Improving Communication With Your Melanoma Care Team [VIDEO]

Watch experts offer tips, tricks and strategies to make sure patients and caregivers are proactive partners with their cancer care team.

March 12, 2024 By Melanoma Research Alliance

Good communication is always challenging but can be especially so when you are undergoing treatment for melanoma. That's because navigating our modern health care system is often an exercise in decoding complex jargon and knowing the right questions to ask while managing stress and other strong emotions.

"Communication is hard—whether you're a patient, clinician, nurse, or administrative person who answers the phone," said Nadia Jabri, a patient advocate and caregiver for her mother who passed away due to melanoma. Jabri joined Dr. Anna Pavlick, an oncologist at Weill Cornell Medicine, and Kristina Baum, another patient advocate, at MRA's 2023 Melanoma >Exchange Patient Forum to discuss why communication matters in melanoma care and how to improve it. They provided tips, tricks, and strategies to make sure patients and caregivers are proactive partners with their care team.

Speak Up!

"It's essential to tell your clinician how much you want to know," said Dr. Pavlick. "Every patient has different needs about the amount of information they want. Some don't want details. Others want to learn everything." Jabri added that sometimes a patient wants to know everything but doesn't always have the right words to even ask a question. In cases like this, the panelists reminded patients and caregivers that sometimes it takes multiple attempts to get your point across — and that's okay because ultimately, it's your life or the life of your loved one that is at stake. "You have to start the conversation, even if it isn't pretty," says Jabri. "You may have to repeatedly remind the clinician that you want to know everything and have them proactively inform you," she said.

"You have the right to know what is happening and to have it explained in a way that you can fully understand."

Robust communication with the care team is especially critical when participating in clinical trials, said Baum, a melanoma survivor. "Things that seem small to you may actually be a big deal." While participating in a Phase 1 clinical trial, Baum started having headaches and nausea, which

she at first attributed to her stressful job on Capitol Hill. When she finally decided to take the initiative and report the symptoms to her medical team, she learned that she had “autoimmune meningitis,” which was a rare adverse response to her experimental therapy. Basically, her immune system recognized her brain as foreign and began attacking it. Because Baum spoke up early, her care team was able to manage the reaction and she had no permanent damage. “Reporting any and all side effects to your care team is so important,” emphasized Jabri. “When in doubt, just report it—you aren’t bothering them.”

Baum’s favorite piece of advice came from a research nurse who told her not to be afraid of being a jerk. “She was absolutely right,” said Baum. “You have to take control and be persistent and consistent. I learned what that looks like.”

Write Questions in Advance of Your Appointment and Have a Game Plan for Each Visit

“I’m a big advocate of lists,” said Dr. Pavlick. “I tell everybody to write down their questions, because once you get to the appointment it’s easy to forget what you wanted to ask.”

In another panel discussion held later that day focused on Living with Melanoma, Ken Billett, a patient advocate and melanoma survivor, suggested bringing a pen and paper to each visit to write down the answers — and even a computer, laptop, or tape recorder, if that works better for you. “Your appointments are your best opportunity to understand what is happening to your body, with your treatment, and what you can expect around the bend,” said Billett.

Jabri suggested sending questions to the provider by email before the visit. “Some clinicians may look them over and some may not. But it signals to your doctor that you have questions in a specific area and can allow them to prepare or make additional time to address them,” said Jabri. “If you propose the idea, they may be open to it. In the end, it will make their job easier.”

Baum also recommended asking for help managing stress and anxiety, which is often a big part of a melanoma journey. This anxiety often appears in the types of questions patients ask their doctors. For example, early in her melanoma journey, she wrote a list of 16 questions, took them to her oncologist, and realized she was asking the same question 16 different ways: Am I dying? “That was my anxiety talking,” she said. “Being depressed or anxious about what you’re dealing with is super normal. Support is out there and you’re not alone.”

Bring a Loved One or Caregiver to Your Appointments

“Four ears are better than two,” said David Marx, a patient advocate on the Living with Melanoma panel. Marx found it helpful to have his wife accompany him on visits. “Sometimes I might not be paying attention, or she might not be paying attention but together: we are a team.”

Caregivers or loved ones can also ask questions or report symptoms that the patient is reluctant to bring up. Jabri said that in her situation, she and her mother discussed symptoms and other challenges that they wanted to discuss with her doctor before each visit. But at the appointment, her mother would often say that everything was just fine. Jabri realized this was her mother's way of trying to be a "good patient," and not raising any flags.

Dr. Pavlick said that if a caregiver has questions that the patient doesn't want to discuss, she will ask the patient for permission to talk with the caregiver alone. Dr. Pavlick will ask the patient to have a seat in the waiting room while she answers the caregiver's questions. "Making sure your support system knows what to expect is important," said Dr. Pavlick. "No one faces melanoma alone."

Recap What You Heard, Ask if That's Right, and Know How to Follow Up

Jabri said that she would often go to appointments worried that she wouldn't be able to write answers fast enough, understand the answers, or read her writing afterward. Fortunately, her provider was open to following up by email. Dr. Pavlick also encourages this, noting that it allows her to clarify information in writing. "I'll often learn that the patient didn't understand what I thought they understood," she said. "I'll forget that they may not know the difference between a CT scan and a PET scan. When you don't understand something — that's okay and normal — but please communicate that. Don't be embarrassed. It's our job to explain what's happening in a way you can understand."

After a clinical visit, Jabri and her mother always planned to debrief together. They would go to a restaurant and discuss what they heard so that they could both be on the same page. "And often we weren't," she said. "Two people always hear things differently, so this became a helpful routine for us."

At the conclusion of the session, Jabri said that patients and caregivers need to "go to school" to learn how to communicate with not just one clinician but multiple clinicians over time. She suggested checking for resources at a local institution that can help with navigating the health care system. A social worker, patient navigator, or psychologist, for example, can help connect the dots with your entire medical team, including multiple specialty providers.

Baum said that the most important thing is to trust your provider and medical team. "If you don't trust them, then find someone else," she said. Dr. Pavlick agreed. "Make sure it's the person that you trust with your life," she said, noting that with Zoom, it's easy to get second opinions. Dr. Pavlick has patients all over the country and will have calls with them together with their local doctors.

Patients and caregivers must also keep in mind that clinicians are not taught communication skills in medical school, said Jabri. "Many doctors do not know everything about dealing with end-of-life

issues or what hospice is like," she said. "Hopefully, we'll have more conversations as equal stakeholders and come up with better ways to talk with each other. We're all in this together."

This post was originally published February 20, 2024, by the Melanoma Research Alliance. It is republished with permission.
