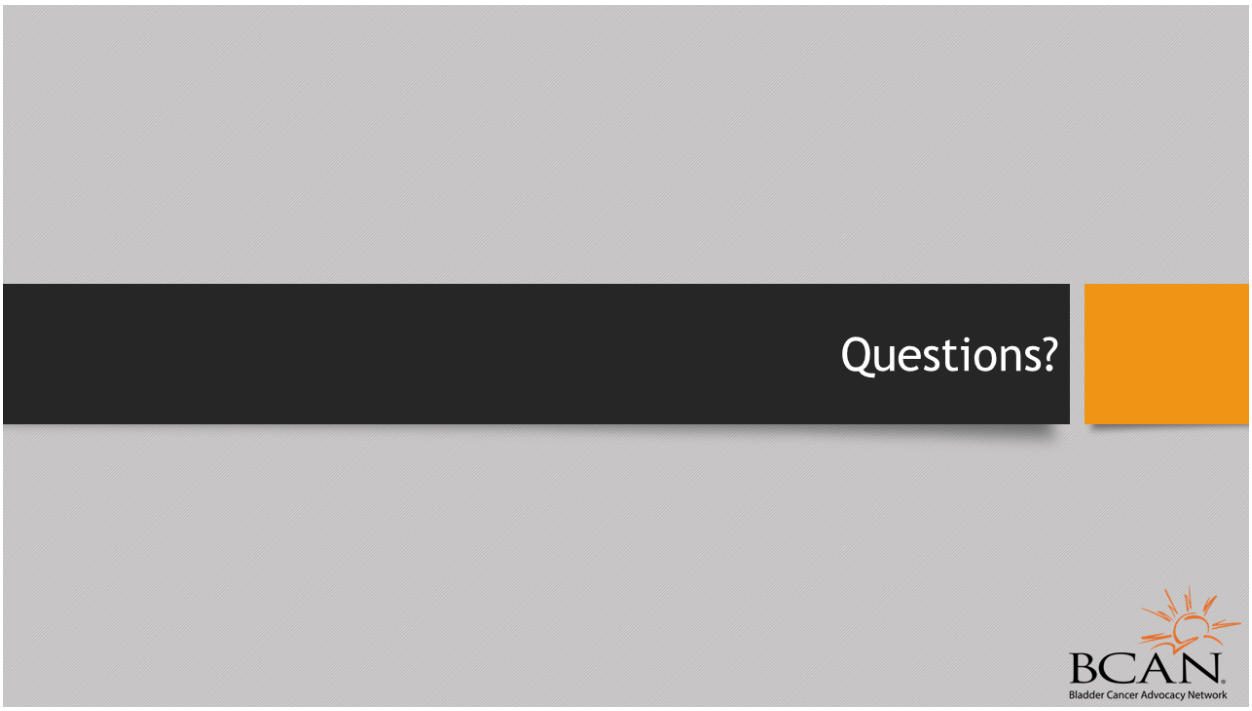

Commonly Asked Questions about Palliative Care

Stephanie: Yeah, absolutely. Please type in all of your questions. I have to say, Libby, that you're probably one of the most preemptive question answerers I've ever seen because every time I wrote down a question, you had answered it on the next slide, because I try to also come up with some questions as well. We do have one. Let's see. Let me just extend this so I can read the whole question at one time. "What are the best practice tools that palliative care programs ought to make available for primary and secondary symptom management: meditation, acupuncture, visualization, cognitive techniques, counseling?" I'm going to toss in is there a role for medical marijuana use in all of that? Can you talk a little bit about some of those things? How would somebody know to ask for certain things to understand that perhaps acupuncture or counseling or visualization assistance might really help them? How would they know what to ask for if the doctor is not as well-informed as you?

Libby: Well, that's an excellent question. I'm not sure how concrete an answer we'll have because I do think that that varies depending on the specific resource in question, and part of that depends on ... There are a few logistical things and a few research or data-driven reasons for that. One resource that I'd like to direct you to that I think is really interesting, that palliative care physicians love and that is available for free, that can help in trying to think about the value of some of these techniques, services, schools of thought, et cetera, is something called Palliative Care Fast Facts. It's a really cool resource that has had a home with different institutions or organizations over the years.

But if you do an internet search for Palliative Care Fast Facts, then you'll see that there are different fast facts about hundreds of different topics. That's a great place to look at what do the palliative care docs think about meditation, and that could give you a hint about when it might be helpful. Same thing with acupuncture. I know that there are palliative care fast facts about a lot of these resources.

Truthfully, what is being shared with the fast facts is existing medical data, but that is really what clinicians use to guide when it's appropriate, because we want to make sure that we're offering the right medicine or the right treatment or technique or practice for the right patient at the right time. Those are some really boiled down ways to look at, "Okay. Well, what does the research show that meditation is helpful with and who and when?"

I don't think there's any other really clear repository that would point you to specific resources, both conventional Western medicine and complementary things like, again, meditation, visualization, Reiki, et cetera. But that is one resource that I can direct you to that is probably the most centralized way.

I also know that there are some ... I'm trying to think about what are some of the other resources that exist and are housed within palliative care that might provide some data about these different resources. I'm trying to think about what that might be.

In my community, there is a community support organization called Turning Point that is local to the Kansas City metropolitan area. But another resource that I think often does post either educational or actual just experiences to learn and/or practice on a regular basis, some of these skillsets and techniques would be something like Gilda's Club.

Gilda's Club was founded in name after Gilda Radner, who passed away of cancer. But Gilda's Club, they call themselves basically an organization that's for anyone whose life is touched by cancer.

Gilda's Club locations exist all over the country in the US and have calendars that are chock-full of not only bonding times and support groups, but also times when they will have acupuncturist come in to speak. They will have yoga classes. They will have someone who will help with therapeutic touch or Reiki and things like that. I think that's another national organization that might be able to direct one to more local resources.

Medical marijuana, the last remaining question, and that, I would say, is very controversial. I think the reason that I think of it now as being controversial is I think there is still some ... Because it is considered illicit on a federal level, I can understand why some providers would feel uncomfortable about it.

But I actually think just the lack of really high-quality data to help guide people like oncologists and palliative care docs and pain management docs who are hungry for that data to know exactly when it's the right resource for whom. Is it the right resource and for what problems is it helpful? That complete lack of ... Not complete lack, but pretty great lack of high-quality data does lead us to being pretty uncomfortable. I will say I think the American Society of Clinical Oncology is coming around to that, and there are supportive care guidelines that are being published. One of them, I think, is going to be about medical marijuana, medical cannabis, et cetera, to try and give clinicians some information about how to prescribe it for patients to use it and when and for what and all of those things.

But I think there is a big lack of that, but it's coming. The American Association of Hospice and Palliative Medicine also is very eager to provide that data to everyone in the medical community and in the patient and caregiver community, too. I think you'll hear more about that.

The last thing I was going to say is I think the general palliative care philosophy is to ask us about a given resource. If either we aren't the most knowledgeable people or we don't have access to it or we're not

the right people, we will help you find it. We would rather be the go-to person and figure it out on the backend. That's our general philosophy.

Stephanie: Okay, so this is asking something a little more specific. One of the attendee's father has bladder cancer. He's 92 years old and in great medical condition. Can you speak to some options for palliative care for somebody who is also dealing with all of the other comorbidities of being older?

Libby: Absolutely. I am so blessed to work as a part of a urologic oncology team, that my surgery coworkers often will refer these patients sort of like your father to me to help look at the big picture and make sure that we all understand what is the most important thing to my patient, to our patient, and what medical care matches up with that.

Actually, while it seems almost backwards to meet a surgeon and then, before any other treatment planning happens, to meet with the palliative care doctor. It feels like you're skipping to the end in some ways of something that would be decided based on the treatment that's chosen.

A huge aspect of palliative care training is actually communication. What we do very explicitly is what really still clinicians do implicitly, which is get to the heart of, well, given what we're facing, what matters the most? What does a good life look like? Where is the line? How are we going to know that we're achieving an acceptable quality of life and making sure that the medical care matches up with that?

I think it depends on the area of the country and the practice study in which your father is receiving care. But I think this is also dependent upon the urologist in question.

But I personally see patients in this situation for preoperative counseling, because I think it's just so important that we are taking a step back if someone is very medically vulnerable, regardless of age, but a nonagenarian typically will be somewhat medically vulnerable. We want to make sure that we know what they care about, what they're willing to risk, and what they're not. Then from there, figuring out what does make sense and what would be a value-add for their medical care and centering their medical care on that.

I think, again, palliative care consultation is very appropriate. A lot of times geriatricians do a lot of primary palliative care. Geriatrics oncologists, I think, do a lot of primary palliative care, meaning they may not have formal training in palliative care, but are experienced in looking at some of these issues.

I think a geriatric oncologist, a geriatrician, a palliative care doc who really, really know your dad would be great people to sit down with and try and look at the big picture and figure out where the line is if there isn't a palliative care resource locally.

Stephanie: I just wanted to make a comment. There's somebody on here who said, "Why doesn't my oncologist or urologist tell us about palliative care? Most of us don't know when or why this may help us." Her husband has stage four cancer and is in pain constantly with neuropathy and doesn't have quality of life. I really think that you addressed that throughout your conversation. I wanted to end with one other question that I think is really promising and interesting. Is palliative care helpful for people dealing with the anxiety of having bladder cancer recurrences even if there's currently no evidence of disease?

Libby: Wow! That is a really insightful question. Yeah. I think palliative care can help. But to be perfectly honest, again, because we work in such an interdisciplinary team, one of the ways that we, at least in my palliative care practice with my colleagues, work is to try and figure out, again, what is the barrier to the good life? Or someone who is really burdened by the anxiety of recurrence, which is, oh my gosh, it is very burdensome, and I wish desperately I could take that away.

The group who I think would probably be the most helpful either ... Palliative care, we might be able to help, but the people who I would turn to if I were anxious about a recurrence personally would be a psychologist, because there are a lot of different schools of thought in psychology. But some of that is trying to reframe things and come up with strategies for managing anxiety that are fruitful and basically prevent the anxiety from being so pervasive.

Anxiety is a very modifiable problem, and psychology care is excellent at that. I think, depending on what the local resources, palliative care, we do have expertise in coping and support. Absolutely. That's part and parcel of what I do, and so I wouldn't say that palliative care wouldn't be helpful. But if it were me, and I had one tool to use in that situation, I would see a psychologist.

We have an onco-psychology program here, but this is bread and butter for people who are practicing psychologists. I think this is a very modifiable set of burden that could certainly be alleviated.

Stephanie: Well, Dr. Wulff-Burchfield, this has been an amazing program. Thank you so much for joining us this evening to really help everyone understand more about palliative care. I'd like to, once again, thank the sponsors of our Patient Insight Webinars, Bristol-Myers Squibb, the EMD Serono-Pfizer partnership, Ferring, Genentech, Janssen Oncology, Merck, and Photocure.