



Dr. Jennifer Taylor: Those are all awesome, highlighting how you separated perspectives, reframed how you looked at things, used that analytical side. Then, how did you take care of that mental health on the flip side, as you went through the decision and then started the treatment? Who did you get support from with that? Maybe Lori can start again.

Lori Roscoe: Sure. I had my husband, who put up with an awful lot of crying, an awful lot of anxiety. My friends, my sisters, my sons, my doctors were incredible sources of support. The resources from BCAN and other sources. All of that was really important, and the help of an excellent psychiatrist at my cancer center who helped me with what Dr. Taylor said, that reframing. She would tell me things like, "This is bad. No one wants to trade places with you, but cancer has an answer and some things don't. You might not like that answer, but there is something. There are people that can help you that have been here before that can guide you." She tried to get me to adopt more of Doug's approach, which was, "This is not good, but this is something that you can do." Learning how to ... Sometimes, I get very tired of that reframing effort, and I just want something good to happen that doesn't require me to say, "Well, it's not as bad as it could be." Obviously, the pandemic and our political situation has made us all somewhat expert in making those mental adjustments. Yeah, medication, meditation, endless talking, lots of researching. Then finally saying, "I trust my doctor. You got to do what ... See if you're strong enough to do it." Basically, anything I could think of.

Dr. Jennifer Taylor: Thanks for that. Rick and Sue, can you talk about working together, supporting each other, making a decision, and how that role helped you make the decision?

Sue Oliver: When I was asked to be part of this panel, I had to sit down and put myself back in time, and kind of relive what my emotions were during this period. I came up with three points that stood out in my mind, as Rick's support person, when we were deciding what to do about his cancer. First, I was thinking that sometimes, spouses are your support person, you differ on the way you're going to process things in this situation. For example, when we were going through the decision making process, my way was to find out as much information as I could. I was on the computer constantly, in the chat groups, whatever, and of course, from our doctor. Rick was more focused on what the doctor said. He did not want to talk at all about anything else related to the bladder cancer. This was unusual because in our relationship, he's the engineer. He likes to figure things out, so this was very, very unusual and it was like, "Hmm. What's going on?"

Therefore, knowing all that, I realized I had to rely on other things, so like my faith. I had to share my fears and concerns with my family, good friends, some co-workers, and not Rick at that time. Why? Because, I guess, I felt he didn't want any more information than was necessary to make the decision. Also, I felt like I needed to remain positive and hopeful for him, so it was important for me to have my own outlet. Secondly, when we were making the decision, I was really focused for a desire for a positive outcome, which drove most of my decision making. As I said, I wanted to get as much information as I could because, for me, whatever gave him the highest survival rate was my goal. I wanted my husband.

I did not think of this at that time, so when I was sitting thinking, I was looking back. I believe a lot of this motivation for all this information was a feeling of a fear of the unknown for him and us, because the BCG treatments didn't work, and I was feeling real helpless in the situation. At the end of the day, the doctor presented all the options and we thought there was no better alternative for him than the cystectomy.

Lastly, is a point I want to make, is once we made the decision, I felt like it was very important for me to show confidence, before, during, and after the surgery that it was the right decision, I believe, because some people may have misgivings about the choice that they're making. Personally, for us, I know Rick did have regrets, as we'll talk about later. As a support person, I thought it was important to listen, but consistently emphasize that he had made the right decision with the information we had.

Dr. Jennifer Taylor: Positive reinforcement, even when it's just being a cheerleader, makes such a difference. That's awesome. Thanks for sharing. Talk about other things that were important to you in making a decision. What else did you consider, Doug? Please unmute, Doug.

Doug Maclean: Thank you so much. When I think about this particular decision, I think about it like a continuum. Imagine, if you will, on one end of that continuum is quality of life. In other words, life doesn't change. It's just as you're living it today. You're living a fantastic life and nothing alters it. The other side of the continuum is survivability. I think you have to decide on that continuum, where are you in your life? You've heard, I think, some people say, "Look, the most important thing is survivability." I think that's fair. I mean, people obviously want to live, and see grandkids and everything else, so that's important. That would push you to one side of that continuum.

I think you've heard from me today, a big part of my life and my wife's life, she's a wonderful caregiver, by the way too, is all of our outdoor things we like to do. We're very active people, always on the go, and so that shoves me more towards the quality of life side of things. I think it's a personal decision. You have to look and see where you are on that, and then that'll dictate what type of decision you make. As you've seen, for me, it's pushed me more towards the, shall we say, the medicinal answers to this disease. I'm fully prepared. I must say though, I have to say that if it comes to the point that none of the medicinal alternatives continue to work, I'm certainly prepared to face a radical cystectomy if it comes to that, but I want to exhaust my alternatives, if you will.

The comfort, for me, I will share with everybody is that I think you need to be diligent. You have to stay on top of this disease. It grows at different rates in different people. I feel confident with my urologist, a

wonderful doctor, Dr. John Gore, that our surveillance of this disease is thorough. If anything were to change, anything were to go dramatically different, we would be on top of it before it was life threatening. Those are some of the things, I think, that help me live with the decisions I've made and the future decisions I will have to make. Just, like I said, it's very personal. I think you need to evaluate your situation, what's important to you, and then decide on the appropriate treatment with that.

Dr. Jennifer Taylor: I think there's been some mention during these discussions about seeing multiple doctors and getting other opinions. I want to emphasize that that is considered an important step to take, and is not regarded by those of us who are on the treating side as offensive or concerning. In a disease like this that is a more rare entity, it's not as common as other forms or states of bladder cancer, it can be a real game changer to get additional information from other specialists.

Doug Maclean: Thank you for bringing that up. I actually had a note here I wanted to share with people, because I have a really live example of how important it is to seek a second opinion. Like Lori, during my treatment and CT scans, they discovered some nodules or some little objects on my lung, one of my lung lobes, and so the first concern was, could this be the cancer having spread to my lungs? I went to one thoracic surgeon, and he looked at it and he said, "My opinion is we got to go in and cut away that part of the lung and make sure there's no cancer there."

Doug Maclean: Well, I just told everybody that I'm a marathoner. Anybody talking about removing any of my lung is a big concern to me. I was fairly panicked by that recommendation. I did seek out a second opinion. I went to another thoracic surgeon, and he recommended no surgery, "Let's do a needle biopsy." The end of the story is, there was no cancer. This was some scar tissue, maybe from years ago, that either a pneumonia or something that had left a little bit of tissue damage in my lung, nothing to worry about. I think that illustrates the importance of definitely getting a second or third opinion. Thank you.

Dr. Jennifer Taylor: Thank you so much for that. As we turn to the point today, you have started treatment, been on treatment, continuing monitoring. Did you have regrets about the decision that you made? How did that occur, and how did you handle it? Maybe we'll start with Rick.

Rick Oliver: For me, as I've spoke, my timeline was pretty quick. I went to see a urologist in September of 2018, and in May 14th, 2019, I was having my bladder removed. It was a whirlwind period in my life. During that time, like I said before, I was really analytical about it, and I didn't even have a lot of time to think. Then after I went through my radical cystectomy, I had another goal, and that was to physically recover because I'm very active. I cycle crazy amounts of distances. 100 miles is no big deal for me. Anyways, I wanted to really get recovered, but then after recovery, I had a lot of time to think and reflect back on what happened. At that point, I really started to have a lot of regret.

I started really second guessing myself, "Did I do the right thing? Did I do the right thing?" In my mind, that kept going on and on. At this point, I really started to do a real lot of research. Prior to my ... When I got my cancer, I did a lot of research but at this point, I was on the computer a lot, and I was reading everything. Every time I read something, I would be reading a lot about people's experiences with this. They would have the same thing I did, and they were able to come through it and keep their bladder. I was like, "Wow." Then, new drugs were coming online, new therapies were coming online. It was really tough.

Then also, during the first six to eight months of my operation, I was having a lot of issues with my appliances. That's a pretty personal thing, and everybody reacts to it differently. For me, I've never really cared about body image or anything like that, but it really hit me. Body image was really there, and being out and having an issue with an appliance, it embarrassed me. It didn't embarrass Sue here. She was just fine. She was like, "Come on, let's go," and I just had just a hard, hard time with that. After about eight weeks, when I finished my physical recovery, I started to have thoughts and regrets, like I said. The previous year had been spent with a lot of emotional highs and lows, but always something to achieve, and that helped occupy my mind, because there was always a goal, there was always a carrot in front of me to grasp. That was really, really tough.

Then I started asking, I was left wondering a lot of things. Sometimes, it's so funny because last night, I was on a call with the area bladder cancer support group. Dr. Inman was on there from Duke, and he was talking about the three questions that people ask when they get bladder cancer. Me, I asked these questions after I had my bladder out, which makes it kind of crazy. Why did this happen to me when it did? Did I make the right choice? Will I ever get better? What is my new normal? That was my process during this time.

Rick Oliver: I didn't handle it very well in the beginning. I wasn't probably the best person to be around, but I was able to discover various methods to help me during this time. One such was a clinical trial that incorporated meditation and contemplation for an eight week period for cancer patients. It was put on by the University of Hawaii, and that was just beyond phenomenal. I mean, it put my mind at ease and it taught me how to be able to relax, and just relax my mind, which was really big. Another thing that ... I found that really helpful and I'm continuing that today. Also, my pastor and church family were really, really helpful. I had two really good close friends that were good listeners, and that's all they did was listen.

Really, the person that helped me the most is sitting next to me right now. You heard from her, her perseverance, her honesty. "No one cares about this. You're the only one that cares about this. No one else does." I've heard that 100,000 times, and I just treasure that every time I hear it, and her positive attitude. With all that support system in place, my emotional and mental state really started to improve. For everyone that's listening, I know you've probably, maybe if you've been on Inspire and read this, it does get better, and it's pretty tremendous how it almost is like a light switch. I can't tell you the exact date. I can't tell you the exact time, but it does and you just start to feel comfortable. That's where I'm at now. I have a new normal, but hey, you see me walking down the street, you'd never know.

Dr. Jennifer Taylor: Thank you for sharing that. I think the mention of mindfulness and meditation by several of you is really crucial and speaks to the importance of that mind game that you need to get through it, and to be a survivor. Doug, do you want to share if you had any regrets and how you're feeling today on treatment?

Doug Maclean: Sure, Jennifer. I guess, I want to share with everybody my personal philosophy just about life in general. I always refer to my looking ahead as forward thinking. I'm a real forward thinker. I learned long ago, I can't ever undo what's happened. Whatever it is, it's happened, and so I don't lose sleep, I don't dwell on it. I just know that looking in the rear view mirror doesn't help me in my drive ahead. I'm always, I guess, assured by that attitude of looking ahead, whatever the decision is.

If I had a cystectomy, I would still approach it the same way and say, "Okay. I'm going to have other decisions ahead. I've got to make those, so let's look ahead." I always want to prepare myself and be ready for those decisions. That's why I encourage everybody to spend a lot of time now, before you get to that fork in the road, so that when it comes, you're ready to make that decision. I guess, no, I haven't had regrets, and I don't regret anything that happens in my life because I always figure I have control over the next decision that I'm about to make. That's just a personal philosophy. Thank you.

Dr. Jennifer Taylor: Thanks for sharing. Lori, do you want to talk about any regrets and how you're doing today?

Lori Roscoe: Sure. I'm doing well. I'm still a work in progress. It's been about nine months since my cystectomy, and then about three months since my lung cancer surgery, and I'm having a hip replacement in a couple of weeks. My son has reminded me that there's no award for having the most surgeries in a particular calendar year, and it was not my intention, believe me. Emotionally ... I'm still physically, I'm still adjusting. I'm adjusting to the way my body looks and the way it functions now, and getting used to, as Rick said, going out in public. It's a process, it really is.

Lori Roscoe: Emotionally, I'm just in a much better place. The crippling anxiety that I felt from my initial diagnosis has more or less subsided. I guess, I would add to Doug's, I like Doug's continuum idea a lot. I would add a third dimension to that, and that would be emotional distress. If you can deal with the surveillance of cystectomies, I couldn't. I just really couldn't do it, and that had to be a factor in my decision. I don't have any regrets. I wish it didn't happen. I will never be one of those people that said, "Cancer was the best thing that ever happened to me." It certainly wasn't, but I'm stronger than I thought I was, and I'm very much at peace with what I've been through. I'm proud of myself. I have learned to ask for help and support, and I'm just happy to be here and be a part of this discussion with other people that have faced, know exactly what this is all about. I'm really, really thrilled to be a part of this.

Dr. Jennifer Taylor: Well, we are happy all of you are here. I want to thank each of you for joining us and sharing things that were so intimate, and so important, and sort of life changing for each of you. Thank you to Lori, and Doug, and Rick, and Sue. I also want to thank our webinar sponsors, BCAN and the CISTO Study. BCAN, as I've learned personally, is an invaluable resource for patients with bladder cancer. We encourage you to visit their website at BCAN.org to access resources. There's information on different types of treatment, finding support, learning about ongoing trials in bladder cancer, and getting involved in the bladder cancer community.

The CISTO Study is also actively enrolling patients who have non-muscle invasive bladder cancer that has returned after a first treatment with BCG. The CISTO Study website listed here is CISTOStudy.org. It has more information on who is eligible to participate in the study. At this time, patients need to be receiving care from an active study site to enroll in the study, but the group is working on a way for people who are not near a site to enroll on their own. If you are interested in learning about participating when we have that process finalized, or to see if you are near an active site, please contact the team at CISTO@uw.edu.