



Greater New York Chapter
42 Broadway, Suite 1724
New York, NY 10004
212-619-1400
f: 212-619-7409
www.als-ny.org

First-Class Mail
U.S. Postage
PAID
New York, N.Y.
Permit No. 7566

Rising Above: A Son's Story by Tom

I was sixteen when my father was diagnosed with Amyotrophic Lateral Sclerosis in 2005. A surgeon by trade, he had to stop working almost immediately-the degeneration began in his arms. An adventurer unaccustomed to barriers, he at first found it difficult to make use of his spare time-so many of his hobbies were served by simple motor functions he could no longer perform. But, ever the inventor, he would look for ways around (an ill-conceived attempt to waterski without using his arms). Although his legs began to deteriorate and he became wheelchair-bound, his spirits remained remarkably high. Two years after diagnosis he was confined to a breathing-assist system and a bed twenty-four hours a day. He passed on in 2007 surrounded by friends and family. He was 53 years old.

This experience may seem a harsh reality, but I have been made a better person for it. Witnessing the trials my father endured, and the fortitude with which he endured them, inspired me to accept what had happened and move on. In his last days, my father would reiterate how proud he was of me and my younger brother. I was determined to continue living that kind of life. He asked us to watch over our mother, who spent countless hours caring for him in the later stages of the disease. I was determined to keep that promise. I wanted to turn this situation on its head and use it to project myself out into the world.

Nine months after my father died, I entered college in New York City to pursue music.

I had always loved music, performing throughout my childhood and into high school, and my father had been such an ardent fan. I knew he would have been inexpressibly proud to see his son go off to school and succeed. I have gone on to encounter new surroundings and people, constantly absorbing and learning. I feel incredibly fortunate to be in such a position.

Perhaps what I went through is impossible to convey in words. But it generated a sense of mysticism within me, a sense of the ethereal. If I can rise above the devastating passing of my father, I can rise above all else. I gained a unique sense of perspective largely through my family's experience with ALS. Now, whenever I think of my father I think of the quirky way he shot a basketball, of the countless patients he treated, of his existence in infinite times and spaces and places and ideas. Death may be permanent, but so too are memories. My ephemeral connection with my father will remain close at hand, always encouraging me to persevere.

Tom is a volunteer at The ALS Association Greater New York Chapter.

Remember to Register: People living with ALS may self-enroll in the National ALS Registry via a secure online web portal at the Centers for Disease Control and Prevention, www.cdc.gov/als. For more info about the registry go to: www.als-ny.org or call the Chapter office at 212 - 619-1400.