

Stephanie Chisolm:

Today we have wonderful presenters for you, and I'm very excited about this program. But I wanted to talk a little bit about the definition of proactive. Proactive means acting in anticipation of future problems, needs, or changes. And when we talk about a proactive patient, we're saying that once a patient has an idea of the big problems going on in their bodies, the thinking goes that they can be more proactive about their health. They can help cut healthcare costs and foster better relationships with their doctors. And we know for a fact that this is challenging and especially important in bladder cancer.

So tonight, BCAN is very delighted to welcome urologist Dr. Steven Riggs and nurse practitioner Mary Dunn for today's program. They both joined us from North Carolina.

Stephanie Chisolm:

So Dr. Riggs, it's a pleasure to have you here. And Mary, it's a pleasure to have you as well. So Dr. Riggs, if you would like to share your screen and put the slides up, you are welcome to do that and I will stop the share. And we just need you to take your mute off when you get ready to go.

OBJECTIVES

- In this webinar, we will discuss tips on how to be a proactive patient and the questions to ask, including the following key topics:
 - How to prepare for meetings with medical professionals
 - How patients can improve their chances of getting the best treatment
 - The value of a second opinion
 - What questions to ask about the procedures and treatment options
 - Where to educate yourself
 - Who and what to bring with you

Stephen Riggs:

Well, thank you so much. I appreciate the opportunity to work with BCAN. It's always a treat. I know Mary and I did this a couple of years ago, and it's a real treat to work with her not only on this but in North Carolina. I think I've personally evolved a little bit in how to think about how to be a proactive patient, and I appreciate the introduction. We're going to just talk about some tips on how to accomplish this. A lot of this is just around engagement, questions to ask, and some of the key topics, how to prepare for your meeting.

How can you think about improving your chances to get the best care? What is the concept of a second opinion? What questions should you ask about the procedures and treatment options? Where to educate yourself, and who and what to bring with you. So this is from my perspective as a urologist and urologic oncologist. And then I think, in a well-thought-out way, Mary will give you a different perspective from her end and the way she looks at it. And I think the balance of those two will hopefully give you some insight.

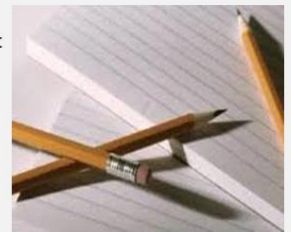
I always tell people, we talk about informed consent. And I think, in medicine, that's a little bit of a misnomer because there's always what I call information asymmetry. It is impossible for you or a patient or really anybody to walk into a doctor's office and understand everything that's going on. And you add in the anxiety around a cancer diagnosis and I believe that becomes amplified. And I think you want to be very cognizant as a patient in the moment to understand and be thoughtful about the emotions you're feeling, and really try to center yourself to start asking some thoughtful questions. And those questions do not have to be perfect. What they accomplish though is they start to engage the physician. And they do that to start to create a connection, because I believe it's that space of that connection that starts to help get a cadence in the conversation to allow you to start exploring what is important to you. And what I have typically found is what is important to one person is not necessarily important to the next.

Stephen Riggs:

So you need to know what that is. That does not come from a textbook. That comes from knowing who you are. And you want to get into a space of comfort. And believe it or not, I will tell you that sometimes some physicians are good at interacting with patients and some, that's not necessarily what they're great at. So you want to sometimes lead up. You want to help your physician get comfortable with you. And you want to be a little bit thoughtful about that. So that is being prepared and being engaged. I have that on the slide. And I think if you can go to the BCAN website or really the NCCN, but the BCAN really is a spectacular website to just start familiarizing yourself with some of the key terms. Because what we tend to do as providers is talk in a language that is not digestible. We've got to catch ourselves.

BEFORE & DURING THE VISIT

- BE PREPARED and be engaged!
 - Familiarize yourself with concepts and medical terms that may be discussed during your visit
 - Ask questions to help your doctor help you!
- Write down 5 questions to bring to your visit
 - For example: Risk factors, staging, genetic factors, low grade vs high grade, what if I chose nothing
 - Take notes
 - Try to bring someone else with you to the visit



And in the moment of the conversation, you've got to help us understand what you do not understand. All right?

So if you ask the questions, you will help us help you. And I think this is the other big thing that people miss or the one thing. You are not going to learn everything about your disease in one visit, right? There is time pressure on everybody. There's pressure on the physician. You want to just understand that. There's some anxiety on your side. There's a lot of things going on at play. And so you want to be a little thoughtful about what you can get out of that visit in that particular time but not make it so broad that you get nothing out of it. And I think that's a really important thought to have in. What am I trying to get out of the visit today? That could be, hey, what's the staging of my cancer? I think that's always important because when you think about it, we stage cancers.

The art of medicine, the art of cancer is do I get the stage right? Do I understand the T, the N, the M? Is that a stage I, is it a stage II, a stage III? A lot of times when we know that, it's very clear what your options are. But a lot of times, we have to invest a lot of energy and a lot of thought about what's the staging, why it might have that staging right or not. So you want to think what that means because once you understand the staging, you'll be able to put that in a bucket and start educating yourself around that.

Stephen Riggs:

And so the other things I just wrote here, low-grade versus high-grade. And I put this in, I'm going to talk about this a little bit later. What if I choose nothing? And I think that depends on the lens with which you look at your disease and where you are in life. And again, that's a personal characteristic, a personal question like, "Hey, do I have to do anything? What if I do nothing? Are there simpler, easier, safer, less-costly options?" And so really, again, just really using the questions to get information and then start to define what's important to you. Take notes. I think that's big. Again, in the dynamic like, hey, I can't write down everything. I personally will draw a lot, write on a grease board for patients in front of them and then let them digest that. But at the same time, you're just jotting yourself some notes.

And if you have a few things organized in preparation for the visit, then you can note underneath that or at least use the words and get clarity around the words to then go back and research on the topic, right? Because what I'm going to preach to you is this dynamic of prepare, listen, and then revisit. Because it's coming at you fast and you need to be respectful of that.

Try to bring someone with the visits. Probably if you said, "Give me one thing to do," bring someone else. They're hearing things differently than you are. They're not emotionally as invested as you are. And they can often help you translate later. Some physicians don't mind you taping the visit. A lot of patients ask me if they can tape the visit. I think it's actually a great idea, so you can listen to it again. And so I would suggest that's a good idea to think about if you just are so overwhelmed.

Stephen Riggs:

What about your options? Well, listen, it quickly jumps to, again, you start out staging, you start out, hey, do you need to do anything else to determine the right stage? Once we understand stage, then we'll really talk about treatment options with cystectomies, the dominant life-changing event that we talk about in bladder cancer, usually associated in generic terms with what we call muscle-invasive disease. And so when you hear that, you want to start thinking, okay, this appears to be an involved surgery. Is this something that this practice or this individual performs a lot? Because again, it's not just the surgeon per se but just the team around them, are they used to the surgery? And you'll

get a little bit a sense of is this somewhere that understands what they're doing, that would provide me a good opportunity to achieve the best possible outcome? Asking what are your outcomes, I find that patients are a little sheepish about this. And again, I think physicians, we will discuss what sometimes the reported data is. I think it's very important to understand what the individual surgeon or surgeons in that group... Do they track their outcomes? And if so, how do they compare to national standards?

Again, you are engaging. I don't know so much you're always looking for a perfect answer. I don't think there is a perfect answer. You're just trying to be an educated and engaged participant. You'll hear about laparoscopic or open surgical approaches. I think if that's of interest to you, if you're thinking one's better or not, you can look for the surgeon to compare and contrast those. And what are the differences? Why would one or the other be favored?

Stephen Riggs:

And then really, again, we talk about personalized medicine all the time. And we tailor a lot of treatments, a lot of options, right? There's often never one perfect answer. There may be a book answer, but there's often not one perfect answer. And that may vacillate between who is sitting in front of us. So why would one be favored over the other? And then really, in particular, why would one be favored for you over the other? I think quality of life is often under-discussed and sometimes over-represented in terms of what we can and cannot do. And so you want to be thoughtful. Listen, cystectomy has a fair number of quality-of-life concerns. And so you want to be thoughtful. What am I giving up? Life's a trade-off, so is treatment. And you want to be thoughtful of where does that balance sit for you as an individual and how you align and your views on what's important and what's not.

And then really within that, there are other treatment options. Your doctor should be talking to you about bladder-sparing options. They are very mainstream now. That doesn't mean they're right for you. They have unique pros and cons. Cystectomy has unique pros and cons. But there's a litany of opportunities of things. As I tell people, that doesn't always mean what I would choose, but that doesn't

TREATMENT OPTIONS

- Muscle Invasive Bladder Cancer: Cystectomy
 - Do you and your practice perform my type of surgery?
 - What are your outcomes?
 - How does this compare to national standards?
 - Do you perform a laparoscopic or open surgical approach?
 - What are the differences in these approaches?
 - Why would one be favored over the other?
 - Which approach to you recommend for me? Why?
 - What will be the affect on my quality of life?

- Muscle Invasive Bladder Cancer: Bladder Sparing
 - Is this something for me to consider?
 - Radiation +/- chemotherapy
 - Radical TUR alone

mean that that's what you won't choose. And I think getting the information about the pluses and minuses to allow you to choose the option that's best for you and understand what those risks are.

Other questions to consider. This really gets down to experience. When you're talking about bladder cancer treatment, really cystectomy, I don't think it's any secret, and this is not unique to medicine; you do more, you usually have better outcomes. Right? You just get better at something. That is whether you sew, whether you play sports. It's really not unique. It's just experience. And getting an understanding of, is this something you do often or not? Do you track your outcomes? Again, just trying to get a sense of, hey, is the person in front of me or the physician or the provider really looking to always constantly improve? That's really what you're asking for. What are their complication rates?

Stephen Riggs:

Cystectomy comes with a lot of risk and a lot of complications. That doesn't mean they're not manageable. I mean, no one's doing cystectomies without zero risk. But do you know what those are? Do they compare favorably to national standards? And just engaging your provider around that. I think you always want to ask about clinical trials. That speaks a little bit to the comprehensiveness of the setting you're in. Most folks who are dealing with bladder cancer a lot are often also dealing and working in the space of clinical trials.

Stephen Riggs:

And so that's often an opportunity or an option that then a lot of patients may want to know about or are interested in. And so discussing that and seeing, if something's of interest to you, if they have it there. Or, hey, how do I look for clinical trials elsewhere? BCAN has a nice resource to search for this. And a lot of providers, including myself, will often help patients look for things that may be of interest to them elsewhere if I don't have something that suits their needs or desires. So other questions I just put in, I think these are big. And this has actually been published, so these are not mine. But I think they're just generic questions that are important to consider. Do I really need this test or

procedure? Listen, medicine continues to be very costly at an individual level and at a system level. And I think you need to be thoughtful about, hey, is this something I really need to do or not? And it can cause some discomfort or some quality-of-life issues just in the testing we do.

Are there simpler, safer options? Sometimes we forget to ask, is there something else I can be doing on the menu of choices, doc? Help me understand which one may be best for me, but also, what are those choices? What happens if I don't do anything? I think patients need to be more active about doing this. Just because we can doesn't mean we should. And sometimes we may not have... We are often compelled, I should say, as surgeons, as providers, to do. Sometimes doing nothing is a better option.

OTHER QUESTIONS TO CONSIDER

- Other Questions:
 - Do I really need this test or procedure?
 - Are there simpler, safer options
 - What happens if I don't do anything?
 - How much will it cost?



And you want to make sure you're able to engage your provider and let them know that you are comfortable talking about that space.

How much will it cost? I think you should always be engaging around that. I think that's often important on a patient's mind. Financial toxicity as well, known and probably under-discussed. And so I'm encouraging you not to be shy about thinking through that with your provider. Diversion types. If you decide you're going to have your bladder out, this concept can be really overwhelming. I suggest you break it up into two visits or at least two discussions with the first being, hey, am I having my bladder out? And then the second being, if I'm going to have my bladder out, what type of diversion am I going to do? Okay. Is it going to be a continent or an incontinent? Those are the two big buckets. And then within those two buckets, really, incontinent is what's an ileal conduit. And then the continent comes down to a catheterizable channel or a neobladder. This is very good information on the BCAN website.

Stephen Riggs:

And this is really one thing in the patient handbook that you can start setting yourself up within that information like, hey, I've got some information about the disease. And then in the back part of the book, they have information about these diversions, they have drawings. They have word retrieval that's on the sixth-grade level, and it's really important for health literacy. And so again, it's really hard to listen about a diversion if you don't have any weapons in your bag. If you have no concepts to even frame it, it's like talking a different


language on the first day and speaking it fluently, it's just not possible. And remember, this is a two-way street. I don't know if I said that at the beginning, but I'll say it again, this is not, I show up and the doctor just feeds you the meal. No one manages your healthcare better than you. You want to show up being an advocate for yourself. And so you want to help your physician help you. I will say that again. Help your physician help you. It's very important.

Again, we talked a little bit about this. This kind of falls in line with the cystectomy. Again, complication rates. How many types of diversions do you perform? What's the breakdown? Most people should know that. Like, "Hey, do I do..." 50% of my patients get continent diversion, 50% incontinent. What does that look like?

Stephen Riggs:

CYSTECTOMY: DIVERSION TYPES

- Concepts can be overwhelming
 - Consider breaking up discussion on type of diversion and decision for cystectomy into separate visits
- Which type do you normally perform?
 - Numbers: complication rates
 - Can I be put in contact with other patients you have performed this surgery/ diversion?
- Which is the best for me? Why?
 - What personal variables should influence this decision?



Stephen Riggs:

We put patients in contact with other patients I've operated on who have diversions. That's probably invaluable, right? I always say it's really easy for me to tell what it's going to be in life to have a neobladder, but it's a lot easier when somebody's telling you who actually has a neobladder. And I bet what they tell you are different. I bet what I tell you... Because I'm telling you what I think it is, what it looks like to me, and that may be very different. And then also, I get into the personal characteristics. And maybe beyond the scope of this, there are certain things that would make people want to think about neobladder or catheterizable channel over conduit or not. And some of those just may be their lifestyle, their dexterity, their beliefs about cosmetics and such. And so you're just going to want to think through that. And again, a lot of that you can start thinking through before the visit by researching really, again, in that BCAN handbook.

Stephen Riggs:

I just think some other general things to give you a sense of the quality of the practice or at least do they do this a lot? Am I in a space at a place that looks beyond the disease? Because the disease, it's not just a one and done, right? We're talking of a lot of things that, Mary, you're going to talk about survivorship, palliative care. Sometimes it's easy to cure the cancer in the moment. It's the long-term treatment or the iterative treatment, or the iterative anxiety, or the follow-up that's really the challenge or where really the needs are. And so just understanding if the place you are currently located is going to be able to support that. Listen, I don't think anybody's going to fault you for seeking a second opinion. I'm not saying you always need to do it. This is just going to have to be a general gestalt like, "Hey, I'm a little uncomfortable," or, "Hey, I'm not connecting with my physician or I'm not understanding, or I just would feel better." And asking your physician, if they were going to seek a second opinion, where would they go? That's a very appropriate question to ask. So I would encourage you to be thoughtful about that.

OTHER PHYSICIANS/OPTIONS

- Do you practice in a multidisciplinary setting?
 - Do you have medical oncologists who specialize in my diagnosis?
 - What is the role of radiation oncologists?
 - Should I see one? Who do you recommend?

- Should I seek a second opinion?
 - If so, do you have any recommendations on who/where?



Stephen Riggs:

Support groups. Again, getting a sense of what's the conference and nature of the setting. Most places are doing this a lot, we'll have support groups. We talked about putting you in contact with similar patients, especially that have the diversion that you're interested in, similar stage. That goes across the litany. That support is invaluable. And a lot of people have found reward in engaging with other patients. And you can do that on the BCAN website as well. And then what other additional support? Again, it's listed here. And I know Mary's going to talk a fair amount about this. This is on the BCAN website. Again, just some resources, some pictures, looking at that ahead of time, being a little thoughtful, being engaged, having some word retrieval. Right? And really setting yourself up for success.

A proactive patient probably has a better chance to probably get better treatment than one that's not, just because you're starting to really understand the landscape. So I can't say that enough.

SUPPORT

- Support groups
 - Do you have one?

- Can you give me contact information for other patients?
 - Especially those in a similar situation (Diversion, Stage)?

- Additional support
 - What do you offer?
 - Social work
 - Psychiatrist/Mental health professional
 - Nutritionist
 - Palliative Care
 - Genetic Counseling



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