"With clinicians, the conversation can’t just be about dollars," said Dr. Lilenbaum, "because their focus is on quality of care. But if we set out to change practice patterns that cause pain and suffering to patients and families, such as going to the ED or spending time in the ICU within 30 days of death, that resonates with clinicians."

Dr. Adelson added, "There’s a growing understanding that we need to prevent those hospitalizations both for the patient’s wellbeing and for society’s healthcare expenses. I think our physicians are starting to talk about good deaths, a peaceful death in hospice, as opposed to the ICU."

Such conversations are difficult for doctors, not just emotionally but professionally, because they must acknowledge that they have no disease slowing treatments left to offer the patient. Dr. Adelson and her team are educating doctors about how to have these discussions, and are encouraging them to think of this moment not as withdrawal of treatment, but as a shift to another form that’s better for the patient—palliative care or hospice care.

"Lots of data show that patients who receive earlier palliative care have a better quality of life, and their family members have less grieving and depression," said Dr. Adelson. To that end, Smilow recently expanded from three clinical sessions of palliative care per week to ten. Dr. Adelson is also collaborating with a healthcare technology company to create a dashboard that measures each doctor, disease team, and care center on certain metrics at the end of a patient’s life. This feedback will help doctors improve their practice patterns and reduce unwarranted treatments, while ensuring that patients know all their options.

"Our care coordinators are experienced oncology nurses who are making a direct impact to ensure our patients have what they need to manage their home care," explained Ms. Lyons. Deanna D’Agostino, RN, BSN, MS, is the coordinator for a patient who has endured several lines of chemotherapy and has now had disease progression. Her husband wanted her to keep receiving treatment, despite being exhausted from doing all the homecare himself. At a meeting with the couple and their oncologist, Ms. D'Agostino outlined other options—palliative homecare, regular homecare, hospice homecare. The oncologist explained that the patient couldn’t tolerate another treatment and that he had nothing more to offer. "The husband was having a hard time letting go," said Ms. D’Agostino, "despite his wife telling him that she just wanted to enjoy her remaining time at home, in comfort and not in pain. They finally agreed to a hospice program. She’s at home now and comfortable."

OCM has been the catalyst for innovations at Smilow that will affirm the hospital's position as a leader in cancer care while positioning it for leadership during the anticipated changes to the healthcare system that lie ahead. "Value based performance is where healthcare is moving," said Dr. Adelson. "OCM gave us the chance to get early experience and to build the clinical infrastructure to transform care now and in the future. Being an early actor also gives us a voice in the national conversation about the changes coming in cancer care delivery."
Dr. Edelson commented, “Marc had beaten the cancer, but found himself unable to live a full life because of the treatments that had kept him alive. His story is one of hope; not only can you beat cancer, but you don’t have to suffer to be cancer free. There are so many options out there if you have the right team assembled.”

The painful ulcers that developed, mainly on Marc’s hips and thighs, required him to take high doses of pain medication just to get through the day. The ulcers did not respond to normal treatment and were deemed unsuitable for free-flap reconstruction. Luckily, Dr. Narayan was able to propose an innovative solution. Knowing Marc’s history and the success of his recent stem cell transplant, Dr. Narayan recommended allogenic fat grafting using fat from his brother John, as a way to alleviate Marc’s pain and restore the skin. This method had never been used before in this way, and would require his brother John to undergo liposuction in order to provide the fat needed.

“Cancer is a family affair, and I was more than willing to help in any way that I could,” said John. “It was great to do the things I love, I am so blessed to have been connected with Yale from the start. I had the best of the best to treat my CTCL and then again to treat the radiation induced ulcers. I can’t imagine having gone through this anywhere else. I wouldn’t be where I am today.”

Dr. Narayan commented that this case provides a basis for a standard of care for the treatment of radiation-induced ulcers in patients with lymphoid malignancies with stem cell transplants. Not only did it restore the skin to the area, but it also alleviated the chronic neuropathic pain that was interfering with Marc’s life, with none of the adverse effects they were concerned about. “This is a game changer for patients dealing with similar effects,” said Dr. Narayan. “Not having to rely on pain medication gives new hope to patients that have beaten their cancer, but are still dealing with side effects.”

Back on the golf course, Marc and John both agreed that while this experience may have brought them closer together genetically speaking, not much else has changed in their relationship. They have always been a tight-knit family, willing to go above and beyond for each other. “I can never repay what my brother has done for me, and I feel so fortunate to have a family where it wasn’t even a question if they would be tested. John just happened to be the winner of the bunch. I’m still dealing with pain and recurring infections, but it’s a long way from where I was. I credit the team at Yale with giving me my life back twice, and there’s no real way to say thank you for that.”

Marc’s story is one of hope. Not only can you beat cancer, but you don’t have to suffer to be cancer free. There are so many options out there if you have the right team assembled.”