



Building Effective Partnerships: Should I Record My Medical Conversations?

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Jack Aiello:

Kristen Carter, so I have a question targeted for nurses, I think, and that is as a patient how do I communicate or partner best with my doctor on treatment decisions? What do you find that works regarding being diagnosed with something called myeloma, which you've probably never heard of, hearing all of these overwhelming terms of IgG and too high a level of protein, which sounded always good to me, how do you—how should patients be interfacing with both their doctors and their nurses?

Kristen Carter:

Well, all my patients have my cell phone number so they tend to call me if they have any questions, but I always tell my patients make sure you write down questions because you know as well as I, when you get in there in front of a doctor who's got a whole list of patients for the day and they're seeing you, they're giving you all this information, and I always call it the deer in the headlight look from the patient because they're brand new. Writing down questions that you think of is always very important.

Having a family member that's right there with you, that maybe they're thinking of things that you haven't really thought to ask. As we're going over side effects and treatment decisions, taking notes is very important because I always have patients, and I will have patients four or five years later, go, remind me, what is my subtype. And we go over this every time and you go, I thought we were doing a really good job of educating. So if you don't understand

something ask to repeat the information. And I always repeated back to the patients and have them repeat it back to me. That way I can see if they really understand what we've gone over.

And just make sure there's an open dialogue. I always tell my patients don't suffer in silence. If you have a side effect we need to know about it. If there's something you don't understand we need to know because that way we can ensure that you're not only understanding but getting appropriate treatment, and if there's side effects that we need to know that we can make adjustments.

Jack Aiello:

The doctors especially seem very busy and sometimes in a little bit more of a hurry than you as a patient want them to because it's difficult for you to absorb the information that they are providing you. How do I slow them down? How do I make sure that I do understand what they are saying, Kristen?

Kristen Carter:

Having a list I think is a really good way to slow down.

Jack Aiello:

I agree.

Kristen Carter:

I have patients that come in and they'll have their list, and I usually go in first. So I work for Dr. Van Rhee, and we have—we manage, actively manage about 700 myeloma patients from all over the country. And so these patients will come in sometimes a thousand miles to see us. We don't want them to be shortchanged on their time because they've travelled all the way from Arkansas, and they've done all the workups, and we certainly don't want them to feel like they didn't get the time after spending money and travel time to get to our academic center. So usually I will go in first and answer any questions that I can answer, and the list is always so important. And we'll say, sit back down, we have the list, and what I can't answer the doctor will answer.

And again I do provide an e-mail or a cell phone, and I have patients that will email me a list of questions that I can turn around and answer for them if they didn't get the information. So I think definitely having a list, having family support if it's available to come with you, I think that does kind of slow the doctor down.

And if you don't understand something you just stop the doctor before they leave the room. Hey, I didn't understand that. You are your own patient advocate, and you've got to make sure that you speak up if there's something you don't understand or if there's something you're not sure about. Or if there's something you're not comfortable with in the treatment planning you need to vocalize that with your doctor or nurse.

Jack Aiello:

Dr. Krishnan or Dr. Richter, any other things that patients have done when you meet with them that you want to pass along to patients on this call?

Dr. Krishnan:

I think the one thing to be honest I've started writing down stuff that the patient said myself because a lot of patients start getting focused on taking notes, and they don't want to miss anything, but then it's very hard to absorb and take notes at the same time. So having someone with you to be your scribe is very helpful. Some doctors, you know, don't mind patients recording them. Some are less comfortable with that. So that's something else you can consider is asking your doctor if that's an option.

I think the other important thing to remember is all the information we get, especially when we talk about transplant, that's not going to be the first time you hear it, so don't—it's not like you need to understand it all right now. This is just information gathering, and that information is going to be repeated again and again by multiple different people.

Jack Aiello:

And Dr. Richter?

Dr. Richter:

I would encourage patients that if they want to record to ask first. We've definitely had some patients where all of a sudden their purse starts beeping and I ask what that is, and they say, oh, I've been recording you. I have no problem, and most of us don't as long as we're told about.

I think it's also—as much as the care teams set goals for each appointment it oftentimes can be a good idea for patients to set goals of what they want to get out of the appointment. So not every appointment is going to be soup to nuts, everything from the diagnosis to the whole treatment, but this appointment, what is going to be my next step with treatment and how do I deal with my toxicity. This next appointment I want to find out about transplants. So setting a couple of discrete goals I think really helps both sides to accomplish what we need to.

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