Take Control After a Melanoma Diagnosis

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You are used to giving the marching orders to your own body, but when cancer steers it in the wrong direction, it can feel like you are no longer in control. Yet this is when it's most important to take control, stressed melanoma physicians, patients, and advocates at the 2019 Melanoma > Exchange Advocate Forum. "You really have to be the CEO of your own health," said melanoma survivor and patient advocate T. J. Sharpe.

Melanoma physician Sapna Patel agreed. Patel, an Associate Professor in the Department of Melanoma Medical Oncology at The University of Texas MD Anderson Cancer Center, noted that although there are things you can't control, such as treatment side effects, there is a lot you can and should be proactive about, including finding the information you need, identifying a clinical trial if appropriate, expressing your wishes and values in regards to your treatment, and managing your supportive team of caregivers and family members.

Finding the Right Information About Melanoma

"What you don't know can hurt you," said Patel. Sharpe added, "Be informed. Do research to understand what the doctor has given you, and what your questions are ahead of time." However, he recognized how overwhelming all the information can be, especially when it is surrounded by so much misinformation that can show up in a Google search. "The hardest thing is finding the right information," Sharpe stressed, and noted a number of good sources for information about melanoma, including the MRA website CureMelanoma.org. He also suggested reaching out to fellow patients who have a unique perspective. Patel pointed out that just like for print media, when scouring the internet, make sure resources are reliable and cite credible sources for their information. "You have to be careful about the information out there," she said. "Although patient blogs can be helpful, they can suggest treatments or tests that worked for them, but may not work or even be appropriate for you."

Get Copies of Your Test Results

Sharpe suggested that patients work to understand their own diagnosis and treatment options, and melanoma survivor and advocate Mark Gorman suggested patients acquire printed copies of all their scan and test results. He noted terrible outcomes he has seen happen because a scan

wasn't communicated to the patient and proper physician. Sharpe agreed, noting he once received a scan report from the emergency room that recommended further follow up that the staff at the emergency room never communicated to him or his regular care team. Patel added that this is why it is important to get scans done before patients see their oncologists so the doctor can review and interpret them together and avoid miscommunication about what those results mean.

Getting a Second Opinion for Melanoma

Part of gathering the right information about your condition is to seek out second opinions or even third or fourth opinions. "It's natural to want to believe in your doctor, but that doesn't mean that he or she knows everything. It's okay to tell your doctor that you want another opinion, and good doctors will encourage you to get one about your diagnosis or treatment plan, especially if you are being seen at a small facility that doesn't have clinical trials or all the treatment options," Sharpe said. Patel agreed, noting that "Second opinions are a must when you are dealing with life and death like we are with cancer."

But Patel cautioned about seeking out so many opinions that it causes delays, which can hamper treatment. "If it gets to be like Baskin Robbins and hard to decide what flavor of treatment to have, and that decision takes three months, the delay can be harmful. I tell patients to act sooner rather than get more opinions, and encourage patients I work with to set a treatment decision deadline so they are not forever searching for opinions," she said. Maura Flynn, a participant in the forum, also pointed out the importance of having an accurate diagnosis and seeking out a pathologist who specializes in identifying skin conditions (dermatopathologist) to provide a second opinion on your skin biopsy, if it was initially examined by a non-specialist.

See a Doctor Who Treats Many Melanoma Patients

Gorman noted that it is also important to see physicians who are experts in the type of cancer you have, especially for rarer cancers like melanoma. "The less common the cancer, the more effort is needed to find a team that sees more of it," he said adding, "You are best served by finding someone for whom melanoma is more common than not." This is especially true when facing rarer melanoma subtypes, including uveal, acral, and mucosal melanoma. Patel agreed, saying "General oncologists have to be abreast of all types of cancer and can't keep up with everything. You are looking out for yourself, whereas the doctor is looking out for a cadre of patients."

Seek out Information About Clinical Trials

Before you start to make treatment decisions, you should get up to speed on all of your options – including clinical trials. This is particularly important for patients with advanced stages of melanoma. Patel noted that patients on clinical trials tend to get better care because they are so closely monitored. "Clinical trials add to the standard of care," she stressed. Sharpe agreed, pointing out that clinical trialists apply the most up-to-date science in their care of patients. "It's likely you won't get worse treatment, and often you get better care when you are part of a clinical trial," he said.

Make Your Needs and Wishes Known

Patel noted that although it is the doctor's job to educate the patient about their condition, he or she also has to respect how much a patient wants to know. She suggested patients convey this to their practitioners, family, and caregivers. For example, not all patients want to know their prognosis, and many just want to know what the next step is ahead of them. Often family members want to know the prognosis and the patient doesn't, she said. "Family and caregivers all have to be on the same page as the patient about this," Patel stressed. They also have to be on the same page about what treatment the patient wants, Sharpe added. A younger patient may want aggressive treatment no matter how low the odds of success, while an older patient might want supportive care that minimizes side effects. "Express your wishes and values to your caregivers, family, and doctors," Sharpe emphasized.

Bring Someone to Your Appointments

It is also important to have family and caregivers at meetings with your doctors. "They need to be there to support, listen, and write down the information because it may be hard for you to comprehend and remember what is said when you are so worried about your future," he said. Patel agreed, noting that when family or caregivers come to an appointment, "they are a second set of eyes, ears, or even a voice," for the patient and they can also help patients determine and write down their questions before meeting with their healthcare providers.

Keep Everyone on the Same Page

But taking control of your health also requires you to take control of your support team, Sharpe pointed out. "I was the quarterback of my caregiving team and had family members doing different things to help, while the head coach was the doctor and medical team. When everyone functions well together, it works well," Sharpe said. Patel suggested that patients indicate a point person on their caregiving/family team to communicate with the doctor.

"I want everyone who cares about the patient to come and be involved, but I don't have the bandwidth to handle five different phone calls about the same patient," she said.

Cut Things Out that Don't Bring You Joy

Taking control may also involve limiting your social circle and saying no to lunch dates, family gatherings, or other social interactions that may be more energy draining than gaining. "You need to cut out the things in life that aren't bringing you joy," Patel said. "It's your life not theirs, so take control of it!" Sharpe added.

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