

Veterans and Bladder Cancer:

**A conversation
about Veterans
Administration
hospitals and how
they can help**

Lisa Loftis, RN, OCN



Stephanie Chisolm:

Okie doke. Well, there's one comment that came in. Please stop saying that bladder cancer is not a presumptive condition. We know that it is. It is just not necessarily included under the PACT Act, and that's one of the things that BCAN is really trying to do because we know that some veterans are able to get coverage when they've been in, what they call, the modern warfare situations where they've been exposed to things like burn pits, but it's not a simple thing. You have to come up with all kinds of paperwork and all kinds of proof and everything. So we're really working to try to make that a little bit easier to make sure that, just like exposure to Agent Orange as a Vietnam era veteran, if you were in country, it's presumed that your bladder cancer might have been related to that. So you get the coverage. We want to make sure that it is in fact covered. So that's a big deal for us.

Stephanie Chisolm:

There was a comment that said you left out the negligence at Camp Lejeune with poisoning Marines and dependents. Yes, that was one of the things we talked about. I talked about it very briefly, but yes, that is certainly one of the key issues. The things that were contaminating the water supply in that whole area impacted not only our active duty members, but also their families that were stationed there that were showering and drinking all of that water. And certainly you can't open your email without seeing something about a lawyer that's trying to get you what you deserve as a result of that. But we know that that is something that there are funds out there available to do that, and there are many occupational exposures that veterans would've had, even sometimes working in buildings where there's a lot of engines running, things like that have led to many different kinds of cancers.

Stephanie Chisolm:

And so all of these things need to be documented and corrected by the VA because people have done this because they were doing their jobs, and it's unfortunate that all of these situations have led to cancer that they might not have been exposed to those particular things. So I'm just looking to see if there's any questions. I see a number of people have put in some fact sheets, so thank you. We'll look at those fact sheets and if they're really going to be helpful, we can add them. There is a question, do you know, does the VA do any genomic testing when they suspect that there's a genetic link, something like

perhaps Lynch syndrome, do they do the genomic testing on the tumor right in the VA or do they have to send you to another institution for that?

Lisa Loftis, RN:

I believe here at our VA we can actually take care of obtaining what's needed and then we send it off for the interpretation, and that takes a few weeks. But yes, that is something that we do offer.

Stephanie Chisolm:

There's another question about blue light cystoscopy, which uses a medication called Cysview that's put into the bladder that soaks into the tumor itself. So when they turn on the blue light on the cystoscopy camera where they're shining the light inside the bladder, they can see the tumor glowing hot pink. It's expensive. Is it in many of the VAs that you know about?

Lisa Loftis, RN:

We do not have it here, and I do not personally know of a VA that has it, but that's not really something I had looked into to see if I could find one that does. So that's an interesting thing that I'll look into further.

Stephanie Chisolm:

Yeah, I'm going to venture guess that it is slowly gaining in popularity around the country, but even there aren't always in a large academic teaching hospital blue light systems because it is expensive. And if they're not seeing a benefit to doing that, they wouldn't necessarily do that. A lot of urologists will tell you that I can see everything just fine with a regular cystoscopy. They also have narrow band imaging, which looks at different types of blood flow to indicate where a tumor could be. So it really is very much an expensive treatment option that is not available everywhere. So I'm not sure. It would certainly be something to ask your VA system about. So if you had a question, find out if they do have it, but I don't know that they have it in every VA system certainly.

Lisa Loftis, RN:

We definitely don't have it here and I've not heard of it being anywhere else.

Stephanie Chisolm:

Okay. All right. Let's see. I had muscle-invasive bladder cancer treated through a clinical trial outside the VA. Now that I'm under monitoring with a neobladder, so their bladder was removed. They have a neobladder. The VA provides me with diapers for my incontinence at no cost. Is there anything else the VA might be able to help me with and who do I talk to about other possible VA cancer-related benefits?

Lisa Loftis, RN:

That would probably be something a social worker could help with, and that social worker could be contacted through the primary care provider at the VA or through urology. And they should be aware of programs and how to get that set up and get it started.

Stephanie Chisolm:

Okay. All right. Here's a question, and this applies not only to where this individual is, but almost anywhere. Is there anything I can do here in Atlanta to help vets get the information from BCAN? Absolutely. That's really easy. BCAN is willing to send information anywhere. What we need to just do is

find out where to send it. So, if you're interested in getting a starter pack of materials to take to your local VA where they can order more information free of charge, we'd be happy to send that to you.

Stephanie Chisolm:

Looks like Steve was saying that the Milwaukee VA has something, and I'm guessing maybe it was about the blue light. I'm not exactly sure. So I think are there any other questions that the people online have? Yes, Steve, thank you for clarifying. So, it looks like there is a blue light cystoscopy available in Milwaukee, which is a little bit of a drive from Albuquerque.

Lisa Loftis, RN:

But sometimes we have patients who are willing to travel. Sometimes we can even assist with the travel depending on the qualifications and the needs.

Stephanie Chisolm:

Great. Great. Well, that's really good to know. And again, so think about this, look for in your VA system, the cancer coordinator, especially the one that's dealing with urologic conditions, and that person should be able to make a referral to the social work department or perhaps some of the other services that might be available to you within the VA. So, any closing comments? Lisa, do you have anything else you wanted to share because this has been really helpful.

Lisa Loftis, RN:

I just want to say that the cancer care coordinator certainly can't do everything and doesn't know everything, but we're a wonderful starting place because the things we don't know, we have a lot of resources and people we can reach out to. So the biggest benefit is instead of calling and trying to figure out who to talk to and talking to someone different each time you call and not getting anywhere to actually check back to follow up, by finding the cancer care coordinator, you've got a one-stop shop. Whatever I don't know, I try to get those answers for you and then I call you back with it. I also tell my patients, if you've not heard back from me in the amount of time you would hope, don't be afraid to call again. Maybe I don't have an update for you, but sometimes you just need to hear that. And I'm happy to take calls, happy to explain things and happy to, if nothing else, just be frustrated with you until we can get it figured out.

Stephanie Chisolm:

Great. And if it's a big thing, it's a national thing. BCAN is here and we know that Vietnam era veterans are covered because of that presumptive condition that they were exposed to Agent Orange or one of those herbicides, and then that would give them the benefits that they're entitled to because of that exposure to these toxins. We're working to try to make sure that the PACT Act where it's looking at environmental toxins in modern warfare includes bladder cancer. That's on our agenda and a promise we're trying to put out there for our veteran community to make sure that we want to ensure that you also are getting the care that you need and the services that you need. Other than that, the environmental exposures at places like Camp Lejeune are pretty well documented and you just have to go and seek care. This has been really informative.

Stephanie Chisolm:

I did not realize there were as many services as you've mentioned at the VA. I know some of the bigger hospitals often have other programs and services, even things like massage therapy and exercise and things like that. It's nice to see that some of that is coming to the VA and being implemented at the VA

for our most vulnerable that have given so much and then end up with bladder cancer as a result of their service. So it's wonderful. Thank you, Lisa. This has been terrific.

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