

The Quality of Life

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As a child I always enjoyed going to the doctor. I inhabited a paradisiacal little coastal town and I played and lived just like other children; well, mostly. The doctors would pay so much attention to me and the newspapers would write stories about me and my *remarkable* abilities and achievements. In school they gave me more time to work on tests and answer questions. Things changed when I became a teenager. On occasion I would walk into poles or park benches. Once I even fell down a flight of stairs. The teachers would sometimes feel very sorry for me and did the best they could. I would simply get up and march on, with the hope that only the teachers saw. I didn't really enjoy participating in athletics with people I didn't know. Socially I felt a little isolated from people, but they told me that all adolescents have that problem; eventually I would grow out of it. They told me that *my* disease was degenerative.

That sense of 'specialness' wore off momentarily when I was sixteen. I went back to my doctor and was again tested. The room was

warm with the light from the window and after dictating the examination with a low voice into his small voice recorder; "*extensive damage to the neural fiber layer 360° with bone spicules, massive disc drusen, and macular edema with 4+ exudate,*" the doctor in a soft but detached melancholy voice asked me if I had ever thought about genetic counseling. I was of age now, and it was about time for me to think about these grown up *issues*. I should seriously consider the consequences and responsibility of bringing a child into the world. Would I condemn that child to a disease resulting in a lesser quality of life, and was I really capable of safely raising a child? I never went back to that doctor; perhaps out of fear, or out of anger, I can't quite explain why. I came in expecting the doctor to give me something, to *add* something to me; not to take something *out* of me. What could have made me feel so empty; like a hose that has been lifted up to let the water run out both ends.

Years later I spoke to my brother, who is one of the three blind siblings in my family I flew home to visit and we stayed up most of one

night talking about those formative years before we all got married. He was also frustrated. As a blind boy in a sighted world he wanted to have the same hopes and dreams as other kids, but every path that the world offered him ended with a barrier that read “blindness.” The questions, familiar to those who are weary of considerations would inevitably arise. Why me. If there is a God, why has he abandoned me to a life of futility? “I really could have messed up my life if I didn’t cling to hope in those years” he said. Lorin, is about 6’3” and has a muscular build. Before becoming a nationally distinguished musician and father of four, he was a physical therapist who worked with Olympic Athletes. Lorin explained it to me like this: “Before I was born, I believe I was given the choice between being blind—but with tremendous opportunity to develop my character, *or* being sighted and not becoming the kind of man I am today. I believe I chose to live a life with disability because I knew I would develop the higher aspects of my soul. I grasped that hope so tight, even past the point of reason or reasonability. And after a short time wandering in the forest, my path showed itself to

me; the path that only I could see, lighted by my enduring hopes and dreams.”

The skeptic might say that Lorin was simply falling back on some elaborate defense mechanism. Regardless, my brother reminded me of Victor Hugo’s prescient words, who pointed out that:

The wealthy young man has a hundred coarse and brilliant distractions; occupations for the baser side of the soul, and he develops these at the expense of the loftier and more delicate sides. The poor young man goes with the spectacles which God furnishes gratis; he gazes at the sky, space, the stars, flowers, children, the humanity among which he is suffering, the creation amid which he beams. He gazes so much on humanity that he perceives its soul, he gazes upon creation to such an extent that he beholds God. He dreams, he feels himself great; he dreams on, and feels himself tender. From the egotism of the man who suffers he passes to the adoration of the man who understands.

We all come to this world with two things which allow us to do the real important work of life: spectacles and a body. The doctor’s work is on the body, and so I would sit across from the microscope that was situated between me and my eye doctor. He would look at my interesting pathological findings. I no longer mind the fact that there is no cure. I understand that a doctor’s livelihood is to preserve and enhance my vision, but when that is not possible what then? Reduce

the likelihood that I may spread it to my children? Not have children? Is this just selfishness on the part of the doctor who wants fewer untreatable diseases to deal with?

Doctors come from a privileged aristocracy of wealth and learning—most of which was handed down to them with much tradition and ceremony. I fear that the tradition of *transference* has allowed doctors to absolve themselves of the responsibility for mistakes they make, and primary among them is this: doctors know not, neither seek to know, sufficient personal grief or tragedy to be able to *condescend with* the patient in our suffering in a way that gives us hope and joy. The lure of comfort and position is too great for the doctor, who keeps her distance, lest she understand grief! Please don't misunderstand me, the last thing I want is for somebody to feel sorry for me, nor do I wish suffering upon the surgeon, but the quiet suffering that softens hearts is the true mark of a healer. For are we not all bound to molder in the ground? Do we not all have reason to yearn for something greater for ourselves; something greater than we may be at

present, or even in the future in spite of the apparent futility of life?

The will to faith, borne from our yearning, is a call to attune our hearts and integrate our character with principles that we devoutly hope, and for which we have reasonable but not certain grounds to believe are true. We are as a balance with weights tethered on each side; sitting in equilibrium to the forces of cynicism and faith. We have both grounds to believe and grounds for doubt, but faith in what? We all create God in our own image, or potential image, and perhaps for the doctor or scientist who works to eliminate pathology, that potential image is a society absent pain, suffering, disability and as a result the absence of the incomparable yearning that results from groping in the dark for some understanding of existence. What will happen when there are no more heroes to save, no more hands hanging low to lift, no more downcast eyes to raise to the light; just everybody with their eyes muddied and hands burdened by mundane materialism.

I am not saying that poverty, disability and suffering, alone are good things, but what kind of people will we become when we can no

longer contemplate the depth of Shakespeare's tragedies, or the pathos of Dostoevsky. Imperfection and fragmentation is not ideal, but is there not some beauty in fragments, however imperfect; something that is noble in all of our somewhat shattered lives? I have always looked at life through a splotchy, fuzzy visual field, but life has taught me that there is more to my experience than sight. Let us recognize and seek together that solemn yearning within each of us which Wordsworth expressed when he said that: "unless above himself he can erect himself, how poor a thing is Man!"

That good may be found even in sickness, the Greeks recognized long ago. They understood that there must be opposition in all things, else, how can we recognize the well if we know not the ill. It was Nietzsche who, speaking of Mozart, rejoiced that "the last chord of centuries-old great European tastes . . . still speaks to us," but he warns that "alas some day [even] this will be gone." The new social-

evolution has brought us the selection of more consumption and droning entertainment while the poor of Africa and three out of every four down-syndrome fetuses perish. Society risks becoming a sterile, tone-deaf, monochromatic mix of individuals who merge but never become miscible. Just as our American cities increasingly become, as John Steinbeck put it: "Gopher holes ringed with trash," so too are our souls becoming as we burrow into ourselves—not really seeking to understand, not full of passion or yearning, reflexively following our base instincts in pursuit of the frothy pleasures of our private lives.

I may be blind, but I don't need pity or misdirected compassion. I want to be understood as a person who breathes, thinks, suffers, and who yearns deeply; a person who occasionally revels in the joy of her existence. I want to be recognized as a person who is intent on using the good parts from my imperfect genetic list for something good—and hopefully grand.

(Author's note—I wrote this about my wife who has a more severe form of Retinitis Pigmentosa, and who comes from a family with three blind siblings. She reads Braille and walks with a long white cane. She was born and raised in Australia and came to the states to attend University. We have been married since May 2003.)