

BEING MORTAL: ILLNESS, MEDICINE, AND WHAT MATTERS IN THE END

Atul Gawande

Reader 1

Reader 2

Reader 3

Narrator

Atul

Father

Neurosurgeon

Dr. Benzel

Reader 1: “A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one’s story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone’s lives.”

– Atul Gawande, *Being Mortal: Medicine and What Matters in the End*

Reader 2: “I’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way. Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same: What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?”

– Atul Gawande, *Being Mortal: Medicine and What Matters in the End*

Narrator: Over the next couple of years, my father’s neck pain progressed. It became difficult for him to sleep comfortably. The tingling in the tips of his left fingers became full-blown numbness and spread to his whole left hand. He found he had trouble feeling the thread when tying sutures during vasectomies. In the spring of 2006, his doctor ordered an MRI of his neck. The findings were a complete shock. The scan revealed a tumor growing inside his spinal cord.

That was the moment when we stepped through the looking glass. Nothing about my father's life and expectations for it would remain the same. Our family was embarking on its own confrontation with the reality of mortality. The No. 2 pencils had been handed out. The timer had started. But we had not even registered that the test had begun.

Neurosurgeon: I advocate operating right away. The situation is dangerous. You could become quadriplegic in weeks. No other options exist – chemotherapy and radiation are not nearly as effective in stopping progression as surgery. The operation has risks, but I'm not too worried about them. I'm more concerned about the tumor. You need to act before it's too late.

Father: It's hard for me to put my trust in an operation that I don't understand – that I don't feel capable of doing myself. How exactly is it done? What kind of instrument do you use to enter the spinal cord? Do you use a microscope? How do you cut through the tumor? How do you cauterize the blood vessels? Couldn't the cautery damage the nerve fibers of the cord?

Narrator: The neurosurgeon didn't much like my father's questions. After the first couple he grew exasperated. He had the air of the renowned professor he was – authoritative, self-certain, and busy with things to do.

Neurosurgeon: Look, the tumor is dangerous. I have a lot of experience treating such tumors. Indeed, no one has more. The decision for you is whether you want to do something about your tumor. If you do, I'm willing to help. If you don't, that is your choice.

Narrator: The Cleveland Clinic surgeon, Dr. Benzel, exuded no less confidence. But he recognized that my father's questions came from fear. So he took the time to answer them, even the annoying ones. Benzel had a way of looking at people that let them know he was really looking at them. He turned his seat away from the computer and planted himself directly in front of them. He did not twitch or fidget or even react when my father talked. He had that Midwesterner's habit of waiting a beat after people have spoken before speaking himself, in order to see if they are really done. Along the way, he probed my father too.

Dr. Benzel: It sounds like you're more worried about what the operation might do to you than what the tumor will.

Father: You're right. I don't want to risk losing my ability to practice surgery for the sake of treatment of uncertain benefits.

Dr. Benzel: I might feel the same way in your shoes.

Narrator: In the end, my father decided to hold off surgery until he felt he needed it. Two and a half years later, he retired from his urological practice. His symptoms continued to worsen. The weakness in his left arm had progressed. He couldn't lift it above sixty degrees. His right hand was losing strength, too. And he was starting to have trouble walking.

Father: There's a heaviness in my legs. I'm afraid, Atul.

Atul: Is it time for surgery?

Father: I don't know.

Atul: I'm worried.

Narrator: I recalled the list of questions Susan Block, a palliative medicine specialist, said mattered most. I posed them to my father one by one.

Atul: Dad, what is your understanding of what is happening to you?

Father: I'm becoming paralyzed.

Atul: And what are your fears if that should happen?

Father: I'm afraid I'll become a burden on your mother and I won't be able to take care of myself anymore. I can't fathom what my life would become.

Atul: What are your goals if you become worse?

Father: I want to complete my responsibilities as the Rotary Club district representative. I want to make sure the college I started in India and my family there will be all right. I'd like to visit them if I can.

Atul: Dad, what trade-offs would you be willing to make or not make to try to stop what is happening? My friend's father, who also had a spinal tumor, said that if he could still watch football on tv and eat chocolate ice-cream that would be enough for him.

Father: I don't think that would be good enough for me at all. Being with people and interacting with them is what I care about most.

Atul: So even paralysis would be tolerable as long as you could enjoy other people's company?

Father: No. I don't think I can accept a life of complete physical paralysis, of needing total care. I want to be able not only to be with people but still in some way be in charge of my life.

Atul: You wouldn't be okay with 24-hour nursing care, then a ventilator, and a feeding tube. It doesn't sound like you want that.

Father: Never! Let me die instead.

Narrator: Those questions were among the hardest I'd asked in my life. I posed them with great trepidation, fearing anger from my father, or depression or the sense that just by raising such questions I was letting him down. But what we felt afterward was relief. We felt clarity.

Reader 3: "In the end, people don't view their life as merely the average of all its moments—which, after all, is mostly nothing much plus some sleep. For human beings, life is meaningful because it is a story. A story has a sense of a whole, and its arc is determined by the significant moments, the ones where something happens. Measurements of people's minute-by-minute levels of pleasure and pain miss this fundamental aspect of human existence. A seemingly happy life may be empty. A seemingly difficult life may be devoted to a great cause. We have purposes larger than ourselves."

— **Atul Gawande, Being Mortal: Medicine and What Matters in the End**