For the last few years, Professor of Molecular Physiology & Biophysics and Pharmacology Joe Patlak has dealt with amyotrophic lateral sclerosis as a “part of my journey through the garden of life,” as he describes it on his internet blog. This essay is just one of the elegant dispatches from that sojourn to be found at http://viewpoint-als.blogspot.com.

Amyotrophic Lateral Sclerosis is a disease of the motor neurons. Although the nervous system has trillions of working cells called neurons, most are fairly small and only responsible for local communication. One type of nerve cell is the motor neuron. They are huge by comparison, like old-growth sequoias, stretching from brain to spinal cord, or from cord out to the muscles themselves. In most people the motor neurons function without interruption throughout life, giving us the ability, usually taken for granted, to deliberately control our movements. ALS affects specifically these mega-neurons, for reasons that are not understood. It often strikes in the prime of life, and when it does, it burns through these old-growth stands with the ferocity of a forest fire. First only minor changes are noticeable, but within the next few years weakness and paralysis spread progressively from one region to the next.

My own case is fairly typical: at age 52 I noticed that my left hand and arm were weakening, and that my legs felt odd, shaky. Working with my neurologist, we ruled out other diseases that could have caused such changes. But nothing fit the symptoms like ALS. In the end it doesn’t matter what name or neurological classification one uses: I am losing motor neurons at a precipitous rate, and there is no known way to do a thing about it. A diagnosis like this stereotypically comes with a warning to “get your affairs in order”. Suddenly the balance of normal life was gone, the footholds vanished. I have been falling for two years. At first the changes were so minor, yet the knowledge of future weighed so heavily. The famed sequence of denial, anger, bargaining, depression, and acceptance came all at once, jumbled, changing daily, hourly. But acceptance came quickly enough. There I was, like an old fashioned cartoon character, hanging midair, several steps beyond the precipice but only slowly realizing how far down the bottom looked. I was falling.

SUDDENLY, I was falling. Time changed, perceptions heightened, the world became a different place. My precipice was nothing more than the slightly uneven threshold at the front door of our local truck rental place. That little extra unanticipated step caused my knee to buckle, and my ALS-weakened legs had no reserve to compensate. Time slows in that moment between standing and landing. I was looking for a handhold, wondering who might be seeing me in my moment of embarrassment, trying at least to fall with grace. I was falling, and in a split second I was journeying out of the world of the able. This is the fall of ALS.

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As a society we love to fall. Some jump from planes for the exhilaration of a few minutes free fall, others seek out the highest peaks to ride down, or the highest cliffs to dive from. It's the ride that counts, the control on the descent, the grace of the final landing. At that moment, hanging still at the top of the precipice, I suddenly had to decide how I would fall, how I might stay in control of the ride, how I might land.

Adaptation is the only defense when ALS is on the rampage. As one muscle failed, I learned to adapt by substituting a different one. If my dominant left hand could no longer write, my right hand wrote instead. If my leg couldn't move, my arm did the work. It's remarkably automatic, although there is always an adjustment period. I had to start adapting my expectations, my relationships, my emotions as always an adjustment period. I had to start adapting my disability would drive us from our home.

We chose, instead, to adapt our housing like I was trying to adapt my body. We worked with an architect experienced in handicapped design, and with a dedicated contractor. We eliminated my need to climb stairs by building a new bedroom and bath room in an addition. We opened up the interior to give a holler. I was discovering that I could stay in control, even while falling. Like Alice in her rabbit hole, I found the well very deep and the fall very slow. I had time to grab at marmalade jars, to probe into cupboards at each level. Falling slowly, but not able to stop or even pause a while. Yet I don't fall alone.

One Thursday evening last spring, Elke and I went to the local repertory theater. We were slowed by the overworked Emergency Department resident to check on my status. But my fears evaporated. All it took was a quick separation of two important concepts, wellness and ability. It took but a few words to say I was well, a look from eye to eye, a light tone of voice. Well meant not ill, and not ill meant not life-threatening potential, who knew what it meant to gradually fall in your abilities. My fall took me through the community of the elderly, and they hospitably treated me as an honored guest. Before leaving I learned the grace of my elders who have come to terms with life as it is and with an impending end.

I have moved on, always drifting downward. Construction was completed, we reloaded our house, and I've moved into position for the next acts of the drama. My legs are nearly useless, one arm is limp, and stomach, back and neck are getting unsustainably weak. A wheelchair is my vehicle of choice these days (indeed, I may be turning into a connoisseur of wheeled personal vehicles). I am passing through the community of the disabled. This seems a more solitary place, as I journey for the wheelchair-bound, I thrill, in my naiveté, at being able, provisions made and ADA regulations addressed. Although our world is far from perfect able, provisions made and ADA regulations addressed. Although our world is far from perfect. Yet the residents have made their mark. Sidewalks and public buildings have ramps, doors are workable, provisions made and ADA regulations addressed. Although our world is far from perfect able, provisions made and ADA regulations addressed. Although our world is far from perfect for the wheelchair-bound, I thrill, in my naiveté, at each success. Without support from the shoulders of the giants who have shaped this landscape, I would have long-since crashed. ALS is a prism, spreading out the spectrum of disability, showing one hue at a time, a continuum of abilities spread out over time. At each point in that spectrum, one can be well or one can be ill, because that is a separate, unconnected gradient. Those who reside in the community of the disabled know this, and now I know it too. Regardless of ability, one can be well and ready to continue the journey. But as my abilities fail, the bottom of the well, the rabbit hole, looms. I may crash land, I may continue to plumb new depths, or I may crumble gracefully into a jumble of arms and legs. Will the ride become too tedious, too painful, too exotic to maintain? Could I really decide to pull out, this close to the end? I can all do I can do now is fall—perhaps to the bottom, still graceful, unable to fall any more.  

On January 11, 2007, friends and colleagues gathered in the HSRF Gallery to celebrate the more than quarter-century career of Joe Patlak. Joe is internationally recognized for his expertise in single molecule biophysics, focusing on ion channels and molecular motors in the cardiovascular system. As an educator, Joe was founding course director of the Cardiovascular, Respiratory, and Renal course within the Vermont Integrated Curriculum and Director of an NIH Training Program in Molecular Mechanisms of Muscle Contraction. One of Joe’s most notable impacts on the College of Medicine was his introduction of the Internet to the College years before it became a commonplace of everyday life.