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What Does a Patient Advocate Do?

By Ellen Kolton

The caller asked me to visit his friend, and when I asked why, he answered, "He needs an advocate." I entered Luke's hospital room on the rehabilitation unit, not entirely sure why I was there. My first impressions of Luke were his friendly face, his vivid blue eyes behind wire rims, and his slow, welcoming smile. He was lying under a blanket when I walked in, so it took me a while to realize that he had suffered a significant trauma. Luke appeared strong and healthy, and at first glance I pictured him as a runner. Looking more carefully, I slowly realized that his arms and legs were missing. He was a body and a head. He had stumps where his limbs had been.

I've encountered plenty of shocking sights, but seeing this strong- looking man was more jarring than viewing brain-injured patients with their bulging heads, people with stinking colostomy bags, even young men with scabbed-over gun-shot wounds. I wanted to run, but instead I said, "Your friend Bill called and said you needed a patient advocate. That would be me. How can I help you?"

Luke smiled. "I didn't know I needed one. What does a patient advocate do? "

The short answer to that question is that we try to resolve conflicts that arise among patients, their families, and clinicians. We tackle problems, or, as we prefer to call them, "concerns"—anything from a long wait in a doctor's office to fractured communication between family and clinicians when a loved one is dying. No two situations are alike, and Luke's circumstance definitely fell in the one-of-a-kind column.

"Are you having a problem? " I asked. He looked down at where his arms and legs used to be, his glance stating the obvious. "Well, I guess you'd say I'm doing well, actually better than I or anyone could have predicted."

He told me his story without drama or blame, seeming incredulous as he listened to himself talk, speaking slowly, pausing to allow me time to absorb what I was hearing. Luke had been a professor of film studies at a local university. Six months ago he had started a sabbatical at a university out west when his legs began to ache. He figured his muscles were sore from having just hauled heavy boxes of books. New on the job, he ignored the pain until it became unbearable. When he finally asked a friend to take him to the hospital, he collapsed and almost died. His identical twin brother rushed to visit, prepared to do whatever it took to save Luke.

Luke had suffered a bizarre series of events starting with developing toxic shock syndrome from a cut on his leg. The infection evolved into necrotizing fasciitis, an insatiable flesh-eating bacteria that would have killed him had physicians not acted promptly, amputating his four limbs. After months in Western hospitals, he was back in Boston to continue treatment. Luke was not a classic patient in the rehabilitation unit of the inner-city trauma center where I work. Most patients were recovering from more typical injuries: acts of

violence, falls, or vehicle accidents that had left them broken or with some degree of paralysis. Luke was there to build strength in his core with the hope of getting prostheses —or possibly arm and leg transplants.

Luke didn't need an advocate. He was the teacher's pet of the rehab unit. Determined to be self-sufficient, he grunted and sweated through his three hour physical therapy sessions, trying to regain his strength and independence. I regularly visited patients on that unit, and their stories and prognoses were disheartening. One of the first young men I met was belligerent as he prepared to be discharged to a third-story walkup. Confined to life in a wheelchair after a bullet had severed his spinal cord, he was fearful and helpless, glued to his anger at the world, refusing to talk to anyone. Another woman had fallen from a window after a night of heavy partying. Like Luke, she tried to be cheerful, but I'd often find her sitting in her wheelchair at the end of the hall, staring out at the world. Her boyfriend was unwilling to commit to a lifetime of caretaking, and she was preparing to return to her reluctant family in Ireland, where she would live in a nursing home, facing a future that promised nothing but care from strangers.

In contrast, Luke appeared immune to self-pity. He started a blog with the word "grateful" in the title. He didn't complain, unlike most of the other inpatients I saw. He was fun to talk to. Our quick connection through mutual interests deepened over the months that he was there. He liked to discuss books and his beloved films. Whenever I saw a movie, I couldn't wait to hear his take.

No matter what we talked about, Luke chose his words carefully, taking every question seriously. In time, I learned more about him and his family. He told me about his twin; they were very close, but very different. John was an environmental conservationist, married, father to a little girl, whom Luke adored. In contrast, Luke was a dreamer, drawn to literature and film, and he was gay. His room was filled with paintings, books, and organic foods brought in by his wide circle of family and friends. Someone had rigged his computer with a long stylus which he gripped between his teeth to type his emails and his blog. He answered his phone the same way.

Luke only asked me for one favor. He told me about his Gabriel, his boyfriend, a handsome, athletic landscape architect who lived a couple of hours away. Their relationship was still in the where-is-it-going stage; but now that Luke would be dependent, the stakes were higher. Would Gabriel sign on for the long game? "You know, my life expectancy is severely shortened by this injury," Luke commented one day, offhandedly. "We have a lot to talk about," he said, "but it's hard because we are always interrupted." He was trying to figure out a way to keep people out so they could be alone. "I'm not talking about sexy, sexy time…We just need to talk privately about our future…to see if we have one."

I offered to make him a "do not disturb" sign. Because Luke cared so much about how things looked I tried to create something with a little class, carefully choosing a sans serif font—something friendly yet serious. Luke seemed pleased, although to my mind the result looked like a summer-camp artifact.

Luke eventually went to a more formal rehab center. For a while we kept in touch. When the film "Beasts of the Southern Wild" came out, I emailed him, as he knew the director and had praised it in advance of its release. I learned that Luke and Gabriel are now living in a refurbished apartment and, he was recently pictured on the front page of the paper, walking with prostheses.

Patients with a lot less to complain about, complain a lot more than Luke ever did. The grace and dignity with which he handled his shrunken life were impressive. He had reason to be angry or bitter, yet he was neither. His acceptance of a horrible freaky fate, his genuine interest in the outside world and the people who cared for him were touching. Maybe Luke didn't need a patient advocate, but this advocate needed a patient like Luke to show me the core of resilience—to witness how someone can remain tall despite being assaulted by a life-altering physically diminishing disease.

I often wonder what makes some people take their blows without rancor, while others become hard and mean. Why does tragedy bring out the best qualities in some people, and the worst in others? People sometimes tell me that they'd never want my job: they see my days as full of conflict and complaint. There is some of that, but then there are people like Luke—although few of the resilient patients I've met have such dramatic stories. I've learned that when people need an advocate, they are seeking a connection. He taught me a lot about gratitude. Luke was easy to like, but even when people are less accessible, I keep trying, with the belief that gratitude may have a lot to do with a patient's starting place. My challenge is to look beyond the vitriol to make a connection.

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