

The Theory of Everything

The extraordinary and the ordinary

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As a physician who specializes in the care of individuals with amyotrophic lateral sclerosis (ALS), I was reluctant to see *The Theory of Everything*, a movie about the life of Stephen Hawking. I generally do not like to spend my leisure time immersed in the subject that dominates my days. However, after reading about the Academy Award nominations and hearing about the movie from friends, I settled down in front of the TV, rented the movie, took a deep breath, and plunged in.

My major impression? I was struck by the ordinariness of his life.

Does that sound absurd? How can the life of one of the world's most brilliant and famous individuals, who also happens to have survived more than 50 years with ALS, be ordinary? When viewed through that prism, it certainly is not. Yet, when I stepped back and viewed Professor Hawking from a physician's perspective, I saw a patient much like those I care for every day.

The large referral hospital where I practice serves a part of Pennsylvania predominantly composed of small cities, even smaller towns, and rural areas. Yet, in many respects my patients' goals, behaviors, and personal lives mirror those of Professor Hawking. When I look at the profound physical and emotional consequences of ALS for him and for his wife, I see the enormous challenges faced by the factory workers, sales clerks, secretaries, police officers, teachers, computer programmers, engineers, custodians, auto mechanics, nurses, and scores of other ordinary patients and their caregivers who come to our center for care.

Professor Hawking's struggles, as presented in the film, were heroic. He struggled to climb stairs, fell while attempting to walk, choked while eating, and lectured in a voice so slurred it was barely intelligible. Yet, he does not seem all that different from so many of my patients who have refused a wheelchair because "I'm not ready for that," or who declined to ask for help because they are so fiercely independent.

I recall a man who insisted on driving his tractor despite the high risk of falling and injuring or killing himself. I think of the teacher who continued to teach or the secretary who continued to work at her desk as her voice became progressively harder to understand.

The bank teller comes to mind who could no longer use her right hand to count money, so instead relied increasingly on her left hand to do her job. Then there was the roofer who continued to climb despite high personal risk, or the auto mechanic who could no longer repair a car, but could still supervise and oversee others.

Why do these individuals persist in these frustrating and unsafe activities? Earlier in my career, I was frustrated when patients with ALS would politely receive and then ignore our advice. Why would they endanger themselves, rather than follow the guidance of professionals who knew what was appropriate and safe?

I am not at all certain that age brings wisdom, but it certainly brings perspective and experience. In the end, all of us, even when limited by a devastating illness, must engage in those activities that bring value to our lives, or life is not worth living. I can provide advice, but ultimately patients must seek a compromise between a meaningful and potentially dangerous life, and one that is safer but less meaningful.

Individuals with ALS adapt and find meaning in various ways. As Professor Hawking's ALS progressed, he suffered a series of losses, and eventually accepted a wheelchair and a communication device. He permitted himself to be carried from one location to another, but managed to maintain his sense of humor and his dignity. This reminded me of my patients who use eye-tracking systems to communicate at a few words a minute, but who preprogram hilarious comments to spring on me and other unsuspecting listeners. I also think of patients who take hours to get dressed, get into their power chairs, and allow themselves to be taken on long trips to attend their children's and grandchildren's musical performances and athletic events. Are they worn out, self-conscious, and embarrassed? That is not what they tell me. Simply being there clearly trumps any inconveniences to them and their families.

Professor Hawking summed it up well:

There should be no boundaries to human endeavor. We are all different. However bad life may seem, there is always something you can do, and succeed at. While there's life, there is hope.¹

So, just as Hawking has pushed the limits of his endurance to continue doing what is meaningful for

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him, our patients, on their own smaller stages, are acting in the same play and assuming the same role.

Life for caregivers may be even more difficult in other ways. When I saw Stephen Hawking's wife, Jane, becoming physically and emotionally exhausted as she cared for him and their children while trying to earn her PhD and manage their household, I thought of our caregivers. They become reluctant to leave the house even for short periods of time, fearing that their loved one will become sick, or fall, or choke, or become uncomfortable, or even die during their absence.

When Hawking and Jane divorced, I saw the tremendous strain that ALS places on all couples. Some bonds strengthen while others strain or break during a life-threatening illness, because people with ALS and their caregivers are human beings, with their strengths and weaknesses, their desires and goals, their needs for companionship and enjoyment. Relationships are complex, and it is difficult or impossible to classify people as good or bad.

I do not in any way mean to diminish the accomplishments and courage of Professor Hawking. The world is a different place because of him. However, Hawking's personal triumphs and tragedies are not all that different from those that occur every day in the lives of thousands of individuals with ALS. *The Theory of Everything*, by highlighting the struggles, courage, resilience, triumphs, and failures experienced by all individuals with ALS and their caregivers, shines a much needed light on the extraordinary challenges and complexities they face. I hope that I am never tested in this way, but if I am, I hope that I can perform with half the grace, dignity, and strength of Stephen and Jane Hawking, and of so many of our patients and their caregivers.

REFERENCE

1. IMDb. Quotes for Stephen Hawking from the Theory of Everything. Available at: <http://www.imdb.com/character/ch0067083/quotes>. Accessed March 1, 2015.

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