

In Sickness and in Health ... Until Death Do Us Part

Asad I. Mian, MD, PhD
Rakhshee Niazi

Correspondence & reprint
requests to Dr. Mian:
amian@bcm.edu

As a young physician I would challenge the potential fatality of illness, and my medical overconfidence scorned the concept of being at death's door. Now that I'm older and hopefully wiser, my exposure to recent illness, dying, and death in my own patients, family, and friends makes me ponder my own mortality. From a nonmedical perspective, overcoming fear of death is part of life. If we consider dying and death to be a journey, then that realization can be quite emancipating and exhilarating. We are then more likely to embrace both life (and death?) more passionately.

End-of-life decision-making has been a huge part of my professional medical training in America. I have had many discussions with my wife, Aysha, about how no heroic measures should be taken if I were to be in a serious motor vehicle collision, or if I developed a neurologic illness or cancer that left me devastated and on a ventilator. An advanced directive is helpful, but despite that, the decision to discontinue care can be a hard one for a spouse.

To get some insight, I approached my teacher, Rakhshee Niazi, who recently lost her husband to amyotrophic lateral sclerosis (ALS). I asked her: "How did you reconcile with your decision to have your husband, Anver, fully resuscitated the time when he ended up on the ventilator and for the subsequent 15 years? Did you and Anver at any point consider do-not-resuscitate (DNR) status? I've never had this discussion with someone who actually had to go through with making such a decision. I've assumed from my cut-and-dried medical perspective that logic would be to let the person go."

The response that I got from her shook me to my soul. It presented a very different perspective and is a stark reminder that there are few absolutes in life.

ANVER'S STORY AS RETOLD BY HIS WIFE I have gone down memory lane these past 2 days as never before since Anver died, laughing and crying by turns. We had so much laughter and so many tears in our lives, but is that not what life is all about?

I met Anver in 1980. He was an MBA involved in the garments export business. We were married in 1984 after a whirlwind and most romantic courtship, full of flowers, long drives with lovely music, beach

parties, and candlelit dinners. He was 31 years old, I was 23. Our son, and only child, was born the year after.

In June 1990, at 37, he complained of cramps in his legs and began to stumble and fall, especially when he turned in midstride—as if his legs were receiving the message to turn a mite later than the rest of his body. By December, he was walking with the aid of a stick. In January 1991, he went to London and was diagnosed with ALS. That was the first we had heard of the disease. The doctor gave him a life expectancy of anywhere between 1 and 5 years—when it was predicted that Anver would be unable to breathe on his own.

About a year before he was put on the ventilator, Anver began having problems breathing. For a long while we thought it was due to lung infections, for although he already had a gastrostomy, he enjoyed a little food by mouth too. He would aspirate and develop lung infections quite frequently.

When he began to feel continuously short of breath his doctor told us our options: the ventilator or coma and death as his oxygen saturation fell. I remember those 2 days and 2 nights that we talked through what it would mean for him to go on the vent. Although neither of us said it, what was really being decided was whether he should live or die ...

He was very clear about one thing. If going on the vent meant spending the rest of his life in hospital, he did not want it. And the only vents available in Karachi were those in hospital ICUs. But then one of those strange coincidences that one can never fathom occurred. A friend mentioned Anver to her sister who lived in New York. The sister's husband was a pulmonologist, and his father happened to be coming back to Pakistan in 2 weeks. He would send us a portable vent. We had not even known they existed.

The morning after I spoke to the pulmonologist in New York, in October 1995, we had to rush Anver to hospital. By the time we reached the emergency room he had no pulse, no blood pressure, and his oxygen saturation was 52%.

By that time, he had by degrees lost all movement in his limbs, had lost his speech, and had to be fed by a tube in his stomach. Except for smiling, his eyes, eyebrows, and thumbs were the only parts of his body he

Listen to Dr. Mian read this account, available exclusively on *Neurology*® for the iPad®.

Note: Rakhshee Niazi has agreed to use real names.

could move. His eyes followed his son whenever he was in our room. His smile lit up our world.

When Anver was diagnosed with ALS, my brother-in-law remembered another man with the same disease—Stephen Hawking at Cambridge University. We wrote to him and a reply came within 8 days telling how he coped, what diet helped him, and what computer program he used to communicate. We got the same computer program, which had been developed by an American for paraplegics. Anver could work it with a switch attached to his thumbs, give us instructions which we could read on the computer screen, and conduct his garments business from his bed. Later, when he lost the movement in his thumbs, we acquired a switch that responded to the movement of his eyebrows. By 1998, Anver had lost the controlled sustained movement of his eyebrows and the computer program became useless. But we had become very proficient in communicating by the movement of his eyes and eyebrows. And that is how we communicated for the remaining 10 years of his life.

Anver agreed to go on the vent with one other condition—that when the time came I would not hesitate to turn it off and that I would do it myself. I asked him how I would know it was time and he said, “You will.” I asked him how I would be able to do it myself and he said, “You will.”

Fifteen years later, when the time came, I knew and I did. I was away from Karachi that day and called home in the morning, as was my norm any time I was out of town. Anver was happily playing the stock market. He went to sleep at 2 PM as was his routine. My son was with him and Anver held on to his hand and, looking upon his son’s face, went to sleep. He did not wake up again.

Just 2 days earlier my son had gotten his first job. He had graduated from university 2 weeks before that, and Anver’s mother had died a month earlier. All her prayers in the last 20 years of her life had been for Anver, her firstborn. I don’t think she could have borne his death. Anver’s father had died 2 years earlier, after multiple strokes robbed him of his language memory. He forgot everyone’s names but Anver’s.

At 4 PM my son called to say he could not wake up his father. I was a 1,000 miles and a 2-hour plane journey away. The earliest flight was at 7 PM. It was the longest flight of my life. My son had taken his father to hospital, and the doctors had told me Anver’s condition was critical. He had no blood pressure and no pulse.

I arrived at 10 PM. He had not woken even once, and even I could see how unreactive his pupils were.

I don’t know if he had any more life written for him, but I knew he would not want that life. I did not have to make any decision; he had made it for me. I only wanted to know, when I turned off the ventilator, whether he would struggle to breathe. The doctor told me no. He also told me to take my time, there was no hurry.

So I said my goodbyes to Anver in all the ways I knew for as long as I wanted to. So did his son, his brothers and sister, the boys who took care of him day and night, and every friend, family member, doctor, nurse, and technician who was there at that time.

After a 15-year reprieve and all the time in the world to say goodbye to him, what more could I ask for; what more could I possibly want? I turned off the ventilator and then I held him. There was no struggle, no spasm, just 2 breaths and a deep sigh, and he was no more. And yet so much more ...

I went to the graveyard to bury him and I dared anyone to tell me I should not. No one did. I kissed his face and covered it before they slid the cover on his grave and I dared anyone to tell me I should not. And no one did. As I turned away, Anver’s brother put his arms round my shoulders. I thought he was comforting me but he just turned me around and pointed to a grave right opposite Anver’s. The tombstone said *Anvery Begum!* Even as tears were rolling down our faces we burst out laughing, for, you see, *Anvery* is the female form of the name Anver and *Begum* means wife!

Many weeks later, the Imam who had led Anver’s burial prayers met me in the graveyard and said he has buried at least one person every day for the past 50 years but he had never had so many shocks in his life as he did that day. First, the wife and 4 of her female friends insisted on coming to the graveyard—not a custom in our culture, though strangely enough, not forbidden in Islam. Second, not only did she intrude upon what is traditionally an all-male affair, the wife insisted upon kissing her husband’s face in full (male) public view just before he is put in the ground, and that too in a culture where the slightest intimacy between husband and wife is considered strictly private. And third, not 15 minutes after he was buried, the brother, sister-in-law, wife, and wife’s friends, with visible signs of grief on their faces, fell about laughing in complete disregard of propriety and the somber nature of the occasion. He must have thought we were stark, raving mad!

I began writing this last night and could not stop. I recalled the marriage vows, “in sickness and in health”; I will add “for better or for worse.” He was so much the better ...

Neurology®

In Sickness and in Health ... Until Death Do Us Part

Asad I. Mian and Rakhshee Niazi

Neurology 2012;79:e185-e186

DOI 10.1212/WNL.0b013e318275977b

This information is current as of November 26, 2012

Updated Information & Services	including high resolution figures, can be found at: http://n.neurology.org/content/79/22/e185.full
Supplementary Material	Supplementary material can be found at: http://n.neurology.org/content/suppl/2012/11/29/79.22.e185.DC1
Subspecialty Collections	This article, along with others on similar topics, appears in the following collection(s): Amyotrophic lateral sclerosis http://n.neurology.org/cgi/collection/amyotrophic_lateral_sclerosis_
Permissions & Licensing	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: http://www.neurology.org/about/about_the_journal#permissions
Reprints	Information about ordering reprints can be found online: http://n.neurology.org/subscribers/advertise

Neurology® is the official journal of the American Academy of Neurology. Published continuously since 1951, it is now a weekly with 48 issues per year. Copyright © 2012 American Academy of Neurology. All rights reserved. Print ISSN: 0028-3878. Online ISSN: 1526-632X.

