Practical Recommendations for Surviving and Thriving Despite Melanoma

At the “Surviving and Thriving Despite Melanoma” panel, experts discussed the emotional rollercoaster of living with melanoma

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Most experts, including the National Cancer Institute, say that a person becomes a survivor from the moment they learn of their cancer diagnosis – for the duration of their life. However, not everyone who has received a melanoma diagnosis considers themselves to be a survivor. Maybe, it’s easier to ‘just move on’ and not think about it – or perhaps, the day-to-day challenges of melanoma are so big that the label feels like a sick tempt of fate.

At the “Surviving and Thriving Despite Melanoma” panel conversation, led by Dr. Sapna Patel of the University of Texas M.D. Anderson Cancer Center, experts discussed the emotional rollercoaster that often is a melanoma journey. “It’s common to experience a range of feelings, including anxiety, fear, guilt, doubt, hesitation, and insecurity – as well as relief and pride once you’ve achieved certain milestones,” said Dr. Patel. “When everything feels like it’s swirling out of control, it’s important to know there are factors under our control, and focusing on those things can help.”

In addition to Dr. Patel, the panel featured insights from behavioral psychologist Dr. Lorenzo Cohen also of M.D. Anderson, clinical psychologist Dr. Betina Yanez of Northwestern University, and Stage 4 melanoma survivor Keith Tolley. Throughout the conversation, held as part of the 2021 MRA Melanoma Exchange Patient Forum, panelists highlighted factors and strategies for melanoma survivors to thrive from day one.

Research suggests six key lifestyle factors that are critically important not just for cancer prevention, but also to help control cancer once you have it. These factors are love and support, stress management, good sleep practices, appropriate exercise and diet, and decreasing environmental exposure to factors that can trigger cancer. “It’s not just about feeling better,” said Dr. Lorenzo, but also about “making our bodies as inhospitable to cancer as possible,” by countering biological processes known to encourage cancer growth or supporting biological processes to improve cancer treatment.

Dietary Do's and Don'ts

For example, MRA-supported researchers recently uncovered that a high-fiber diet appears to increase the effectiveness of immunotherapies. For this reason, Dr. Patel suggested that probably Atkins or paleo diets that advise you to reduce fiber and carbohydrate content may not be best for patients on these treatments. In general, diets heavy in plant-based foods tend to be healthier. However, both she and Dr. Cohen stressed the importance of eating whole foods in their original form, as opposed to those that have been highly processed. This means that while a simple salad is a great option, a 'veggie burger' should only be eaten in moderation.

Patients should also avoid foods with added sugars due to the insulin spikes they cause. Spikes in insulin increase inflammation throughout the body, which can encourage cancer or increase treatment side effects, Cohen said.

Relieving Stress and 'Scanxiety'

Dr. Cohen also noted that investigators found psychological stress can make the environment surrounding a tumor more hospitable to cancer growth. He recommended reducing stress with regular meditation, yoga, prayer, or other spiritual practices. Click here for self-care tips.

Melanoma survivor and patient advocate Keith Tolley noted that his spirituality helped reduce his fear of the unknown. This fear caused a lot of anxiety, especially before getting the results of his scans. To counter that "scanxiety," he found it helpful to focus on the present moment and on specific things that he did know, such as: "right now, I am okay."

Dr. Cohen added that imagining the worst-case scenario creates additional stress and other maladaptive physiological responses in the here and now, so instead he suggested: "If something negative comes up in a future scan, deal with it then. Until then, worrying about it won't help and is only going to be harmful."

"I found it helpful to talk through my fears with someone else on my support team—usually my wife or kids," said Keith. "Being able to name the fear and get input from others brings reality back into any imaginations that I let run away to dark places."

Dr. Patel agreed, "If you play the 'what if' game, you've expended the sands in the hourglass on a negative emotion when there are plenty of things to feel positive or grateful for."

"However, if you experience elevated and persistent levels of stress and anxiety that interrupt your ability to socialize, sleep or eat well, or other daily activities, you should seek out the care of a social worker, psychologist, or psychiatrist who specializes in cancer," said Dr. Betina Yanez of the Robert H. Lurie Comprehensive Cancer Center at Northwestern University.

Behavioral health providers your oncologist or nurse practitioner can refer you to will deploy cognitive behavioral therapy or other strategies that can help patients during and after treatment, she added. Yanez also suggested tapping Gilda's Club (now the Cancer Support Community),

Imerman Angels, or other national organizations that provide support for cancer patients. These organizations can offer art, music, or other kinds of therapy, and support groups for patients and their caregivers. Dr. Patel also suggested several online resources, including cancer survivorship sites hosted by the American Society for Clinical Oncology and the National Coalition for Cancer Survivorship.

Combatting Fatigue and Mucositis

Fatigue is a common side effect of many cancer treatments, and Dr. Cohen stressed the abundant evidence showing exercise is a good way to combat such fatigue, even though it seems counterintuitive. He related that he experienced this fatigue himself after receiving combination immunotherapy. "I felt like my feet were in cement blocks and all I wanted to do was to flop on the couch," he said. But he found that after walking halfway around the block, "the fatigue started melting away."

Another side effect he experienced was inflamed mucus membranes in his mouth that made it hard for him to eat. He found a tea or mouth rinse with cloves, a numbing substance, to be helpful before eating. He suggested drinking a tea made with cloves, cinnamon, cardamom, and other spices known to decrease inflammation before meals for those experiencing mucositis.

NOTE: It is very important that you report all side effects—both mild and serious—to your doctor and care team!

Communicating Side Effects

Throughout the conversation, panelists stressed the importance of good communication between the patient and their care providers. Throughout your journey with melanoma, few relationships are more important than the bond between you and your doctor(s). You are a team, and teams work best when the communication flows freely in both directions. This communication is especially important in regards to letting providers know immediately if you develop any side effects from your treatments. Click here for tips on how to improve communication with your care team.

Dr. Yanez pointed out that the newer immunotherapies don't have the same side effects as standard chemotherapies, and because some can become serious if not addressed quickly, the earlier these side effects are reported, the better. Dr. Yanez helped create an online platform at her institution with support of a 2018 research grant from MRA to help patients report their side effects and adverse events as quickly as possible after noticing that many patients waited until their next appointment weeks later to do so. Her online system delivers a checklist of side effects to patients in between their medical oncology visits. If a patient reports a serious side effect, the system is then able to alert their providers within hours.

Although patients can be hesitant to report side effects to their providers on the weekends or during holidays, Dr. Cohen stressed "It is critical to share an adverse event regardless of the time of day, day of the month, or whether it is a big deal or not. We need to rely on medical experts to

tell us if it’s something we can do something about or if it is something that just needs to be known.” Dr. Patel agreed and noted that clinicians don’t view interruptions of their weekends or holidays by such reporting as bothersome. “We love and support you and want to know about your side effects as soon as possible,” she said, adding that if providers are not on call at the time, their partners will address any issues that surface.

Keith noted that it was difficult for him to distinguish sometimes if what he was experiencing was due to his treatment or the disease itself. “The great advice I got from my oncologist was to tell her everything new or different that was happening immediately,” he said, noting that she also told his wife and family this to prevent him from dismissing or “toughing out” any problems he was having. Keith, who has 15 grandchildren, summed up his cancer journey with some good news: “I’m learning to live in a post-treatment world, which I’m praying will continue indefinitely.”

Watch the full panel discussion here.

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