



Speaking Up About How You Really Are Feeling

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Andrew Schorr:

Laura, one of the things that people worry about or feel, are the side effects of some of these powerful medicines that are used. What would you tell folks about speaking up for themselves, and really, if they're feeling tingling or nausea, that it's okay to speak up about it?

Laura Beemiller:

They can't help if you don't let them know what to help with, and that's why I think it's great that you include the families and support people when you see patients because, you're right, I'll hear patients say, I don't want to bother them that I've got a little bit of nausea. I say, well, why not? That's what you paid your co-pay for. That's why you're coming to see them. That's what their job is. You don't go to a refrigerator store to not talk to somebody about what's the best brand to buy in terms of a refrigerator, so why are you coming to the doctor's office to tell them everything is great? Well, no. You tell them what's going on. And if everything is great, fantastic, but if something is bothering you, that's your job to tell them. They can't manage something—they can't help out if you don't let them know.

Whether that's, I'm not sleeping well, I'm up six times a night, my feet are tingling, I'm having trouble carrying things, my fingers are numb, I've got some nausea, whatever it happens to be. I can't focus. I can't concentrate at work. I'm an accountant and those numbers are just kind of getting jumbled. I'm fighting with my spouse more. I am short-tempered. Or, you know what, I just don't feel like doing anything some days. Those are so important to tell your physician,

because they can't help manage anything if they don't know. And you just trusted them to do everything else for you. Why would you not trust them to help you in every aspect of the disease?

Andrew Schorr:

Hmm.

Dr. Lonial:

"Everything is great" visits are okay, too. I will say that.

Laura Beemiller:

That's good also.

Andrew Schorr:

Dr. Lonial, there are things you can do for fatigue, for nausea, for bone concerns, right? I mean, you have an arsenal for that, too.

Dr. Lonial:

Yeah. I think depending upon the specific side effect, and I think the one that is most critical for us to know about, is the neuropathy-related side effects, numbness and tingling in the hands and the feet, which is often preceded by achiness in the legs. Achiness often precedes patients getting pretty significant neuropathy, and it's usually very subtle. I just feel like it hurts like I've been working out a lot. I just feel like there's something in my calves or my thighs that's not letting me do what I normally do, and that to us is often a sign that in the next cycle at current dose and schedule we're going to see something, in terms of neuropathy. Those are kinds of subtle things that, had we not heard, we won't make interventions, to adjust the dose.

In fatigue, often certainly, with drugs like Revlimid (lenalidomide) or some of the HDACs, that can be a dose effect. Sometimes you need to go down on the dose. And while we think we know what the doses are for all of these medicines, you are individuals. Your body metabolizes these drugs differently than the person next to you, so there are subtleties to each of you separate from the disease, that help us to tailor our treatments a little bit, and we do need to get that kind of feedback to adjust or to make appropriate supportive care changes.

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