

No One Told Me I Was Dying

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No one told John he was dying.

Before I met John, he had already survived lung cancer twice. He was first diagnosed after a lesion was identified on a screening CT scan. This was treated with partial resection of his right lung. Rehab was challenging, but he persevered, returning home to a full, independent life where he worked full time and enjoyed his wife and family.

Two years later surveillance imaging discovered a new spot on his left lung. A biopsy confirmed this was cancer, different from his first pathologically, a second primary lung cancer. Truly bad luck and the effect of smoking for fifty years. He pushed forward with both chemotherapy and radiation resulting in remission. After the second battle with cancer, life became more difficult for John.

Radiation helped kill the cancer but also damaged healthy lung tissue. During the course of his treatment, a pulmonary embolism, recurrent episodes of heart failure, infections, and escalating pulmonary arterial pressures continued to stress his poor lungs. They became reliant on continuous oxygen for support. He spent most of his waking hours in hospitals, rehab centers, and medical offices, leaving little time for home and family. Uncomfortable hospital beds, white coats, needle pokes, and oxygen tanks became very familiar to John. Life became more about what his lungs needed, and less about what John needed. He gradually declined and his independent life once filled with work, friends, and family became a distant memory.

I was a second-year internal medicine resident when I met John in the Emergency Department. He was being admitted for a recurrent episode of undifferentiated hypoxemia. I could tell that he and his wife were scared. When I looked into John's eyes, I could see they were hungry for air. His wife's eyes expressed concern fluctuating between John, his oxygen saturation, and me.

"Hey John, I'm Doctor G. I'm one of the residents and I'll be admitting you to the hospital. I heard you've been short of breath." He nodded in agreement. "Who's here with you today?"

"Hey doc." He replied followed by a three second pause to catch his breath. "This is my wife."

"It's nice to meet both of you. I'm sorry it's under these circumstances, but I promise we will take really good care of you while you're here." After asking John and his wife to tell me about his medical history and recent symptoms, I followed with, "John what are you most worried about?"

“I’m really worried I won’t be able to find more air.” Short pause. “I’m worried one day this is not going to get better.” John seemed to recognize there would be a time when medicine could not offer a solution to his problem. I wondered if anyone had discussed this with him. Without knowing it, he had opened a door to discuss end of life.

“You’ve been through a lot John. What have other doctors and specialist told you about your lung disease?”

“They told me I shouldn’t have smoked for all those years. That I have bad lungs from all that smoking... and the two cancers.”

I could tell our conversation was tiring him out. His abdomen moved paradoxically during inspiration and his neck muscles tugged with all their might to support a deconditioned diaphragm. He must have felt like a broken record repeating his story over and over again with each new medical encounter, but I had a few more important questions for John, so I pushed on. “It sounds like you’ve been told your lung disease is pretty severe. And I’ve read your medical history, so I know it’s been a rough go over the past few years. Has anyone talked with you about how much time you might have left?”

I could sense the mood shift in the room. Fear and anxiety turned first to surprise, then contemplation. Pausing for air between sentences he replied, “I haven’t thought about time. I know I will die from my lungs, but I’ve survived cancer twice. I figure I have a few more years in me.”

I knew it was time for me to wrap things up when respiratory therapy arrived to set up BiPAP. I was hopeful it would relieve his work of breathing, but it would be nearly impossible to have a meaningful conversation with him through the beeping and roaring of the positive pressure machine once it was started. “I don’t know how much time you have left John, but it may be shorter than you think. I’m worried your lungs are getting worse.” A short pause, this time for me to catch my breath, “I’m worried you are dying.”

It seemed like an hour passed before he replied. This time, the pause was not to catch his breath. He looked over at his wife. “No one told me I was dying. If I don’t have much time left, I don’t want to spend what’s left in the hospital. I want to go home.” There was no trace of denial or anger. In his heart of hearts, he knew what I said to be true.

“I hear you John.” In silence his wife took his left hand. I offered mine, and he held it tight. Not a handshake but an embrace.

With permission from John, I invited the palliative medicine team to meet with him the day after his admission. They helped us to continue exploring John's goals and offer ideas to improve his symptoms. We shifted focus from treating lung disease, back taking care of John and his symptoms. At discharge he decided to go home with more support provided through hospice. John spent his remaining months at home with family. The clinic visits, lab draws, bouts of testing, and long commutes to and from the hospital were replaced by familiar visiting nurses, a skinnied down medication list focused on his comfort, and supportive home health services. Small doses of oral morphine relieved his air hunger and knowing it was available alleviated the associated anxiety. He was treated for pneumonia and a COPD exacerbation at home with a short course of antibiotics and steroids when he developed symptoms, saving a trip to the emergency department and the inevitable admission that would have followed. John never returned to a hospital. He died at home four months after enrolling with hospice.

I told John that he was dying. I hated telling John that he was dying. But I'm glad I did.