just... not my cysto appointment, but I have a couple of things that I want to go over when I'm dressed. Can we do a virtual appointment?" Never hurts to ask.

**Patricia Rios:**

Yeah, and I like that about maximizing the healthcare team that you have there and also asking if you could speak to them after or it could be taken to another room. I think that's a really great advice, and I think that's the goal of this presentation is for patients to feel empowered, to be able to ask this and make these requests.

**Nurse Becci Hannigan:**

Closed mouths don't get fed. So, definitely.

**Patricia Rios:**

We'll remember that next time. Okay, so another question here from this person who says they heard that a PET scan is a good idea, but doctors don't order them because insurance won't typically pay for them. Do you think a PET scan should be done if you get diagnosed with bladder cancer?

**Nurse Becci Hannigan:**

So, there are different reasons why a PET scan would be done. Oftentimes it's because things are seen on a CT scan. If a doctor is not ordering it just because he thinks insurance won't pay for it, I would say I'd have to disagree with that. First of all, if a PET scan is warranted, insurance will pay for it and by that, I mean, you take your order to the imaging place and they say, "Hey, it was denied." So, then there's always an appeal. Well, actually, the first thing is they'll ask for what's called clinicals, and that's going to be your doctor's office notes, previous scans, lab results, those types of things. Clinicals get sent in. They get reviewed. Once again, they could be denied. Then you have an appeal and it gets sent up to a higher level. If that appeal gets denied, then there is what's called a peer-to-peer.

I have in my entire five years never had a peer-to-peer denied once Dr. Lerner gets on the phone, and basically what it is is a doctor from the insurance company calls your doctor and they fight it out basically and they argue why this scan should be done. PET scans are important scans. So, I would say have the doctor order it. If he thinks that, "Well, I don't order them because they get denied." No, go ahead and order it for me, sir. Let me run it through my insurance and then that information is always communicated with the patient. So, it's not something that's done just in the back office. That insurance calls me and says that Mrs. Smith has been declined. Mrs. Smith also knows. So, Mrs. Smith is empowered to call the office, "Hey, I see here I was declined. Did you appeal it? I need you to appeal it."

And you harass and you harass and then well, okay, the appeal was declined. Then I need you to do a peer-to-peer. One of the things you need to know about peer-to-peers is they're very time-limited. Very often it has to be done within 24 and 48 hours, can be very challenging. So, I would say ask your doctor to order whatever tests that he feels is appropriate regardless of whether he thinks your insurance is going to approve it. Now, there are some insurances that I can tell you right off are not going to approve a PET scan. So, I know as a staff member that I'm going to have to do a prior authorization. I'm going to have to start that process early and that's another question that you can ask your insurance company. So, what if I needed a PET scan? Is that going to be covered? And very often it's going to go back to the coding if there is appropriate coding. A diagnosis of cancer is usually a good reason to do a PET scan because that is pretty much a number one way that we find out if anything has metastasized or spread distant from wherever the initial source is.

**Patricia Rios:**

Excellent. So, my takeaways are ask, ask, and don't be afraid to ask.

**Nurse Becci Hannigan:**

Don't be afraid to ask.

**Patricia Rios:**

Yes. Well, thank you everybody for joining us today. We have run out of time. We hope you'll join us next month.

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