

What Patients Want Their Doctors to Know

Patients' quality of life can be positively impacted when doctors are mindful of three things about patient-doctor interaction.

By Whitney L. Ward



ONE OF THE most basic human needs is the desire for human relationships. But, relationships can be difficult. To make them work, there has to be the perfect blended recipe of a dash of giving and a pinch of taking. Yet, despite the blood, sweat and tears, without special people in our lives, we would feel a void.

For those of us with a chronic illness such as a primary immunodeficiency disease (PI), doctors are included in the list of special people. We PI patients may not have asked for these men and women with white coats to play a significant

role in our lives, but for better or worse, we need them. Our immune-suppressed bodies depend on specialists, which can be frustrating, especially when it seems we are just a number or a medical case being shuffled through a revolving door of other medical cases. However, mutual admiration and respect between doctors and patients is possible when doctors care about their patients' concerns, show compassion about any fears they may have and understand the three things patients want their doctors to know about patient-doctor interaction.

1) Patients want a relationship with their doctors that has depth.

There are two types of doctors. There are those who have conversations with their patients about life and what exciting things they are involved in. And, there are those who just get down to brass tacks: “This is how you’re doing, and this is what needs to be changed in your patient care; see you in six months.” It’s clear to me which doctor/patient relationship has a stronger connection. The National Institutes of Health estimates 25 million to 30 million Americans are living with a rare disease, and the National Health Council estimates 133 million Americans have a chronic illness. These Americans are a blended community of men, women and children who need compassion and assurance during scary unknowns and uncertain futures. While there are doctor/patient lines that can’t be crossed, when doctors want to invest in their patients and get to know who they are aside from their medical cases, it eases the patients’ fears and allows them to have another level of trust in the care they are receiving.

I was 6 years old when my PI began to significantly affect my health. It was a new and frightening experience, but the relationship I had with my rheumatologist helped with my anxiety. At every visit, he would sit me on the examining table, look at my mom and say, “OK, mom, you just sit over there and stay quiet. Whitney and I need to chat for a few minutes.” And, that’s what we did. We talked about school, shoes, clothes, how my sister was doing — how life was outside of my disease — and because of this, I was comfortable and ready when it came to discuss my health.

Doctors who take the time to interact on a personal level with their patients make a difference in their patients’ lives. When a milestone happens in life, these doctors are on the list of people patients want to share it with, because they celebrate with them. The doctors who make the biggest impact are the ones who not only care about their patients’ medical lives, but also their quality of life.

2) Patients don’t want their dreams belittled or diminished.

When patients tell their doctors they are going to attempt to do something that may risk their health, the doctors’ initial response may be to diminish or belittle their patients’ dreams. Patients need to understand their doctors care about them and their well-being, so their response stems from fear.

Doctors are human, too, and not only do they remember when their patients were at their worst physically, they also have the medical knowledge of what could happen to their patients’ health if they take risks. That being said, doctors have to remember their patients know when their bodies are weak or strong. They know when they can push their bodies and when their bodies have said, “That’s enough!” The millions of people living in this country with a disease can make a difference and impact this world if they are encouraged to not allow their disease define their abilities and ambitions. If patients aren’t allowed to try, they will never know what limitations they can surpass. For those with a chronic illness, that type of fulfillment and purpose is important.

My immunology nurse practitioner once told me with a chuckle: “Whitney, your doctor and I don’t want you to live in a bubble, but some of the things you attempt to do scare us to death!” I can’t tell you how happy her comment made me, because it showed me I’m truly defining my disease. And, even though it made my doctor nervous, he was beginning to understand how important it was to allow me to dream.

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3) Patients don’t want their doctors, in their excitement about a teaching moment, to treat them like a human petri dish.

At one time or another, most PI patients have heard one of these phrases from their specialist: “You aren’t textbook,” “We talk a lot about your disease with our colleagues because it’s so rare” or “You’re very unique.” Fact of life: Most PI patients will be “teaching moments” for doctors because, in

the medical world, we aren't "horses," we're "zebras." All PI patients understand this.

However, when specialists bring in another colleague, resident or fellow so they can show them their patients' medical abnormalities, it sometimes takes a toll on these patients' emotions and self-esteem. All patients know the routine: The doctor comes in the room, tells the patient he or she looks good, and then asks if the resident or fellow can look at the patient's deformities. When this happens, patients often wonder, "Are they trying to tell me I look 'good' for someone with a rare disease that produces rare abnormalities?" According to a National Health Interview Survey conducted by the Centers for Disease Control and Prevention in 2018, 68.2 percent of Americans see a doctor every six months or less. Who wants to be reminded *that* frequently that the embarrassing blemishes or noticeable deformities aren't "normal"?

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I have a specialist who has been treating me for almost 17 years. We have a great relationship, and I know he truly cares about my well-being. But, when I first began seeing him, tactfulness wasn't his strong point. Nearly every appointment, he would ask to see the warts on my feet that my immune-compromised body produced. When I agreed to his request, he would back away from me, standing as far from me as he possibly could with his hands behind his back, craning his neck to get a good look at my "abnormal feet."

One day when I was in my late teens, he asked, "Whitney, can I see your feet?" Of course, I obliged, but on this day, I was quite fed up with his insistence of observing my "scientifically abnormal feet." I turned my back to him to take my shoes and socks off, and for the first time in our doctor/patient relationship, he was standing right beside me, but I didn't know. I took the first shoe and sock off without a hitch. I then took the second shoe off, but then had trouble with my sock. It was stuck. I pulled and pulled, and then finally yanked it off as hard as I could. The sock flew behind me and hit my doctor right in the face. I giggled, my doctor was shocked and offended, and my mother looked like she was about ready to clock me. Today, my immunologist and I look back on the incident and laugh. But, that awkward incident was a breakthrough that made my specialist realize he needed to treat me with more compassion and not as a science experiment.

Doctors aren't intentionally malicious, but they are scientists. And, in their excitement to potentially learn something from their patients' condition, they sometimes forget their patients are insecure and self-conscious about their medical deformities, so their doctors' teaching moments make them feel like a medical oddity on display. Patients understand teaching moments are essential for scientists to have medical breakthroughs so more people can be helped. However, doctors need to remember that during those teaching moments, they should go the extra mile to make patients feel comfortable, understanding the vulnerabilities patients might experience when being exposed in such a way.

Seeing the Whole Person, Not Just the Case

PI patients and others with chronic illnesses rely on their doctors to help improve their quality of life. This relationship is not a preference; it's a necessity. When doctors look past the medical case and truly see the patients sitting across from them, they understand that the care and treatment they provide their patients can give them the ability to live life to the fullest, filled with dignity and purpose despite their patients' diseases. ■

WHITNEY L. WARD was not only the first person in the world diagnosed with MAGIS syndrome, she had the honor of naming the new primary immune deficiency. MAGIS means "more" in Latin, and Whitney hopes to instill in her readers the message they are *more* than their disease. Find out more about Whitney's journey at www.whitneylaneward.com.