

Cripple's Kid

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It's hard to pinpoint the exact time I learned my father had multiple sclerosis, only that my life seems evenly divided between the time before and after I heard the news. I was about eleven. We were living in Madison, Wisconsin and life consisted largely of trips to the beach, baseball, family picnics, and the like. It was in its own way an idyllic experience while not being different from that of anyone else I knew. It was idyllic, I guess, in a typical way. Typically idyllic, though my parents were truly never typical of anything.

My father was a violinist, trained at Curtis, who had made his debut at Town Hall and was in a modest way famous, or at least well known nationally for a younger fiddler. He had come to Madison in 1947 to join the Pro Arte Quartet, which was then in residence at the University of Wisconsin, though the real reason was the opportunity to concertize with Rudolf Kolisch, Schoenberg's brother-in-law, who had recently come to lead the quartet. My father was a protégé of Kolisch's and had previously played in the Kolisch Quartet in New York. He would have done almost anything the older man wanted him to do, which led to a wide variety of pursuits including chess, Go, and a fierce dedication to Wilhelm Reich's orgone theory.

My mother was also an artist, though a painter and potter who had trained first at Alfred and then at the Art Students' League. To say she was not as serious as my father would not be true, but she was not as well known and was happy to come to Wisconsin, which she saw as a better place to raise kids than Manhattan. They were New York bohemians in a sea of Midwestern ordinariness, though because of their gifts they were not merely tolerated by the natives but admired. My father didn't appreciate this, however, hated small-town life and frequently referred to himself as a "prisoner of Madison, Wisconsin." Had he been more candid, he might have amended this to "a willing prisoner" but that wasn't his style. He lived large and saw things his own way.

I doubt that either of my parents had intended to stay in Madison for long. At 28, my father was by far the youngest member of the Quartet and while he understood this to be a great opportunity for him musically, I imagine he saw himself playing with Kolisch for a few years and then returning to civilization and resuming his own performing career. One thing I know is that

he didn't plan on getting sick, but then who ever does? And at first the nature of his illness was a mystery. Little was known of MS at the time and when he developed the characteristic vision problems, the first approach of his doctors was to perform an operation on his optic nerve. This, of course, was a failure since there was nothing wrong with his optic nerve.

In time, my father's eyesight improved but then he had lightheadedness and problems with balance and fine muscle control. One night, he fell onstage and another time he tripped on the street, cutting his jaw but damaging his pride most of all. Eventually, the diagnosis was made and our lives changed forever. However I had seen myself before, I would now think of myself primarily as the son of an invalid rather than the son of a famous musician, and our family was as clearly marked by this as if someone had actually put a sign on the door. It was the way we were seen by others and how we saw ourselves. Or as a friend rather unkindly but honestly put it one fall afternoon in 1958, I was a cripple's kid, and a cripple's kid I would remain.

Eventually my father was forced to retire from the university and we left Madison. My mother took a job at the Milwaukee extension. What may have been idyllic before was idyllic no more.

Although an uncle was similarly afflicted, MS was not thought to be a familial disease at that time, and my parents went to considerable effort to assure my brother and me that this was something we would never experience, that we would instead live long, healthy lives. As far as I can tell, my brother accepted this, so why wasn't I similarly convinced? Why in later life, whenever I would stumble over nothing, would I attribute it jokingly to the inevitable onset of the disease; why, when my eyes would occasionally lose focus when looking at a page, did I fear it was an early sign of MS? Why? Well, why not? After all, our family seemed doomed. Two grandparents had died in their forties and another uncle had died on the operating table while undergoing a supposedly routine operation for gallstones.

Moreover, I was surrounded by disease in the wider world. The boy across the street contracted polio in the epidemic of the early fifties as did another a block away who bore a hole in his throat from the iron lung to prove it. A hemophiliac lived two doors away and the woman next door was taken away with tuberculosis in the dead of night by an ambulance. An albino lived across the back fence and while as far as I knew this wasn't contagious, you never could tell for sure. I grew up feeling that the world was a dire and dangerous place, and in high school read Poe's "The Masque of the Red Death" as stark realism rather than fantasy.

Given all this, it's odd that I don't remember illness being a frequent topic of discussion in our home. My mother, a Southern aristocrat who had outraged her family by marrying a Jewish musician, believed in maintaining a stiff upper lip at all times. A gracious woman with a soft Kentucky accent despite her long absence from Lexington, she maintained her optimistic attitude to the end. When she was dying of breast cancer at a relatively early age, she insisted in her high fluting voice to friends that she had had a good life, despite losing both parents, a baby shortly after birth, and her husband to chronic illness. "Only you would say so, Ruthie," an old friend intoned.

Stoicism in the face of tragedy was the ethos in our home. For us, the accoutrements of invalidism were part of daily life: the waiting wheelchair, the parallel bars in the dining room, the Canadian canes leaning against the wall, the adult diapers, the Heuer lift in the corner, the handholds in the bathroom and the reinforced bars encircling the toilet. All seemed absolutely ordinary to me and were neither unusual nor depressing with the passage of time.

Things gradually changed for the worse, and by the time I was a teenager my father needed help whenever we went out. Frequently he rested heavily on my brother and me, calling us his million-dollar walking canes. But I was also aware in that unenlightened time of disapproving stares from neighbors who apparently assumed my father's unsteadiness was due to failings of character. Just as in Madison initially, he was suspected of being a drunk, so now people often seemed to resent my father for having embarrassed *them* by daring to appear at the restaurant or movie where normal, healthy people had congregated. It was in its own way typical of the times, an American insistence on normality. Handicapped children were kept squirreled away in special schools where they wouldn't contaminate their more fortunate peers. A woman from the Multiple Sclerosis Society told me people didn't want to receive their newsletter for fear the postman would spread the word about their infirmity. As far as I could tell my father never noticed any of this, or perhaps he didn't care. But my brother and I did and we were appropriately outraged for him about it.

What was perhaps most surprising—after I metabolized the idea of an illness that could not be cured—was my father's reaction to having suffered this fate. It seemed to have no effect on his sense of himself. The term invalid, carrying with it the suggestion of some kind of illegitimacy, never seemed to penetrate. He still thought of himself as a musician and would refer casually to his height as though he were able to stand upright. No longer the sole support of the family, no longer the breadwinner or a recognizable figure around town, one

might have expected anger and defensiveness to follow, but my father was calm, even sweet. My mother claimed the disease had actually affected his temperament for the better. I wouldn't go that far, but he was accepting of his condition to the point that he didn't even acknowledge it. Certainly, he didn't consider the disease to be an important part of his life, regardless of the draconian effect it had had on his career and family.

I asked him once if he felt angry to have lost his musical life so precipitously when it had begun with such unexpected brilliance. He looked at me with a half-smile on his face, as if talking to an idiot. "I never really liked it," he said. "The traveling, the lousy food, trying to get your laundry done in the middle of the night in a strange town, all of that. There was never any place to practice in the hotel and I was away from your mother too much." He shrugged. "It was a living. I did it because I was good at it, but that was all."

Not satisfied, I pressed on. But he had been famous, people had known who he was. Didn't he miss that? My father shrugged. "It's nice at first," he said, "to be recognized, but it becomes a bore and the people who aren't insincere don't know anything about what you're doing. Your friends, the other musicians know, but they're not that impressed because they're all doing the same thing."

What about being confined to his room, eventually to a wheelchair? This seemed to interest him only marginally. "What was I going to do? Run the hundred-yard dash? I was always an intellectual even though I never graduated from college. When I wasn't working, I always had a book I was reading. Now I can do that all the time."

This seemed like denial to me, but it didn't upset my father to talk about it. He also rejected the traditional battlefield metaphor of illness, the idea that he was fighting MS, hanging in against the enemy. "How can you fight bacteria?" he asked logically. "I guess I'm a conscientious objector, but really, it's kind of a ridiculous idea, isn't it? I don't think God has a plan or that there's a reason for any of this. It just happened, that's all. I think that's harder for people to accept than the fantasy that there's a plan, even if the plan screws up their lives. I see it differently. As far as I'm concerned, we live in a random universe and what happened to me is a random event."

Which meant, as we'd find out later, that he was the perfect patient, pleasant, cooperative, often funny, because in his view nothing had really happened in a personal way. He would never "rage against the dying of the light," because to him there was nothing to rage against. I often wished, however, that he had been more affected in that way, more vulnerable, perhaps more human. To me, he was as he'd always been: superior, commanding, as aloof from my

passion for sports and contemptuous of conventional values as he had been when he was an international recording artist.

In a sense, his refusal to react meant that I had to react for him: his unwillingness to become angry made me angry; his lack of outrage at the manifest unfairness of our situation inflamed my sense of justice; his lack of embarrassment at the telltale spots of urine on his pants, the coffee on his shirt, made me cringe with shame. I became, in short, his emotional shadow, feeling all those things it would have been understandable for him to feel, if he had been a different kind of person.

I was not conscious then of all this; that came later. Nor did I think of myself as living under a cloud. But the sickroom ambiance of our house induced a kind of passive pessimism in me. Why try in school or indeed in anything if you were just going to have it ruined inevitably by illness? And, paradoxically, the reverse: that it was precisely my father's brilliance and early success that had done him in. Damned if you do and if you don't. Whatever the reason, I was a mediocre student at best, making only a C-plus average at my blue-collar high school and later nearly flunking out of college.

The fact that my father accepted his situation did not mean he didn't yearn for surcease. My adolescence was filled with stories of experimental treatments, miracle cures and correspondence with homeopaths and physicians in far-off places. Periodically we would be packed into the Plymouth and taken to places like Michigan City, Indiana and Mobile, Alabama, when my father heard a new approach was being tried. We even traveled once to the Berkshires when my father had heard a man named Joseph Pilates was having remarkable success there with a series of abdominal exercises. Along the way there were hot wraps, mud baths, electrical stimulation, acupuncture and a dizzying variety of herbs and medications that filled our small kitchen table and spilled over into the pantry.

In all this my father was calm and methodical in his approach, never the least bit hysterical or urgent, and catholic in his willingness to seek guidance from any part of the medical world. Though he was for the most part conservative in his habits and believed in western medicine, he listened to advice from chiropractors, psychologists and faith-healers as well as from his neurologist at the University of Wisconsin. There was of course no internet in those days, but my father was a born networker and communicated faithfully by mail with people as far away as Germany and Japan. No one had all the answers. In fact, he was fond of saying no one had *any* answers. As far as I could tell, they weren't even sure of the right questions to ask.

When I expressed skepticism that he'd discover a cure this way, he smiled and said, "Maybe not, but I found a man in Minnesota who'll freeze you. Then when they do find a cure some day you can just thaw me out and we'll go from there." In the end cryogenics failed him, like everything else, but I remember feeling honored to be included, pleased that he saw me as having a role in his eventual renaissance into a world free of illness and heartbreak. Now when I read of the struggle among family members over Ted Williams' body and his desire to have his body preserved, I think of my father and wonder if in some way I did him a disservice by not seeking out the man in Minnesota, though by the time he died, my father's body was not really in a state to be preserved for any future time.

Years later, after I had left home and was living in Massachusetts, a colleague called to say he had a friend who had recently contracted MS. The friend was a writer who had moved to Northampton from New York because he imagined life in our small town would be more amenable for an invalid. Now he had read a novel of mine, which dealt obliquely with the disease, and wished to meet me.

Calls like this always filled me with dread. When the book was published, the marketing director had been thrilled because unlike many novels he said this book was "about something" which meant he could devise a catchy handle in order to pitch it to television and radio talk shows. Like most writers, I thought the book was about language and characters, but nevertheless I was booked on a variety of media as an expert on the subject of death and dying, with predictably awful results. I always felt insubstantial and essentially false as I tried gamely to talk about my book with those who called in looking for guidance. Still, I agreed to have lunch with my colleague's friend because how could I realistically say no?

We met at a fern-filled restaurant downtown and I immediately saw that the man was sicker than I had expected him to be. He was still walking, but not easily, and had a short, jerky gait. We talked about our respective writing projects and his hopes for a university position, but then he said, "Let me get to the point of this lunch. I have a son." He hesitated as if he expected to be congratulated and then drank some water. "The reason I wanted to talk to you is I was interested in what it was like for an adolescent boy to have a father who was this sick and getting sicker all the time. I wanted to know how it affected you, really what I should be doing. I mean I can't go hiking or play sports but your dad couldn't either and you turned out all right."

My immediate response was to feel intruded upon. Generally, you wouldn't expect a complete stranger to ask about your psychosocial adjustment to a

traumatic event, but this man spoke with the entitlement of the sick. He had a right to know about me because something similar had happened to him. I understood. Still, I wasn't used to talking about my personal reactions to things and didn't really enjoy hearing others' confessions. It was part of the reason I became a writer; it allowed me to keep life at a distance while still examining it.

The other man was looking at me expectantly and I had never felt so helpless, really so useless in my life. It was not unlike the callers to the radio shows in Chicago and Houston wanting to know how to deal with terminal illness, except that this man was here, hovering over his spinach salad, expecting me to say something brilliant, suggesting that I knew more than I did about the unknowable.

I was flattered by the idea that I had turned out well, though my ex-wife would disagree, but even if it were true I had little understanding of the process that had produced this result and even less how to replicate it. Not only had my family done nothing to help us cope with the disease, no one had even talked about it except as a necessary nuisance and inconvenience.

I can't remember what I told the man that day but the lunch was unsuccessful and we never saw each other again except once when I recognized him from across the street, water-bugging along in his odd limping style, perhaps going to meet someone else who would be more helpful than I had been. I thought of crossing the street, asking how he was doing but the truth is that while I felt sorry for him and his wife and son, I had nothing useful to say so continued on my way without even waving.

There came a time in early middle age, after I'd left New England and moved to Colorado, when I realized that I wouldn't contract MS, though even writing it now makes me feel fearful and superstitious. There are those strange late-onset cases and who's to say I'd be immune? Still, I had become a kind of touchstone for students and younger staff members who were afflicted and since Colorado has a mysteriously high percentage of cases, there have been a number of them over the years.

I always try to be sympathetic and helpful, but the truth is I have little more to say to them than I did to the writer in Northampton. Chronic illness settles over you like a blanket, obscuring everything else, insisting on a kind of monomania that makes sense only to the initiate, those who are sick or related to someone who is. Unimaginable to the healthy who often substitute pity for understanding, it becomes one's constant companion, the large certainty in your life, the thing you will never be without and a way you will inevitably be seen by others who are seldom truly kind. It stalks you in periods of remission

and illusory good health and always wins in the end, as it did with my father who ended up toothless and senile in a nursing home in Pennsylvania, not far from the white-collar prison where some of the Watergate burglars did time.

His roommate at the nursing home was a retired gay Air Force captain, something that alarmed the home's administrator until my brother pointed out logically that neither of them could actually move and thus my father need not fear unwelcome sexual advances. Actually, I'm not sure my father would have minded, though his repertoire was replete with jokes about homosexuals. As it was, he died alone and celibate, and few in the area could have known this was the last stop for a former child prodigy.

For me, it goes on, though now I seldom worry about my own health. Occasionally I think of my daughter contracting the disease, imagining it nimble enough to skip generations and find her in North Carolina where she is a resident at Duke and has an interest, appropriately, in neurology. But such concerns are transient. What truly remains is what's left of the trauma of seeing a life—four lives, really—impersonally ravaged while others stood by largely unaffected.

What remains is what I now think of as a youthful superstitious belief that early success in some measure brought on the illness—as if the evil eye my grandmother spat on had indeed found her son. I continue to suffer what I can only think of as survivor's guilt: I'm keenly aware of the greater gifts of my father and uncle, the tragedy of their lives, and the fact that mine continues to rumble on without incident. Why, I wonder, should I have escaped; why should anyone? I look at my daughter's *Harrison's Principles of Internal Medicine* and marvel not merely at the sheer number of diseases enumerated there, but at the fact that anyone enjoys good health and takes it for granted.

Healthy at sixty, I feel an obligation to work as long as I can, to use the time my father wasn't given. Remembering his faltering steps on the parallel bars, I run marathons and go on long hikes, as if it's a makeup for something he would never have wanted to do. But in an almost childish rebellion against this impulse, I also waste time on sports, movies, television, coffee with friends, pissing away the time I have. Yet even this, if I'm completely honest with myself, I recognize as a delayed reaction to the certain knowledge that I've come through: I've made it, am healthier than most, and have lived a full life. It's undeniable, but in that secret essential place in my psyche, I reject the resonance of that truth. Despite all evidence to the contrary, I feel that I'm not past this and will likely never be. Ten years after his death, I dream frequently of my father and know that I'll remain, at base and always, a cripple's kid. ☞