



Stephanie Chisolm: I'd like to invite Donna and Sam to put their videos back on. I'm really excited to have this whole new Treatment Talk series to really bring that patient voice. I'd like to introduce Miss Donna Calderbank and then Mr. Sam Paolini is going to jump on in just a minute. So welcome, this is really wonderful to be able to have you all share your experience. So we'll start ladies first. Donna, can you just give us a short overview of your journey through the chemotherapy space?

Donna Calderbank: So in December 2018 I was diagnosed with the predominant muscle-invasive urothelial carcinoma, high grade, so I had to have the chemotherapy before surgery to remove my bladder. I was blessed to be able to be treated by the best at the best. I also am grateful to have been offered to be a part of a clinical trial, which added immunotherapy to my chemo regime. My three week rotation consisted of the cisplatin, the gemcitabine, and the nivolumab, two weeks on, one week off, in four cycles. So in my mind the additional immunotherapy medication offered another layer of potential cure. Dr. Sonpadve was, and is, so well-versed in bladder cancer treatment. When he discusses your options, you just know that you are in expert hands.

One month after my last cycle of chemo-immunotherapy, I had CAT scans to determine my body's response to the treatment, and whether the tumor had shrunk enough to have it surgically removed. It had, so on May 8th of '19, I had a radical cystectomy with concurrent urostomy. I remain bladder cancer-free so far to date.

While receiving the chemo-immunotherapy regime at Dana Farber, I was given what they call supportive care medications through the IV. I experienced difficulty when given magnesium. That's one of the medications that you have to get during the treatment. It had to be administered very slowly in order for me not to feel extremely foggy and have significant visual disturbances, which made me very woozy and nauseated. I also would recommend that you discuss IV access with your oncologist. I was 60 years old, in good general health, with great venous access, but by the middle to the end of my four cycle treatments, I had very sore veins in both arms. I would recommend discussing the placement of a port-a-cath prior to starting your chemo if there is any question about your venous access.

Donna Calderbank: As far as side effects, my most significant side effect was fatigue. Obviously, it worsened the more chemo that was administered. Initially, I bounced back within a week, but by the end, I barely bounced back after the week break.

I was fortunate to have been able to have a leave of absence from work. I could not have worked due to the fatigue. I also had friends and family that transported and stayed with me during my chemo administration. I often marveled at the other chemo patients who were able to get themselves there and back on their own.

The nausea was easily controlled with the oral meds at home, as well as the meds that they give you concurrently with your chemo. I did not have hair loss, I had hair thinning, but you could just cut it short and gel it up, and you could hardly see it. And thinking long and hard about the long-term side effects that I was left with after my chemo, I do have a low-level ringing in my ears, but it does not affect my hearing at all. And funny too, when you got chemo there was a little cart that came around and gave you lunch, and part of the lunch, I was so excited, was Lay's potato chips. But now the thought of and the sight of a Lay's potato chip bag causes instant nausea. Those are my side effects, long-term.

Stephanie Chisolm: Wow. Okay, thank you so much. How about you, Samuel? What's your chemotherapy experience like?

Samuel Paolini: Let me see what's going on here. I found out that I had bladder cancer in the summer of 2020. And at that particular time, I had come to work, I urinated blood, and there was a local oncologist that I knew. I went in to see him, and he's the one that found out that I had it. So when I realized what was going on, fortunately I'm very close to Boston and I said, "I'm going into Boston for my operation. I'm not going to go to a local hospital."

I called up Dana Farber and I talked to them on the phone, to somebody, and they told me it was going to be about a month. All then all of a sudden she said, "Oh wait a minute. There's a cancellation on Monday. I can put you in. Would you like it?" I said, "Absolutely." Fortunately, I didn't even realize it at the time, it was with Dr. Guru Sonpadve.

And so, we went in the following Monday, myself and my three children. We sat down with him, and I had, fortunately a whole sheet in regards to my situation, so he could read and see objective what was going on. And he went on to tell me the different programs, and basically in my situation, he said that he felt that chemo and then operating on my bladder, and he would also take out my prostate and lymph nodes. And he said, "We approach for chemo treatment for four months, and then the operation."

And as soon as I heard chemo, I said, "Hold on, doc. I'm 80 years old, and I'm not going to go through it. I heard too many horror stories." I was really, really not going to do it, but he went on to tell me exactly what he said to you people, "They've come a long way now and that it isn't like it used to be, Sam. You won't get as sick."

I listened to him and I felt very secure with what he told me, and I agreed to do it. And I went on the treatment program of four months, whatever it was. I think it was four months, it was a three week program. The first week was the long week, the second week was a shorter week, and then the third week was off, and that went on until the time of ... I started in September and it went on until approximately January.

Samuel Paolini: And at that time, personally, I've been very fortunate; I was never sick. They gave me the first thing you do when you're sit there for your infusion, the first bag that they plug into you is a bag that helps you not get nauseated. And then they also give you pills. They gave us two set of pills, and they said, "You take the first pill if you feel nauseated, and then if that doesn't work, take the second one." Well fortunately, I took the pill one time in all the period of my treatment, and I was never sick one time. I actually went to work every single day, and I only missed work the days that went in to get my treatments. So actually, I did extremely well. I was very, very, very fortunate as I say, not to be getting sick.

The only thing I did do is I did feel a little nausea once in a while, and I kid about this but my best friend became Ritz crackers, and when I felt a little nausea, I'd take a few Ritz crackers, and that'd help me out and that was it. And the other thing that would happen, at least with me, is I lost my taste, my appetite. I did not have the appetite, and I still don't. I don't really have the same appetite I had before. It's better, but not like it was. I had probably 50% I was eating what I normally ate. But I was able to eat everything, just not as much. So actually, my treatment and what I went through, was very, very fortunate from the day I had my operation to today. I'm living a normal life. And once you go through the treatments, as I say, and once you get it done, and the chemo to me, again I'm repeating, I had no problem whatsoever with it. It was fine, and I could never complain. Dr. Sonpavde is an angel, as far as I'm concerned, what he has done with me.

I have just a funny story. It was during Christmastime that I was going through my treatments and my family came over and we all shared presents. One of my presents was a box of Ritz crackers. I always got a big kick out of that. But basically, I don't know how much more I can tell you. The only thing I can say is that Dr. Sonpavde what he did, as far as my treatments are concerned, what I went through, was excellent. I had no problems whatsoever, as I said. I went to work every day [inaudible 00:36:46] and I'm living a normal life, and I'm living a normal life now, as far as after the treatment is concerned. After he did my operation, as I say, I've gone to work every day. I was home for a while and then I was going to work every day now. I'm living a very normal life. And I again repeat, I thank Dr. Sonpavde for everything he's done, and basically that's the summation of it.

It's quick and fast, but I'm just telling you people that are out there, I know I was nervous when I went in there, and my family was nervous when we went in there, and it turned out to be exactly what the doctor told me, that we would go through it and we won't have a problem. At least with me, that was the case. And that is my story.

Stephanie Chisolm: Well, Sam and Donna, thank you for sharing. Sam I have a question for you. Can you eat Ritz crackers now?

Samuel Paolini: No, I can eat them, but I don't anymore. No.

Stephanie Chisolm: You don't want to eat Ritz crackers, just like Donna doesn't want to eat potato chips.

Samuel Paolini: Yeah, not exactly in that respect, no. They were my best friend, I'll tell you. I would feel lousy, and I would just open up that Ritz crackers, have three or four crackers and my stomach would calm right down. And I've been very fortunate in that respect.

The only thing I did do, that I have to mention, I don't know if this is unusual, but I put on 18 pounds of fluid. I weigh myself every day, I always have most of my life, and I always was used to weighing myself. In just one day, all of sudden I got on the scale and a pound at a day, every time it came up, it came up.

Eighteen days later, I was back to my normal weight. And that's the only really thing that really happened to me that was anything different than prior to having the operation.

Stephanie Chisolm: Great. Well, this is good. So let me just ask a general question first. Is there anything that you, as patients, wish you had asked or been surprised by in this treatment as you were going through this decision making process, because you didn't get to choose which chemotherapy treatments you were on, but as you were going through, was there anything you wish you had asked as a patient that perhaps you think other people should think about and ask their doctors about?

Samuel Paolini: It's a good question. No, because when we sat down with the doctor, it was a pretty lovely situation, and because my family was there, we were all throwing questions at him. And when I was there, we pretty much had everything, it was pretty cut and dried, basically. He said, "This is the best way to treat your situation." I said, "Is there any way can you cut out ..." because what happened with me is I had two cysts in my cancer. One cyst was not cancerous, the other one had gone through into my outer layer. So I says, "Can't you just cut it out?" And I said, "And just give me the treatment?" And the doctor told me, "Sam," he says, "My job is to do the best thing I can for you, and the best thing to do is remove that bladder. And removing that bladder, and removing your prostate, and also removing the lymph nodes is going to give you the best chance."

In my situation also, a couple weeks afterwards, the Doctor called me up. "Sam I've got great news." And I said, "What's that?" He said, "You're completely cancer-free." He says, "Everything that was in there is gone, you have no cancer in your body." And just this past week I just went in, because I go in every few months and now they check me, they give me a CAT scan, and blood work, and it came back, the doctor called me, he said, "Sam, everything is fine. We found nothing different in your body."

So it's been a year. I'm 81 years old now and I'm living a normal life. I'm calling you from work right now. Really, I keep repeating. People ask me, "How are you doing, Sam?" I says, "I'm doing everything." The only difference in my life now is ... don't get offended by what I'm going to say, but I pee in a bag instead of peeing out of my penis. That's the bottom line, really. Other than that, I'm living in a very normal way.

Stephanie Chisolm: Okay. Great. Donna, anything to add before we open it up for questions from our participants?

Samuel Paolini: Well, the only thing I would add is that I'm sure most people are probably like myself, and the mind spinning around what's going to happen to me and what's going to go on? And as I said, earlier you heard from the other participant and she was fatigued, and it affected her in a different way. But in my particular case, as I said, I'm being very honest with you, I never missed a day of work other than the day I went in to have my treatment. Never got sick one day. Went out to eat. Ate everything I wanted to eat, just did not eat as much of it. And as I say, I thank God every day, I really do, because he was very good to me, and I just don't know what else to tell you, other than the fact as I say, I'm sitting here talking to you and I'm living a normal life.

Stephanie Chisolm: It sounds like you and Donna were both very hardy New Englanders, that you really did make it through the chemotherapy with flying colors. And maybe that's a New England thing, a Boston thing, but I know that not everybody can go through as smoothly and as easily. Donna, did you have anything else to add before we open it up to questions from the audience?

Donna Calderbank: No, I just wanted to reiterate the fact that given the fact that gemcitabine is so caustic to your blood vessels, you should really talk to your oncologist about a port-a-cath prior to the treatment because it really was very sore. That's all.

BCAN would like to thank our
Treatment Talk sponsors

**EMD
SERONO**

Pfizer

 **FerGene™**

 **MERCK**
INVENTING FOR LIFE

for their support.


BCAN.
Bladder Cancer Advocacy Network