

## The Myth of the White Coat

Allison Larson

I used to think the white coat was a shield behind which I could defend my family and myself from the ravages of disease. The bleached antiseptic barrier that separated doctors from patients would be my amulet of health. But illness was a cunning adversary, and didn't play by my rules.

My dad was 54 when he showed the first signs of the cancer that would swiftly claim his life. I was halfway through my first year of medical school. I knew almost nothing about cancer since our oncology block wasn't scheduled until early second year. In fact, I still thought of cancer as a single disease that happened to start in different body parts.

While I was elbow-deep in anatomy, Dad developed a pesky hacking cough. He had been losing weight too and his fingertips were peeling. Neither my parents nor I gave much thought to any of these things until Dad's cough became constant and hard to ignore. His boss suggested he take a little time off work to see a doctor, rest, and recover.

Dad went to see Mom's primary care doctor. He had seen her once before when he turned 50, at Mom's absolute insistence. He refused to go for check-ups after that. When Mom asked him why, he said, "She doesn't think sailing is a real sport and wants me to do more to lose weight."

Mom responded, "You're just embarrassed about having a woman check your prostate."

Dad called me right after his appointment and put me on speakerphone so both Mom and I could be part of the conversation.

Dad said, "I told her I was there for my cough, but for some reason she kept focusing on the bump on my back."

"What bump?" Mom and I said in near unison.

Dad sighed. He began sheepishly, "It's from sailing. It's been there for 5 years. I fell pretty hard onto a winch handle when we needed to do a last-minute jibe." In Dad-speak, pretty hard meant he got really hurt.

He said, "I still had a bump there a year later, when I went to see the doctor the first time. She said it was probably a collection of dried blood, a hematoma. She's worried because it's bigger

than it was 4 years ago. I told her, that's because I keep bumping it. She's sending me for an MRI. I don't see why she's making a fuss over this."

I thought Dad was likely right that the bump on his back was a hematoma. Still, a pesky whisper in the recesses of my mind kept asking, *What if it's cancer?* I wondered where that notion came from. I tried to push it away, but the idea's intrusive tentacles kept creeping back into my thoughts.

This voice was the infant form of what would grow to become my second persona, my doctor self. It was barely recognizable, made up of fragments of neuroscience from my undergrad days and bits of cell biology and anatomy from medical school. A wobbly scaffold on which to hang even the simplest of clinical judgments.

When Dad called me with his MRI results, I wasn't prepared for the news. Even though thoughts of the big C were skulking around in my mind, the idea of Dad having a serious medical problem still seemed inconceivable.

Dad's voice was tense and strained when he told me, "They saw a mass in my back muscle. It looks like cancer. They also saw a quarter-sized spot on my lung. I'm going to see an oncologist on Monday."

I didn't cry when I heard this. I held my breath and clenched my stomach willing it to turn to steel so that this blow could bounce right off me. Over and over I told myself that the lump on his back and spot in his lung would be easily fixable. Still, despite my mantra of hope, it was as if one of those tiny shriveled black cancer cells had lodged itself in my core and begun to sprout spiny roots that needled me.

In a quavering voice, I told Dad that I was sure everything was going to be ok.

After the oncology appointment my parents called me. Mom started crying immediately and couldn't calm down enough to say anything.

Dad said, "It didn't go well. He started by telling me that my odds weren't good. I asked him what kind of cancer I had and he said it could be sarcoma or lymphoma. I asked what my chances were of living five years. He said, 'Five years? Oh, you have no chance of living five years'."

Mom was distraught. Inside my head I wasn't doing much better, but it was not my moment to fall apart. I couldn't believe the odds were really that bad.

Mom managed to speak, her voice choked and her words pronounced with such extreme effort that she had to pause to form each one. "I don't understand why they can't just cut it out and get rid of it."

Dad said, "I'm going to have the lump biopsied on Thursday and the oncologist scheduled me to start chemo in a month." He spit out the month part scornfully. Dad continued, "He

wants me to wait an entire month before beginning treatment. It's obvious he's written me off for dead."

His pitch rose and his voice cracked a little at the word dead. I managed to say something about how the doctor must be wrong. We didn't linger on the phone. Both of us were having a tough time holding back our tears.

I couldn't imagine Dad not being around. He knew everything about my life, from what kind of doctor I wanted to be that month, to what I ate for lunch last Wednesday. He was always there to help me. If my car was making a funny noise, he tried to diagnose the problem by listening to the sound over the phone. He had carefully proofread all fifteen versions of my medical school application essays.

Then there was the future. For years, my parents and I planned for them to move near me once I finished training. They were going to help me set up a practice and take care of my kids.

Dad had his biopsy. The results were inconclusive. There was too much necrosis (cell death) to be able to discover the cancer type. I thought it had to be a good sign that the cancer was already partly dead.

Mom, Dad and I agreed that Dad couldn't be treated by a doctor who believed he had no shot at surviving. My parents called over to the oncology group at Johns Hopkins, where I was going to school. We needed expert help and Hopkins was one of the best hospitals in the country. The oncology front desk told him they couldn't give him an appointment until he knew whether he had lymphoma or sarcoma. Dad explained to me that such a fancy hospital probably wouldn't give an appointment to just any old person who called up. I was surprised. I hadn't expected barriers just to get in the door. My parents and I didn't know how to find out Dad's diagnosis. Here I was studying to be a doctor, but I didn't know the first thing about cancer. I thought that by entering medicine, I would be able to do all the right things to help my family. I supposed I just hadn't gotten there soon enough.

So I did the only thing I knew how to do. I went to the medical library and instead of studying for my classes, I pored through texts and journal articles about cancer. I was certain that all the answers to our problems lay somewhere in the stacks. I just needed to unearth the right tome.

Lymphoma proved a confusing jumble of different diseases. Some lymphomas weren't that bad and people lived a long time. But I had trouble figuring out one from another. I decided to focus on sarcoma in an attempt understand cancer. I learned that the main predictor of outcome in sarcoma was stage at diagnosis. There were four stages, Stage I being the best with an 83% five-year survival. Stage IV was the worst with a stunning 16% five-year survival, and this was talking about people who had treatment.

For some reason five years was the time-to-beat for all cancers. To me, five years seemed way too short. I was thinking more along the lines of thirty years. I went through a table to

determine Dad's stage, assuming that he had sarcoma. I reread the table three times before realizing that I was not making a mistake. The solitary spot on his lung would advance him all the way to stage IV. I slowly pushed the sarcoma information to the side. There was only one thing to do in this situation. I was going to hope and pray for lymphoma.

The next week I flew home for spring break. When I stepped off the plane, I felt jittery anticipation, like I was heading into a big exam. I walked slowly, feet shuffling down the gleaming white hallway. I wanted to put off the moment when I had to face Dad and his cancerous intruder. In a childish way, I thought that if I didn't witness the cancer, then there was a chance it wasn't really there. Seeing Dad would seal the cancer into reality, like a pathologist affixing a slide with a diagnosis.

I hesitated before stepping out from behind the security checkpoint. I forced a small smile and made my way into the waiting crowd. At first I didn't see them. As always, I was looking for Dad. He had a presence that stood out, mostly because of the way his face would light up at the sight of me. I saw Mom waving and did a double take. I almost didn't recognize the shadow-like figure of Dad, half hidden behind her slender frame. His back was hunched and his black hair newly thinning, a self-conscious smile on his face. He lost about 50 pounds since I saw him 2 months before, and somehow his aura had shrunken along with his waistline. His confident demeanor was gone, replaced by doubt and uncertainty. My first thought was, *oh my God - he's dying*. I forced myself not to look away and to keep smiling, so they wouldn't guess what I was thinking. I strode forward giving them both big hugs. It was a silent greeting, none of us knew quite what to say.

My boyfriend Craig told his father about our oncologist issues. Craig's father gave us the contact information of a family friend, who was a doctor at Hopkins. Mom thanked him effusively on the phone telling him, "You helped save his life."

After hanging up, she turned to me with wide eyes and said, "You helped save his life too." She assumed I had something to do with Craig's father getting involved, which I didn't. I shrugged uncomfortably. I liked the sound of Dad's life being saved, but it seemed premature to say so.

My parents and I planned to drive to Baltimore together at the end of the week. Dad was going to be admitted to the hospital to have tests done. Once we had a diagnosis, he would be set up with the right specialist.

I was thrilled and relieved that Dad would be taken care of at Hopkins. Surely the giants at this mecca of medicine would come up with some almighty elixir of healing. After all, I knew that people there were curing cancer in bunnies. Yes, bunnies. I had a lecture a few months before by a famous cancer researcher. I told my parents about the talk. "He showed us pictures of this bunny named Happy."

"Happy?" Mom asked.

"Yes," I said, remembering the black and white profile of a hare raised up on his hind legs, ears

at attention. “Happy had cancer all over his liver. They gave him a new drug and all of his cancer melted away.” Our class had let out a collective gasp at that.

I said to Mom and Dad, “He told us bunnies like Happy are survivors.”

My parents liked that there were survivors at Hopkins, even if the only ones I knew of had cottontails.

Dad called the original oncologist’s office and cancelled his follow-up appointment. He smiled as he proudly announced, “I will be going to Johns Hopkins for my care.” Dad told me, “I know the oncologist thinks my chances are bad but I just feel like I’m going to be the person that beats this.”

When we arrived in Baltimore, Dad was admitted to Johns Hopkins Hospital. He had all kinds of tests done, including a lung biopsy. Early the next morning, I strode through the hallways waving my ID around and slid into his room. He pointed to my badge and commented, “They’ll let you anywhere with that.” He seemed impressed. Dad had on his pajamas and bathrobe from home. He looked out of place without the standard issue blue checked backless gown.

I was with him when the resident physicians made their rounds. The two senior residents, a man and a woman, walked over to his bed. They stood side-by-side with matching clipboards and moved in unison, like conjoined twins. They started a little at the sight of his pajamas. His garb blurred the usually clear distinction between doctor and patient. “How happy are you with the care you’re receiving here?” the man asked.

I was a bit taken aback by that question. This wasn’t a 5 star hotel. Survival was my priority, not a pleasant stay.

Dad said, “Things are moving forward, and that’s good. Everyone has been very nice.” Their faces both lit up at that. They spoke about the roles of the various doctors that made up Dad’s medical team. Then they practically square-danced out the door, glowing with praise.

The slides from Dad’s original back biopsy were sent to Hopkins. The pathologist there was able to spot a pattern within the dying tissue. He gave a diagnosis - synovial sarcoma. Soon after, Dad’s lung biopsy results came back. The growth in his lung was metastatic sarcoma.

This diagnosis sealed his fate. What followed over the next month was inevitable. Dad had worsening trouble breathing as flecks of cancer erupted all over his lungs, like stars appearing in the darkening night. He enrolled in a clinical trial, on which we pinned all our hopes. The experimental drug inadvertently sped up cancer growth and Dad died in the intensive care unit (ICU) two days after his second infusion.

The oncology team that bore witness to Dad’s final days included a sarcoma specialist who was at Dad’s bedside within an hour of his admission to the ICU. He entered the room without saying anything or even looking at Mom or me. He stood in silent vigil at the foot of Dad’s

bed for several minutes, his face serious and sad. The team's fellow, a smart and friendly doctor who had finished her residency and was doing specialized training in oncology, was shocked to see Dad in the ICU. She told me, "He was so determined to beat this. I believed him. I really thought he was going to do it." I shrugged at that, not knowing what to say. I had thought it was up to them to get rid of the cancer, not Dad.

It would take years before I understood that neither I nor the gurus in their long coats had failed Dad. Sometimes the disease wins no matter how much you know and how much you do. The white coat offers no guarantees, and no protection. This understanding changed me as a person and as a doctor. When I look at patients now, I see someone's mother, someone's husband, someone's son. I see my future self, sick and afraid. Sometimes I have little to offer other than compassion and a willing ear. I hope that when it is my turn to sit in the straight-backed chair across from a stethoscoped doctor, and receive my final diagnosis, that they can give me the same.

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