

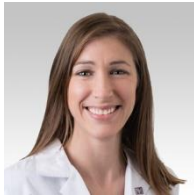
WHAT I HAD WISHED I HAD KNOWN WHEN I WAS FIRST DIAGNOSED WITH BLADDER CANCER | OCT 28, 2020

With Dr. Joshua Meeks and Dr. Alicia Morgans
Feinberg School of Medicine, Northwestern University

Meet Our Presenters:



Dr. Josh Meeks: Dr. Meeks is an Assistant Professor of Urology at the Northwestern University Feinberg School of Medicine, as well as Section Chief of Robotic Surgery at the Jesse Brown VA Medical Center. He is urologic surgeon with expertise in the diagnosis, treatment, and management of bladder cancer.



Dr. Alicia Morgans: Dr. Morgans is an Associate Professor of Medicine in Hematology and Oncology at the Northwestern University Feinberg School of Medicine. Her primary focus is hematology and medical oncology, with a special interest in genitourinary cancers.



Darrell Nakagawa is a long-time volunteer with BCAN. Darrell was originally destined for the opera stage, and appeared with national and international stars in performances in Hawaii, Houston, and Cincinnati. Since his diagnosis in May of 2017, he's continued to live a very active life.

Ann Mardon is a patient advocate who received treatment at Northwestern Medicine. She spent most of her early career on the East Coast teaching elementary school, and she's a recent transplant to Chicago to be close to her grandkids.

Dr. Morgans: Very good, very good. Ann, can you walk us through, because you had a complicated story, too, that took place over years. You had an initial procedure and then you had further surgery.

Ann Mardon: Right. Initially I had the Neobladder. I remember so very little. Things came back afterwards, but I really remember very little from the hospital. I guess I was really out of it, but when I did come to realize what was going on, I guess it was probably four or five days later that I really knew what was going on. I was ready to get out of there. Dr. Meeks knows. I'm like, "I'm ready to get out." I think I really annoyed one of the PT people because he said, "I have to see you walk. I have to see you go up the stairs." I'm like, "I can do anything you want," and I did it and then I never saw him back the next day because they let me go. I was determined I was getting out of there. I was very happy because I basically... My new normal was setting an alarm for every four hours just to remind me to go to the bathroom. I still believe to this day that I somehow felt it, that I had to go, too. But that was my new normal, and that was fine. That lasted for three years.

Then all of a sudden I just couldn't stop leaking. I thought it was normal. I was like, "Okay, this is okay." But then finally I mentioned it to Dr. Meeks, and we found out at that point that the cancer had come back. So what was going to happen now was to have a channel put in and have, I guess this is right, Dr. Meeks. Everything was turned so now I would pass from my bellybutton, and that was going to be my new normal. That was done, and I was actually... I think I adjusted really well in my opinion. It wasn't going to let me down. I was like, "This is not going to stop us from doing things and living the life we want." We're retired. We have our grandkids. We want to do things. And it hasn't stopped me. It really hasn't. I cath now every three hours. It's just something I do. Everybody hears my alarm going off when the family is here, and it's like, "Okay, Gammy get to the bathroom." It's like a joke in our family. Not a joke, but you know. They're very accepting of everything.

That was the time when I met Dr. Morgans was when that surgery, because Dr. Meeks recommended that I have the chemo first before the surgery. Chemo only lasted the two sessions and then I got the infected and I ended up in the hospital. Right after that, as soon as possible, that's when I had the surgery to have the channel put in. Again, I got home. I recovered, and I thought I was doing pretty well, and other than the hernia surgeries... Oh, no. I did have another surgery, right? Three years after that I had another surgery because I was still leaking, and Dr. Meeks and Dr. Kell

Ann Mardon: Thank you. Dr. Meeks and Dr. Kell redesigned the channel, I imagine. Everything is working fine. I don't get into all the terms, and Dr. Meeks knows. My husband comes along and listens to everything that's going on because I just don't get into all the medical terms. I know what's happening. I look at Dr. Meeks' little pictures when he draws those, and that's how I know what I'm doing.

When I look back at it, it wasn't an easy journey, but I was determined I was not going to sit on the couch day after day watching HGTV. I was getting out there. I was going to do what I had to do, and I did it. I did it. I'm going to keep on doing it.

Dr. Morgans: That's wonderful. As for both of you, and then after we finish these questions, I'll pass back to Dr. Meeks, both of you, we were fortunate enough to see you at Northwestern. Northwestern is a comprehensive cancer center. We have a tumor board where we talk about people like the two of you, all of the urologists, medical oncologists, radiation team, the pathologist, the radiologists who read the images. We all get together, lots of trainees, and we talk about what we think

is going on and how we think we can best move forward, and actually in a fun way they're arguments about, "this is best, this is best," and we come to a consensus where we think that we're going to do the best for the person who is trusting us with his care or her care.

Not everybody has the opportunity to go to a comprehensive cancer center, because there are only a number in the country, and they're often in the cities, and obviously not everyone lives in the city. Do you have any advice for folks as they are trying to navigate the real world where they don't necessarily have access? Should they think about a second opinion? Would that have been valuable to you? Would that have helped you with trust or with anything else? Can you comment on that? What do you think, Darrell?

Darrell Nakagawa: Actually, one of my family of choice recommended getting a second opinion at MD Anderson, and I said, "Well, I don't know how to do that and I'm not sure if my insurance company would pay for it." Having been a long-term patient at Northwestern, I was pretty confident of all of the opinions. I don't think it would have changed any of the diagnoses. I'm pretty sure that I got the best care possible.

Dr. Morgans: You don't have to say that just because you're sitting in front of us, Darrell. That's kind of you. But, Ann, for you, say you were in a place where you didn't have a Dr. Meeks, because I have to say Dr. Meeks, he instills confidence and trust, and all doctors try, but not every doctor is the right fit for the right patient, and not every doctor actually has specialty and expertise in bladder cancer. You may see a urologist who typically does non-cancer stuff. They deal with kidney stones, they deal with irritated voiding symptoms, or leaking and urinary incontinence. There are lots of things that urologists have to take care of. Only certain urologists are really cancer doctors. If you were outside of that system, do you think it would have been valuable for you to get a second opinion? There are just folks, I think, who have asked some questions that they don't always have access. Is it worth it for a one-time opinion to get the confidence in your team? Darrell's nodding, but we'll ask Ann and we'll go back to you, Darrell.

Ann Mardon: If I wasn't living in Chicago and I didn't meet Dr. Meeks an hour after I was told I had cancer, if it was a different doctor, I really do think if I was somewhere else I would have gotten a second opinion. My sister is a retired nurse, and that's her first thing was like, "You're getting a second opinion, right?" But Dr. Meeks made me feel so comfortable, and that's why I think you really need to trust your doctor, probably no matter where he is, as long as you trust your doctor and you know his or her background and whatever, I don't think a second opinion is needed, but if you have any doubts whatsoever I think you should. I didn't need to do that, thankfully, and I trusted my instincts and I was obviously right and everything worked well. But I think if I were living somewhere else, like there was a time when we lived in New Hampshire. I don't know if I would have trusted just any doctor there. I think I would have gone to one of the big hospitals and got a second opinion.

Dr. Meeks: Do you think you felt that, because as a community we try to provide a whole enrichment for you. Again, we've gotten better about that. We have support groups now for our patients. We have specifically even a woman's bladder cancer support group, again, trying to do a better job at this.

Ann Mardon: Yeah, I think that's really important. I wish I would have had that, but I guess it's hard to say. There was something about Northwestern, which I had never been there for anything before

other than to visit my daughters, but there was something about you, Dr. Meeks, and the hospital. I really felt comfortable and reading the information online, because I don't know what's on there now, but what I did read at the time was very helpful and made me feel good about what was happening. Not good about what was happening, but made me feel that what I knew was good and I trusted it, but I really think if I were living somewhere else other than Chicago or New York, I would have gotten a second opinion. I really do.

Dr. Morgans: I just want to emphasize to anybody listening, I'm certainly not trying to say that Northwestern is the best. I think they're great, but I think the point that I want to make and the point that I wanted to hear from Darrell and Ann about is that it is helpful if you live somewhere where you don't have access to people who really take care of bladder cancer all the time, if you don't know where to go, you can go on BCAN's website. You can ask the folks at BCAN. They can help you find a way to feel confident in the decision and the plan for you, because there are people who specialize in bladder cancer, and that's the group that really should help you make those final choices and to feel confident. I'm going to pass it back to Josh for some more questions.

Dr. Meeks: I think there's some folks who are going to be looking at this that are looking... We'll talk about other treatments, because I want to talk about... You both elected to have surgery. I want to talk about other options in a minute, but as you both had an operation, can you tell us... Ann you said you woke up essentially and you were ready to go home.

Ann Mardon: Right.

Dr. Meeks: But for that hospital stay on average, I remember Darrell you were pretty fast at also getting out of the hospital. I think about five days is about average, which puts us probably somewhere in the middle. There are some folks who are a little shorter, some a little longer, throughout the US. Can you tell us about that hospital time period right after surgery? What was that like for you as a patient? Was there any particular hiccups? How did you feel? What did you feel like in the hospital? When you go home, that begins another part of the journey. That's probably six to eight weeks after surgery before, as you said, that you were really more like yourself. Can you just give us a little bit of an update on that? Do you remember what that was like and things that stick out in your mind?

Ann Mardon: I do remember I was in a lot of pain. I remember that. I remember the button. I remember everyone reassuring me that if you have the pain button, yeah. I just remember laying there. Well, not just laying there, because I was getting up to sit in a chair, do the walks like I was told, but it was just the time that... I think I was just looking ahead. When am I going to get out of here? When am I going to get out of here? Not that there was anything wrong happening. I was very comfortable being there. Everyone was helpful. I looked forward every morning to having the doctors come in and the whole team-

Dr. Meeks: Can I ask about pain? Because, again, I think that's what a lot of the fear about surgery is is pain. We really try to address that. We've actually got some better ways since then, but did you think pain was a major issue for you?

Ann Mardon: It probably was. The major issue was the pain. But I think I also have a high level of pain. It was bad, but I used the pain button. Getting up and walking was hard. I'll admit that was not

easy. I'll admit I cheated a couple of times on your chart, Dr. Meeks, and checked off that I walked when I didn't.

Dr. Meeks: Oh. Cheat.

Ann Mardon: I did it. I did do it. I would get up into the chair, and from the chair to the bed. That was probably the hardest of it. It's just getting your body back to feeling normal, because you can't move the way you would normally move. I'm not used to sitting still. You know that the walking had to be hard, because I'm always on the go and I did not want to walk and I did not want to sit in a chair. It was really between my husband and the nurses and the doctors saying, "You have to, you have to." I did it because I had to because I wanted to get out of there, but it wasn't the easiest. I'll admit. I'm not going to say the hospital stay was the best.

Dr. Meeks: Darrell, is that pretty similar to what you experienced?

Darrell Nakagawa: Well, actually post-recovery I went up to a regular floor, so you had to influence them to send me down to the urology floor, and that helped have them have the experience of all that I could go through. I had a little trouble getting out of bed the first time, and actually one of the pain meds in my abdomen came out. I wasn't feeling any pain anyway, so pain was not an issue for me. Even walking was... I was out walking on day one, so it was pretty uneventful for me, and even PT said at our first meeting I could do everything that he needed to check the boxes for, so it wasn't major for me.

The biggest hiccup for me was feeling confident with changing the bag and getting it right. That's what I was looking to home healthcare for, and they didn't have the right resources, so I said, "Screw it. I'll just learn how to do it by myself and figure out how to do it right."

