Conquering Fear and Metastatic Lung Cancer

Emotions play a powerful role in living with cancer, a truth AJ Patel learned a decade ago when he was diagnosed with metastatic lung cancer.

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Fear—of death, of pain, of disability, of the unknown—can be overwhelming for someone who has cancer. When you're in its paralyzing grip, it can be nearly impossible to think clearly and make decisions. It can even lead to delays in critical tests and life-sustaining treatments.

AJ Patel is intimately familiar with that kind of fear. It took up residence in his psyche in 2013 when he was diagnosed with Stage IV metastatic non-small-cell lung cancer (NSCLC). At the time, he was a 47-year-old physically fit runner and semiprofessional soccer referee living in Irvine, California, with his wife of 20 years and their daughter (age 10) and two sons (12 and 17). He worked as a legal analyst for a large insurance company (and still does). "I rarely saw a doctor," he says. "I was rarely sick."

Two years earlier, in 2011, first his kids and then his work colleagues noticed that he was constantly clearing his throat. So he saw his primary care doctor, who referred him to an ear, nose and throat specialist, who in turn recommended an allergist. Over the next two years, "I was bouncing around from physician to physician with no real solution," Patel says. Meanwhile, his throat congestion was getting worse. In February 2013, Patel changed physicians and pressed his new doctor to do more testing. A lung X-ray revealed a nodule in his left lung, but the doctor saw no reason to worry and recommended repeating the X-ray in six months if symptoms persisted. That June, on a family trip, he coughed up blood, but he didn't want to upset the happy gathering, so he didn't tell his wife until it happened again in July. He was in a panic, wondering whether he had tuberculosis (TB) because, he remembered, "people cough up blood with TB."

He did test positive for TB but only because of the TB vaccine he had received as a toddler in the United Kingdom (his parents had emigrated there from India). Next, the doctor ordered another chest X-ray, which showed the same nodule. Patel pressed for more testing, so his doctor ordered a CT scan. It revealed lung masses suggestive of metastatic cancer. It had been a tragedy of errors.

Building a House of Fear

Patel's doctor sent him home with a business card for a pulmonologist, but when his wife called for an appointment, neither that doctor nor dozens of others she called could see her husband for months. "I was crying every day, thinking, What's wrong with me? Why do I have these masses? Do I really have cancer?" he recalls. Finally, after three days of nonstop calling, his wife secured an appointment with a pulmonologist, who looked at the CT film and ordered a biopsy. On Patel's second visit, the doctor cried on his shoulder, telling him, "I'm sorry, but you have lung cancer, and it's really serious."

Patel was having none of it. He believed that only smokers got lung cancer (in actuality, about 20% of people with lung cancer never smoked), and his previous medical encounters had left him skeptical and distrustful. "You can't be looking at AJ Patel," he said. "I don't believe your chart. I don't believe the diagnosis. I just need to go away and think about this." In response, his doctor said, "AJ, if you don't do something, you will die in six months."

The foundation for fear had already been built, recalls Patel, "but now I was beginning to feel the framing of the house of death." All he could think about was not being around to celebrate Christmas with his family. After 10 miserable days, he forced himself to search the internet. There, he saw gloom and doom, including a 5% five-year survival rate. "If I went into a depression spiral, I went right there," he says.

But after a day of web surfing, a link to LUNGevity and the words "a foundation for lung cancer patients and survivors" caught his eye. He dialed the website's patient advocate number, and, to his astonishment, a woman answered. "The empathy, care and concern was so overpowering," he says. The woman recommended that he see an oncologist specializing in lung cancer and gave him the name of one nearby. Hearing his despair, she also connected him with Matt Ellefson in South Dakota, who had been living with Stage IV lung cancer for four years.

"For someone like me, suspected to be Stage IV, hearing someone surviving four years was really encouraging and uplifting," Patel says. "It gave me strength and hope, which is what cancer patients really need. Suddenly, the house of death being constructed in my head fell apart."

That conversation also helped provide Patel with the tools he needed to advocate for himself. "Matt educated me completely about the disease, what I should expect in my first meeting with the oncologist, what kind of questions to ask," he says. It was like a crash course on NSCLC from a Stage IV survivor who knew all the ins and outs.

More bad news was coming, however. The lung oncologist Patel consulted sent him for a brain MRI, which revealed numerous brain tumors—his cancer had metastasized.

The Uncle Who Stepped Up

Growing up in London, Patel had lived with an uncle, a successful businessman, for six years as he completed high school. He found this uncle rude and abrasive, although usually right. His uncle opposed Patel's move to the United States (Patel emigrated in 1997). They didn't speak for years. But when Patel was diagnosed with cancer, he mentioned it to his uncle's son, a cousin with whom he got along better. "The next thing I knew, my uncle called and said, 'What's going on? Let me get on FaceTime with the doctors,'" he says. "He was on FaceTime with everybody, and I was thinking, I'm so grateful this guy is here. He's fighting in my camp. Every question was really powerful."

His uncle supported Patel in his decision to have a craniotomy in September 2013 to remove two brain tumors. It was his first surgery—he hadn't been a candidate for lung surgery—so it also provided tissue for genetic biomarker testing for the first time. During the surgery, Patel says, "I had so many seizures on the table, they thought they were going to lose me."

Afterward, when he was in intensive care, his uncle, who had flown in for the operation, pushed the neurosurgeon to summon a neurologist to manage the electrical activity in his nephew's brain minute by minute until he was stable, likely saving his life. "It was very powerful to know that I had this kind of pit bull in my tool bag who could advocate for me when my voice was taken away from me," Patel says, choking up.

One day, while Patel was still in the hospital, his oncologist entered his room excitedly waving her arms: She had found a biomarker for his tumor. It was ROS1, a mutation only around 1% of people with NSCLC have. Although there wasn't a specific treatment at that time, his oncologist prescribed a medication intended for those with the more common ALK biomarker. "She realized from her analysis of the drug profile that it should work for me," he says. "It turned out to be the best thing in my life because it changed the trajectory of my treatment."

AJ PatelAri Michelson

How the House of Fear Crumbled

Nonetheless, for the next two years, Patel struggled with depression. His recovery from surgery was slow and laborious; the brain tumors had affected the right side of his body and his motor skills. He spent months relearning to walk, and his right hand is permanently impaired. He endured radiation to his brain and four rounds of grueling chemotherapy, which has caused neuropathy in his hands and feet. He lived in three-month intervals, from scan to scan, in anticipation of bad news. “I couldn’t shake the house of fear and death.”

Questions plagued Patel: Why had he gotten cancer? Was he a bad person? If so, where had he gone wrong? But he couldn't find answers "from God or any church or synagogue or anywhere." Then someone suggested meditation. In November 2016, he signed up for a 10-day course of Vipassana, an ancient breath-based meditation. Every day from 4:30 a.m. to 9 p.m., except for meal and bathroom breaks, he sat in silent meditation. "Within five minutes, my legs and back began to hurt. I couldn't feel my toes anymore. I thought, There's no way I can survive this," Patel says. But with nowhere else to turn, he persisted, motivated by the others surrounding him. On day four, he had an epiphany. The pain in his legs and back disappeared and didn't return, and he could focus on the teachings.

"The experience completely changed my life," he says. "I touched within me a dimension that is impossible to explain, something that opened up like a flower. I was able to understand things that I had never understood."

Since then, Patel's life has been transformed. He continues to meditate for the calm that it brings him, his mat nearby so he can snatch 10-minute meditation "naps." "I've discovered what people regard as a higher power or bliss is really within us," he says. He has been on the ALK/ROS1 inhibitor he was originally prescribed for nine years now, and though he still has challenges, he says, "I don't worry about them. I feel a lot happier, and the house of death that I had has all crumbled and been eviscerated. I'm no longer fearful, no longer scared of any treatment. I'm no longer scared of death. This has been a beautiful gift."

Giving Back

Patel was a shy introvert when he was diagnosed with NSCLC and too embarrassed to tell his story. But a friend encouraged him to reach out and help others, telling Patel that he had a special way of communicating that could help those in need who have cancer. "Hope is a commodity that I didn't realize is better than gold. It carries people forward," he says. "I realized that my voice can make a difference."

Patel has become an advocate for people with many forms of cancer and their families. He consults with the Department of Defense, advising scientists from a patient perspective as they allocate lung cancer research funds. Patel has also worked with pharmaceutical companies and testing companies, and he successfully advocated for a 2021 California law expanding patient access to the kind of cancer biomarker testing that helped him survive. He works with the Lung Cancer Foundation of America (LCFA), which supports lung cancer research, appearing in several of their Hope With Answers podcasts, and he has a blog linked to the LCFA website.

"When you are told that you have any stage or kind of cancer, you have been given a warning letter that your life is in jeopardy," Patel says. It's critical to sit down and take stock. "Reexamine your life and realize that the things you're griping about—the bills, your job, the mortgage—are all physical things, tangible things, that are just temporary. The only thing that is permanent is the people that you touch, whether strangers or not; when you touch somebody, they will remember. So just stick out your hand, lift them up as best you can and move on, keep marching forward. And

that will enrich your life. It will touch your soul, and it will touch the other person, whether they realize it in that moment or not. You will have just improved humankind.”

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