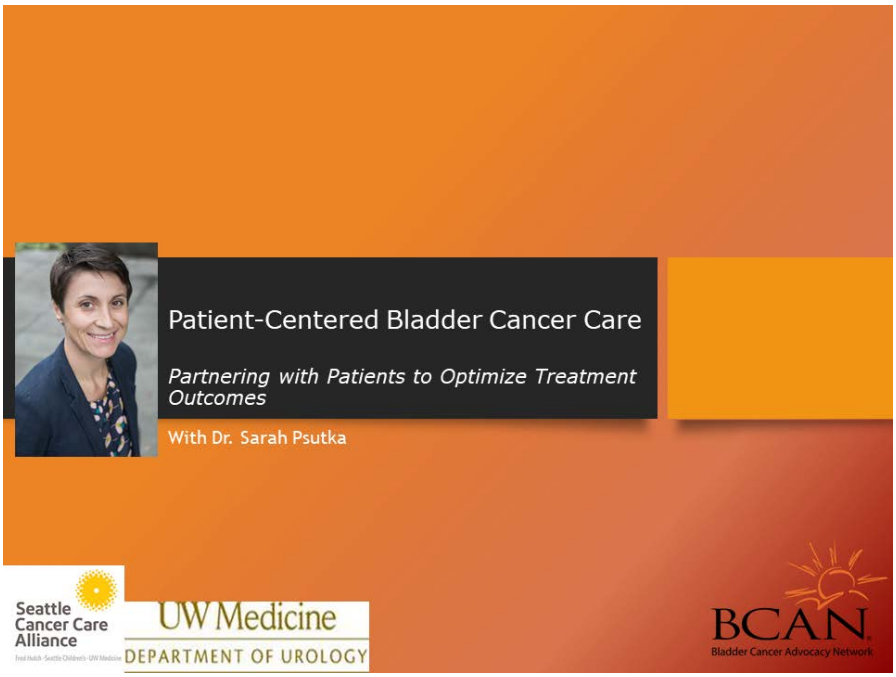

Patient Questions about Prehab and Nutrition

Stephanie C.: First question was really asking whether you had any knowledge about long-term effects of BCG and lung issues, such as infections or inflammation.

Dr. Psutka: That's a good question. I suspect that the person who is asking that is probably talking about it because they're worried about the fact that BCG is the tuberculosis vaccine, and it's a really astute question. I'm not personally aware of any strong evidence that BCG increases the risk of long-term lung infections. BCG, as you know, is locally given to the bladder for two main reasons. One is the medicine is actually taken up by the bladder cancer cells, and it's cytotoxic, it kills those cells, just by virtue of the actual sort of mechanism of the drug. It also activates the different levels of immunity within the bladder to kind of supercharge or weaponize the immune system within the bladder itself to ultimately fight the cancer and decrease the risk of recurrence and also progression.

In terms of systemic absorption that would impact long-term lung health, it shouldn't do that. It ultimately, if the drug is systemically absorbed, which can happen in a very small number of patients, that's actually considered a pretty significant complication. That usually happens if it's given at the same time as you have a urinary tract infection. That would be sort of one potential source of where you could have some long-term lung problems, but in general, that's not a commonly cited side effect.

Stephanie C.: There's another question, it's kind of specific but I think it does give you some insight, maybe you can provide some insight. In light of the harmful effects of

systemic chemotherapy discussed in this webinar, how strongly should one consider having a cystectomy prior to having muscle invasive bladder cancer. In my case, I'm an otherwise healthy male, 45 years old, 6'3", 185 pounds who exercises regularly. I've been diagnosed with high grade T1 and high grade CIS. After the third TURBT was performed six weeks following an initial six weeks of BCG immunotherapy. Should this be a consideration for this patient?

Dr. Psutka: Yeah, that's a good question. That's a bit different because that patient, thankfully, at this point, doesn't have muscle invasive disease, but clearly has very aggressive non-muscle invasive disease. Actually, our recommendation for that patient would be an upfront cystectomy without chemotherapy. We don't usually recommend chemotherapy before bladder cancer surgery or radical cystectomy unless that patient has disease clearly documented in the muscle, so stage two disease. For patients who have TI high grade disease or recurrent BCG refractory CIS, the treatment, the standard of care would be an upfront cystectomy, and that would be the recommendation. Then, if after surgery, the final pathology shows that there is cancer, it's a higher stage, that's a good opportunity to talk to your doctor and see if, one, you might be a candidate for a clinical trial, there are a couple trials right now, looking at using chemotherapy or immunotherapy after radical cystectomy. But it's not something we would generally offer to that specific patient before cystectomy.

Stephanie C.: Here's another question. First, having a patient advocate, in my case, my wife served in this extremely important role, and the value of that? Then, second, would it have helped for me to visit with a nutritionist prior to surgery instead of afterwards because I lost 25 pounds, but might have been able to avoid it? Third, similarly, would it have helped to have pelvic floor physical therapy prior to the radical cystectomy because it was needed post-cystectomy, and thus a pre- and post-comparison would have helped me along the way, providing both bases for pelvic floor muscle strengthening before radical cystectomy?

How does the patient go about asking for these things or identifying patient advocate or getting to see a nutritionist prior to therapy if your doctor's office isn't suggesting that? How do you bring this up? What about that pelvic floor physical therapy? What's that role for patients? I know you have a physical therapist there in the Seattle Cancer Care Alliance, so can you talk a little bit about how people would access prehab elsewhere?

Dr. Psutka: This patient has brought up some really important points. If you're going through a radical cystectomy, having an advocate or somebody who's with you to help you voice your concerns, especially if you're not feeling well, is key. This is what I'm talking about, about rallying the calvary and making sure you've got a close friend or a family member who you trust, who you can be authentic with and not be trying to be the strong person who's not complaining. You want somebody who can really go to bat for you and say, "Hey, you know what? I'm recognizing that this person who I know really well is not feeling well or looks different in this fashion." I think, in general, just making sure that you are adequately supported is critical.

If you don't have somebody that you can think of, talking to your physician about that so that they can maybe have social work meet with you, sometimes we can have an extra set of ears. I think it's just, in general, I always tell patients please bring your family to these meetings because it's so hard to remember everything that we're going to talk about anyhow, having that family member who's there, taking notes furiously while you're just trying to engage with the doctors is a key and very helpful thing to do. Now, how do you advocate for yourself and say, "Hey, I need a nutrition evaluation or I need a pelvic floor PT eval or I need a PT eval?" That's a tough one, but I think basically you just can't be afraid to talk about what you need. This is the moment where you have to advocate for yourself.

Now, one thing that's really interesting I think the nutritional sort of changes with bladder cancer. We're just starting to really understand. I know that seems kind of crazy that it's 2019 and we're talking about that. But I will tell you that a lot of cancer centers now are actually engaging patients and doing nutritional assessments or nutritional screening prior to cystectomy to identify patients who might be at risk for major weight loss after surgery and getting nutrition on board early. A lot of cancer centers do have cancer center nutritionists that are available. I certainly check in with patients all the time about their weight loss and how their diet is going because I think it's really key.

You should not be afraid to ask and say, "I think I actually need to speak with a nutritionist." Now, one thing you brought up though is that you lost 25 pounds after surgery. That's also, unfortunately, not uncommon. A big part of that is probably muscle mass loss. Because patients, after this operation, a lot of times don't get active very quickly, they don't feel well enough to do so, lying in bed, doesn't take long for muscles to waste or to sort of melt away when you're not being active on a daily basis. This is where I say that tough love piece kind of comes in, but basically, we really do need to get you kind of up and moving after surgery to try to avoid some of that.

The second part of it, of course, is most people don't move very well after surgery, whether it's related to delayed return of bowel function or just food not tasting good. Having that nutritional evaluation is pretty critical. Definitely, I think that, to answer your point, how could I have gotten a nutritionist on earlier, I think you have to ask for it. In general, this is where you do need to advocate for your own need, but also, I think just having a higher awareness as a patient to talking to your physician who's integrating all of these other aspects of care is really key.

In terms of pelvic floor physical therapy, especially before a neobladder surgery, I think it is important to do it upfront. I guess you can liken it to what we tell patients who have prostate cancer to do before they have their prostates removed, or women who are about to have a child, we do start talking about those Kegel exercises and learning about pelvic floor control, muscular control early. I think, ultimately, hindsight is 20/20. It's hard to say look back and say, "You know what? I would have really benefited from this before," but I think it's something that your question, hopefully, is helping other patients who might be making these decisions understand the important of engaging. It's just the same as you should talk to your physician about your sexual health, your fertility interests, all of those things that might be tough to talk about, potentially embarrassing,

just because they're not things that we commonly talk about in society. This is the moment to just let all that go and say, "Hey, I need to really kind of hunker down and get to the nitty gritty around this," and especially say, "I'm worried about my recovery, is there something I can be doing now to prepare my body for this operation?"

Stephanie C.: Well, thank you so much. What a great answer. For people who have some interest in learning more about nutrition, I invite you to visit BCAN.org, and look for our nutrition page. We have some conversations videos where Diane Quale, our co-founder, is interviewing a registered dietitian who's also a scientist. We also have a chef who, he also happens to be an oncology nurse, preparing some recipes. There's some tasty foods on there, but also a lot of good information for things that you can do throughout your treatment to help make sure that you're getting enough adequate nutrition.

So, thank you so much, Dr. Psutka. I would like to thank our sponsors again, Bristol-Myers Squibb, and EMD Serono, Pfizer, Ferring, Genentch, Photocure, and Merck for making the Patient Insight Webinar series possible.