

NEW YORK TIMES BESTSELLER

ALWAYS LOOKING UP

The Adventures
of an Incurable
Optimist

Author of the #1 NEW YORK TIMES bestseller LUCKY MAN

MICHAEL J. FOX

Always Looking Up

The Adventures of an Incurable Optimist

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For Tracy, Sam, Aquinnah, Schuyler, and Esme.

And for Karen.

With love.

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Prologue



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In the opening pages of *Lucky Man*, I described a morning in Florida nineteen years ago when I woke up with a hangover and a twitching left pinky finger. In the intervening years, my life has seen many changes. Most mornings, for example, I awake to find my left pinky finger perfectly still--it's the rest of my body that's shaking uncontrollably. Technically, my body is only fully at peace when my mind is completely at rest--that is, asleep. Low brain activity means fewer neurons firing, or in my case, misfiring. As I awaken, before my conscious mind really knows what's happening, my body has already gotten the news in the form of insistent neural instructions to twist, twitch, and contort. Any chance of slipping back into sleep is lost.

This morning Tracy is already up, dealing out breakfasts and readying the kids for school. I blindly fumble a plastic vial from the nightstand, dry-swallow a couple of pills, and then fall immediately into the first series of actions that, while largely automatic, demand a practiced determination. I swing my legs around to the side of the bed, and the instant my feet hit the floor, the two of them are in an argument. A condition called "dystonia," a regular complement to Parkinson's, cramps my feet severely and curls them inward, pressing my ankles toward the floor and the soles of my feet toward each other as though they were about to close together in prayer. I snake my right foot out toward the edge of the rug and toe-hook one of my hard leather loafers. I force my foot into the shoe, repeat the process with the left, and then cautiously stand up. Chastened by the unyielding confines of the leather, my feet begin to behave themselves. The spasms have stopped, but the aching will persist for the

next twenty minutes or so.

First stop: the bathroom. I'll spare you the initial details of my visit, except to say that with PD, it is essential to put the seat up. Grasping the toothpaste is nothing compared to the effort it takes to coordinate the two-handed task of wrangling the toothbrush and strangling out a line of paste onto the bristles. By now, my right hand has started up again, rotating at the wrist in a circular motion, perfect for what I'm about to do. My left hand guides my right hand up to my mouth, and once the back of the Oral-B touches the inside of my upper lip, I let go. It's like releasing the tension on a slingshot and compares favorably to the most powerful state-of-the-art electric toothbrush on the market. With no off switch, stopping means seizing my right wrist with my left hand, forcing it down to the sink basin, and shaking the brush loose as though disarming a knife-wielding attacker. I can usually tell whether shaving is a good idea on any particular day, and this morning, like most, I decide it's too early to risk bloodshed. I opt for a quick pass with an electric stubble trimmer. *Miami Vice* lives.

A bench in the shower takes the pressure off my feet, and the steady drumbeat of the water on my back has a therapeutic effect, though if I sit here much longer, I might never get up. Getting dressed is made easier by the pills, which have begun to assert their influence. I avoid clothing with too many buttons or laces, although I'm still addicted to Levi's 501s, making me a fashion victim in the truest sense of the word. In lieu of proper brushing, I raise my twitching fingers up to my hairline and, raking it back, hope for the best. Executing a slow shuffle (my legs haven't yet earned my trust for the day), I make my way out to greet my family.

At the turn from our bedroom into the hallway, there is an old full-length mirror in a wooden frame. I can't help but catch a glimpse of myself as I pass. Turning fully toward the glass, I consider what I see. This reflected version of myself, wet, shaking, ruffled, pinched, and slightly stooped, would be alarming were it not for the self-satisfied expression pasted across my face. I would ask the obvious question, "What are you smiling about?," but I already know the answer: "It just gets better from here."...

How to Lose Your Brain Without Losing Your Mind--that was my original title for the memoir written eight years ago. On the second or third page of the earliest draft, I made reference to myself as being a "lucky man." After a few edits, I kept going back to those two words, and eventually they found their way onto the cover of the book. They fit then, and they still do now.

As the title for this new book, *Always Looking Up* works on a couple of levels. First off--let's just get this one out of the way--it's a short joke. At a fraction of an inch under five-foot-five, much of my interaction with the world and the people in it has required that I tilt my head backward and direct my gaze upward. However, this isn't a manifesto about the hardships of the vertically challenged. Frankly, my height or lack thereof never bothered me much. Although there's no doubt that it's contributed to a certain mental toughness. I've made the most of the head start one gains from being underestimated. And that's more to the point of it--*Always Looking Up* alludes to an emotional, psychological, intellectual, and spiritual outlook that has served me throughout my life and, perhaps, even saved me throughout my life with Parkinson's.

It's not that I don't feel the aching pain of loss. Physical strength, spontaneity, physical balance, manual dexterity, the freedom to do the work I want to do when I want to do it, the confidence that I can always be there for my family when they need me--all of these have been, if not completely lost to Parkinson's, at least drastically compromised.

The last ten years of my life, which is really the stuff of this book, began with such a loss: my retirement from *Spin City*. I found myself struggling with a strange new dynamic: the shifting of public and private personas. I had been Mike the actor, then Mike the actor with PD. Now was I just Mike with PD? Parkinson's had consumed my career and, in a sense, had become my career. But where did all of this leave *me*? I had to build a new life when I was already pretty happy with the old one. I'd been blessed with a twenty-five-year career in a job that I loved. I had a brilliant, beautiful, funny, supportive wife and an expanding brood of irrepressible kids. If I had to give up any part of this, how could I possibly protect myself from losing all of it?

The answer had very little to do with "protection" and everything to do with perspective. The only unavailable choice was whether or not to have Parkinson's. Everything else was up to me. I could concentrate on the loss--rush in with whatever stopgap measures my ego could manufacture. I could rely on my old friend from the nineties, denial. Or I could just get on with my life and see if maybe those holes started filling in themselves. Over the last ten years, they have, in the most amazing ways.

What follows is a memoir of this last decade. But unlike *Lucky Man*, it is thematic rather than chronological. Work, Politics, Faith, and Family. These are the struts of my existence. These are the critical supports of my life.

Together they form a bulwark against the ravages of Parkinson's disease. My identity has so much to do with my ability to self-express, to assert my creativity and productive worth (*work*), my rights and the rights of whatever communities I'm a part of and therefore responsible to (*politics*), my freedom to seek spiritual purpose (*faith*) and to explore the complex bonds I share with those I love most (*family*) and without whom I would have long since succumbed to darker forces.

While not a strict narrative, *Always Looking Up* describes a journey of self-discovery and reinvention. The story is a testament to the consolations that get me through and give meaning to every area of my life.

For everything this disease has taken, something with greater value has been given--sometimes just a marker that points me in a new direction that I might not otherwise have traveled. So, sure, it may be one step forward and two steps back, but after a time with Parkinson's, I've learned that what is important is making that one step count; always looking up.

*** PART ONE ***

Work



ALANFIL

Into the Great Wide Open

In many ways, day-to-day life is tougher now than it was when *Lucky Man* was published. I thought I was in rough shape in 2000 when I retired from *Spin City*. The twin hammers of producing and performing in one hundred episodes over a four-year span had knocked me on my ass. Brain surgery two years earlier had reduced the emphatic tremor on my left side but had done nothing to diminish the trembling on my right and in my legs. Titrating medication was a daily battle with a shape-shifting enemy. The segues between being "on" and "off" my meds, transitions that under ideal circumstances transpired like quasi-civil conversations, had deteriorated into a belligerent riot of interruptions and cross talk. In a futile attempt to be "on" at the optimal times--that is, when I was performing--I would try to get through my producing duties with as little levodopa (or "L-Dopa," the synthetic dopamine that Parkinson's patients take to control symptoms) in my system as possible, so that when I had to act, I could up the dose and be steady in front of the cameras. Rarely, if ever, did I get it right. Getting it wrong--erring on the side of too much levodopa--brought on a torrent of dyskinesias; uncontrollable movements like undulating, weaving, rocking, and bobbing. The cruel joke was that I didn't notice it as much going through my paces as I did afterward when I watched the footage in the editing room.

Having decided halfway through the fourth season that my physical condition would not allow me to do a fifth, I began to wonder if I'd even make it through the thirteen or so episodes that remained. My daily regimen of drugs (which, by the way, have no psychotropic effect--no buzz whatsoever) affected my speech patterns and sometimes caused me to slur my words or hesitate before saying my lines--a real bitch when you're trying to time a joke. As for physical comedy, hell, I was just trying to avoid physical tragedy.

Although everyone--cast, crew, and audience--knew by this point that I had Parkinson's, I was still attempting to play a character who did not. Whatever comedic or dramatic complexity a particular scene called for, my greatest acting challenge was always acting like I didn't have Parkinson's. Though I continued to employ the same old bag of tricks that had served me for years--manipulating hand props to control tremulous hands, leaning against walls, desks, and fellow actors, shifting in a chair or behind a table to cover my uncontrollable leg and foot movements--the advance in symptoms was forcing me to update my repertoire. I discovered that, for short periods of time, I could direct all the energy coursing through my body to one particular extremity--a hand, leg, or foot. So when blocking a scene, I would position myself (and the rest of the cast as well) in such a way as to best conceal the appendage in which the surge of Parkinsonian energy was manifest. Like I said, it's the same sort of thing I'd been doing for years, and my thinking was that once I could explain to people why I was doing it, it would make the whole process that much smoother.

But it didn't make it any easier. It was still tough. Now people just had a better idea of why it was tough. My friend Michael Boatman played Carter Heywood, the mayor's minority affairs liaison on the show. One day we were rehearsing a scene that

required both of us to pass through the mayor's office door simultaneously and in opposite directions. Scripts in hand, we started to walk the scene, but when we both got to the door, instead of passing by Michael, I froze directly in front of him. "You gotta move," I said, rather more bluntly than intended.

Michael is one of the nicest guys on the planet, but he was a little confused and taken aback by my direction. "What?" he replied.

"You gotta move. I can't move until you move."

He eventually complied, and after the rehearsal, I tried to explain what had just happened.

Occasionally, when my brain asks my body to perform simple tasks that involve some degree of judgment regarding spatial relationships, the message gets lost in transmission. It takes some form of outside stimulus, like the movement of an obstacle or, curiously, even the introduction of an obstacle, for me to move forward. Some Parkies who freeze when walking can resume again when a ruler is placed in front of their feet and they are forced to step over it. Michael, of course, accepted my explanation and even managed to laugh with me about the strangeness of it all.

Over the course of a day, a week, a month, a year, countless situations would arise when similar explanations were required, and that, in and of itself, became a fatiguing responsibility. The Jekyll-and-Hyde difference between when the meds were working and when they weren't understandably confused people. Those around me had a difficult time reconciling the energetic, expressive Mike Flaherty that they would see in front of the camera with the shuffling, masked-face Mike Fox that they would encounter as he went about his business behind the scenes. My producing partner, Nelle Fortenberry, remembers more than a few occasions when department heads and other members of the cast and crew would step into her office, close the door, and beg her to tell them why I was mad at them.

"What makes you think he's mad at you?" she would reply.

"I just passed him in the hallway, and he didn't smile or wave or even slow down."

Nelle would repeatedly explain that one of the symptoms of PD is a dearth of facial animation--the Parkinson's mask. In addition, something as simple as turning my head over my shoulder to convey a greeting can be an actual physical impossibility. Once I have any degree of momentum while walking, the expenditure of energy required to stop and start again can be ten times as taxing as it is for a normal-brained person.

Away from the set, it was Nelle with whom I most often interacted on a day-to-day basis, along with executive producers Bill Lawrence and David Rosenthal, and our director, Andy Cadiff. This was when I put on my producing hat, and we'd wade through production budgets, future story lines, script drafts, proposals for set designs, post-production issues, cast and crew grievances, and the rest of the minutiae that comes with churning out a new episode of television every seven days. Believe it or not, it could be fun. But it could also be grueling. Problems were like popcorn; as we worked our way through the bowl we had in front of us, it seemed like there was a big popper outside the office door, constantly manufacturing a new batch.

Sometimes I'd laugh when Nelle would lay out the new challenges for the day. I'd remind her that, however big the problems were, they wouldn't be *my* biggest. I didn't

mean this as a complaint but as a comment on a perspective I'd gained from my situation.

If I could go back today and speak to the me of 2000, as I waged my daily battles with Parkinson's disease, I'd have this to say: "You ain't seen nothing yet!"

In fact, having the benefit of my experience since, I know now that it was going to get a lot worse before it got...well...a lot worse. Still, with what I have learned since about managing stress through creative scheduling, and the current generation of drugs that were just around the corner, I probably could have done a full seven seasons. That's not to say for a minute that I wish I had. My decision to leave *Spin City* was the right call at the right time.

By then, making a decision about what to commit my time and energy to came down to how I felt about something as opposed to what I thought about it. Certainly, my decision to retire from *Spin City* in the spring of 2000, effective at the end of the fourth season, was all "feel."

The decision happened late in the afternoon on the last day of the twentieth century. My family and I were snorkeling the pristine waters off St. John's in the U.S. Virgin Islands. We'd been visiting this beach for years, and had never seen a sea turtle. Having finally spotted one gliding through the sea grass just inside the coral reef, I swam slowly behind it, keeping a respectful distance. When I finally emerged from the water, I kicked off my flippers, walked over to where Tracy was toweling off the kids, grabbed a towel for myself, and informed her that I was leaving the show. It may have been a bone-deep exhaustion from battling symptoms every day just to do my job, or maybe it was just the sublime indifference of that turtle, but a switch had flipped, and depending on how I chose to accept it, a light had either just turned on or just turned off. If the perfunctory nature of my announcement startled Tracy, she covered it well. Certainly it was her moment to fill. She could have laughed it off like a weak throw-away joke or just pretended to ignore it, tacitly offering me the space to reconsider. Or she could have said, "Are you out of your fucking mind?" After all, what I was so casually proposing would bring about sweeping changes in each of our lives, as well as the kids'. I didn't even mention the turtle, fearing that she would think I was only consulting her for a second opinion. Whatever rough patches there had been in our marriage had usually arisen when one of us--okay, me--acted unilaterally. Bottom line, she could have reacted in any of a number of ways. But what she did was look me in the eye, utter a single word, "Good," and pull me into a wet, sandy embrace.

For the few remaining days of the vacation, we didn't talk about it much. If I was waiting for her to talk me out of it, that wasn't happening.

But could the break really have been that simple, that clean? This was a momentous decision, easily one of the most important in my life, and I was just blurring it out.

Well, yes--in a sense. Never once after my encounter with the sea turtle have I wavered in my conviction that it was the right thing for me to do and the right time for me to do it. But it was hard too. Not a hard decision to make, but a hard decision to have made. As with any turning point or instance when a new road is chosen and an old one forsaken, there are consequences. Here it was, New Year's Eve, the cusp of not only a new year, but a new millennium, and my resolution was to leave behind everything that I had resolved to achieve, acquire, and accumulate over the previous

twenty years. I knew I wouldn't just be leaving the show--I would be putting aside my life as an actor. While I always had difficulty thinking of myself as an artist, I took pride in being a craftsman. I think I understood that even though, officially, my retirement was from *Spin City* and not my career as a whole, I couldn't just tweak the schedule or the working conditions and expect to take on another leading role in a television series or film. This was it. I was essentially pulling the plug. Adios. Bye-bye.

John Gielgud, revered for his decades on the English stage and famous for playing Dudley Moore's butler in *Arthur*, once described his life's work in this way: "Acting is half shame, half glory. Shame at exhibiting yourself, glory when you can forget yourself." As a sixteen-year-old, just embarking upon a career, I could relate. I dabbled in the other arts, for a time envisioning a future as a writer, commercial artist, or musician, but it was acting that came most naturally to me. At an age when most people (and I was no exception) feel ungainly, awkward, and unlovable, I'd found something for which I seemed to have a facility. I could be anyone, anything, any size, any shape, transport myself to any place or time. And if I did it right, there was the bonus of approbation from those whom I was otherwise hard-pressed to please. Roles in school plays and locally produced film and television productions encouraged me to test my potential, and soon I became more and more aware that my real limitations were geographical. I needed to go to where the work was.

Acting provided a life beyond anything I could imagine--and I had a fervent imagination. At eighteen, my aspirations led me to Los Angeles. I stuck through humiliating and seemingly pointless auditions and routine rejections, with the occasional reward of a small TV gig or national commercial that would pay my rent and keep my spirits afloat. Then came success, and with it a new confidence in my craftsmanship and the courage to try new things; some with positive results, some not so positive, but never with regret.

Acting was an occupation that required me to be both an observer and participant in the world. Throughout my many years in comedy, I relied upon an intuitive ability to find the humor in almost any situation. There's always a "funny part." An actor's palette is the entirety of the human experience. A career as long and busy as mine had allowed me to empathize and connect with people in a way no other profession could have. And of course, there were the tangible benefits: travel, a financial windfall, goodwill beyond any deserving. Perhaps the greatest gift of all came courtesy of a fortuitous piece of casting: meeting Tracy on the set of *Family Ties*.

I never went to college; I didn't even finish high school. Being an actor was the only career I'd known, and now, on the inferred advice of a turtle, I was ready to leave it as easily as I had towed the seawater off my sunburned back?

Deep down I knew that my love of working--that megavolt crackle that licked up my spine when a well-written joke was well-timed and well-received--was still there. A hard-earned comfort had developed after so many years of performing--not laziness, but a reasonable confidence that no matter what emotion, intention, or attitude I needed to access, that arrow would be in my quiver when I reached for it. As a younger actor, I could sometimes obscure my insecurity about the integrity of a given moment with some deft piece of physicality: Alex Keaton, putting his hands in his pockets and leaping backward onto the kitchen counter; Marty McFly, duck-walking,

windmilling, and power-sliding through "Johnny B. Goode"; Brantley Foster, hulking in the elevator clad only in boxer shorts; or even Mike Flaherty, stripping off his sweat-pants in midair while executing a full flip over the bed and his waiting girlfriend. I could always rely on the physical. The unfortunate irony was that at a time when I felt in full possession of the emotional and intellectual dimensions of my performing identity, I could no longer count on my body to play along. I didn't want to make choices as an actor based on disability rather than ability.

Although I can't claim any lucid memories of the evening, I'm pretty sure I spent New Year's Eve of 1979, my first as a young actor living in California, getting drunk off my ass and making wild resolutions about all that I would accomplish in the coming decades. Now, twenty years later, enjoying a quiet, sober tropical New Year's Eve with my family and reflecting upon all that young man had accomplished, I prepared to step into an uncertain future.

SOUNDSTAGE D, CHELSEA PIERS MARCH 17, 2000

For a television series, especially a sitcom, one hundred episodes represents an important threshold. Traditionally, the century mark is the minimum required to successfully launch a show into syndication. Going into season four, we expected, according to our twenty-two-show schedule, to finish the season with ninety-six shows in the can.

Our syndication deal was already in place, so it wasn't technically crucial that we produce those extra four. But while at peace with my decision to leave the show, I became fixated on that milestone. This could have meant adding another month of production for which we had neither the time nor the money. So, rather than allowing myself to ease out of the show, I had created a logistical conundrum that required sometimes shooting one and a half shows per week, thus being able to bank six episodes in four weeks. The plan was for a one-hour finale, edited into two shows for syndication. Filmed over two weeks, for the most part without a studio audience, the storyline would also call for a day of location shooting in Washington, DC. All of this pre-filmed material, rough-edited and assembled, could then be screened for the final New York studio audience with live scenes interspersed.

I'm sure it was a difficult period for the cast and the crew, although for the last month and a half of the season, we knew that my leaving would mark not the end of *Spin City* but, rather, a transition. The show would continue. Charlie Sheen signed on as the new deputy mayor, and production would be moved to Los Angeles, where Charlie and *Spin City* co-creator Gary Goldberg lived. (Gary would reassume executive producer duties.) Of course, this would be the New York-based crew's final season. For the audience, then, this would not be a farewell to the show, just a farewell to the character of Mike Flaherty.

The final episode was tricky to conceive and execute because the entire situation was rife with verisimilitude. Mike Flaherty, for reasons that were not entirely fair, was being forced to prematurely leave the job he loved. I could relate, and the other actors seemed as concerned for me as their alter egos were for Mike. It was all one and the same. This was it. It was really over.

The fictional Mike Flaherty's prospects were better than mine. He'd probably work again. But would I? Doubtful. At least, not like this, performing week-in, week-out, in front of a live studio audience.

I worked closely with David Rosenthal, Bill Lawrence, and the rest of the writing staff to ensure that Mike would have at least one substantial scene with each of the show's regular characters. This was both to give the audience a sense of closure on each of these relationships and to allow me one last chance to share the stage with each of these gifted performers, whom I had come to care so much about over the previous four years. The whole thing was loaded with emotion; the logistical burden we'd created only compounded the exhaustion that had me retiring in the first place. Beyond the soundstage, my plans to leave the show created another wave of support and affection comparable to what I'd experienced two years earlier when I made public my PD diagnosis. There was a tremendous media interest in those last days of my tenure, with members of the press on set, observing our prep for my final show. Everyone--cast, crew, writers, and production staff--was at once at the top of his or her game and in a total fog. But they, at least, grasped something that seemed to be eluding me. This final episode marked a turning point in my life, a tectonic shift. I might have looked around, understood what had been set in motion and what would soon grind to a halt, and said, "Oh, shit! What have I done?"

I had sailed into waters too narrow and too shallow to turn the boat around. It's not that I was totally unaware of what was happening; I was caught up in the emotion like everyone else. And I felt guilty too, knowing that by choosing to change my life's direction, I had thrown so many others off course; hopefully not irreversibly, but probably unexpectedly. Or maybe it wasn't so unexpected. Everyone could see my battle fatigue. And the final push to bring it all to a close in a fitting way, the pressure to hit the one-hundred-episode mark, and the physical demands of simultaneously performing and producing only reinforced the ultimate wisdom of my decision. But the imperative that I get these last few laughs and collapse across the finish line precluded any thoughts about what I was falling into on the other side of that invisible threshold. For now, what drove me to keep going was the need to stop.

Even if I didn't appear to be saying, "Oh, shit!," I did it by proxy. In order to find a way for Mike Flaherty to leave his job at City Hall (and for me to leave *Spin City*), we had to create that moment for him, and this safe remove provided me with a little perspective.

This was the conceit: Though innocent of any wrongdoing himself, the mayor of New York is implicated in a scandal linking City Hall to organized crime. Seeing no way to spin his boss out of the jam, Mike's only recourse is to take the fall himself. He agrees to resign from his post. His coworkers are shocked, and he himself is shaken, but he is also certain that leaving is the only right thing to do. And so he goes about severing his ties to the job that has defined him. After his last day at work, at home with his girlfriend and coworker Caitlin, Mike voices his anxiety. What the hell is he going to do now?

CAITLIN IS PLACING FOOD ON THE TABLE--DINNER FOR TWO.
MICHAEL ENTERS.

Caitlin

Hi.

Michael

Hey, you didn't make it to the bar.

Caitlin

Things were a little crazy at the office.

Michael

Yeah, I heard they lost somebody pretty valuable today.

Caitlin

He was just eye candy.

I've often felt that Heather Locklear is underestimated as an actress, for the most part because she's so natural and effortless in front of the camera. Further proof of her ability, though, was right in front of me as we worked on this last episode. Caitlin might have been a rock, but Heather was a mess, crying before and after every take. She was great that week, as she had been throughout the season. Brought in, after all, to help lighten my load as the going got tougher, Heather had done a spectacular job, just as Caitlin was doing for the soon-to-be-former deputy mayor.

The exchange that closed the scene, however, was really all about me and Tracy, an acknowledgment of how much I am empowered by her belief in me, in the life and family we have built together. Sometimes I have only the courage of her convictions, her unflinching support, and her assurance, almost matter-of-fact, that I should trust my heart, my gut, and her love. Reprising not just a moment from our recent history together, the words and emotions evoked remembrances of other times when I had offered my doubts and fears to my wife--drinking, career crises, Parkinson's--and she had not judged them, just shared them. When all appears lost, I look to Tracy to help me find it again--or, better yet, be with me for as long as it takes for something new to arrive. And longer.

MICHAEL SITS DOWN AT THE TABLE. FOR THE FIRST TIME IN A LONG WHILE HE TAKES A DEEP BREATH.

Michael

You know what, it's okay. I'm gonna bounce back from this, right?

Caitlin

Of course, Mike.

Michael

It's not over, right?

Caitlin

It's a long way from over.

Michael

It's weird, for as long as I can remember, every morning I've had somewhere to go, something to do. What am I going to do tomorrow when that alarm goes off?

Caitlin

I wouldn't set it.

On show night, the place was packed. The press was there and so was everyone from the network and the studio; my family had flown in from Vancouver; and all of the writers and producers who had worked on the show over the last four years had returned to say good-bye. Even with all the special guests, seats had been saved for regular civilians, those loyal audience members who had shown up every show night since the beginning. And of course, Tracy spent most of the evening just offstage, by the floor monitors with Gary, both of them in tears as they watched the episode and this chapter of our lives come to a close.

At the end of the night, I ran out to join the cast for curtain call, which we planned to include as part of the episode. I wore Mike Flaherty's Fordham letterman's jacket and embraced each of the cast members and waved good-bye. Behind all of this played the song "Glory Days," which Bruce Springsteen had kindly given us permission to use. It was a sentimental choice, but it was also meant to be ironic. *Time slips away and leaves you with nothing, mister, but boring stories of Glory Days.* Surely, my glory days hadn't come to an end. I would have more stories to tell.

After the show, we packed into a nearby restaurant we had booked for that night. We danced and partied, laughed our asses off, and said our good-byes. That night when Tracy and I got home and went to bed, I didn't set the alarm.

Shaking but Stirred

When I was diagnosed in 1991, I was determined to absorb the blow, suck up all the fear, pain, confusion, and doubt, and be grateful that a small group of friends and family were there to catch whatever spilled over. I understood that symptoms were a lagging indicator of the disease's progress, and that gave me the time and privacy I needed to process the situation. Similarly, when I disclosed my condition in 1998, after seven years of measuring the size and weight of the burden I had been carrying, I was, for the most part, just seeking relief from the strain. While nervous about how people were going to react when I told them the truth, I was far more concerned with their reactions if I continued to withhold it.

To be brutally honest, for much of that time, I was the only person in the world with Parkinson's. Of course, I mean that in the abstract. I had become acutely aware of people around me who appeared to have the symptoms of Parkinson's disease, but as long as they didn't know to identify with me, I was in no rush to identify with them. My situation allowed, if not complete denial, at least a thick padding of insulation. That would change.

I didn't burst out of this isolation with an agenda. Going public was a difficult decision, and I had misgivings. My subjective experience was now an objective fact in

the wider world. It didn't belong to just me anymore--though I quickly learned that it hadn't belonged to just me in the first place. More than a million other Americans and their families were going through the same thing; some openly, some in secret due to concerns of being misunderstood and marginalized. I represented something to them, and whether any of us would have planned it this way, I now represented them in the minds of other people.

I recognized both a responsibility to this new community as well as an opportunity to do something positive. I could relate to the patients who wrote to me, particularly those online in Parkinson's chat rooms. (I did this mostly under an invented *nom de PD*, but it would get awkward when they'd ask me what I thought of *me*.) One of the biggest revelations was, in spite of all our common travails, how different our experiences could be. Parkinson's disease takes many forms--for some reason, everyone gets their own version. A drug therapy or surgery that works for one may not work for another. Our reactions--emotional, psychological, and physical--vary greatly, and this obviously affects our ability to cope.

My interactions with the larger PD population put another dimension of my good fortune into stark relief. For whatever reason, I had been spared the torture of depression. By this, I don't mean that I hadn't had bouts of sadness, fear, or anxiety about my situation, although at times I had to cut through a layer of denial to recognize it. But clinical depression is a common symptom faced by approximately 40 percent of PD patients. Like dementia, it may be present from the beginning, appear over time, or show up suddenly in the later stages. As I said though, apart from the expected ups and downs of a life with Parkinson's, I don't struggle with the chemical imbalance that triggers severe depression.

I never logged out of the online PD forums without realizing how fortunate I was. My family, my relative youth, my financial situation, as well as my public position gave me a tremendous advantage in dealing with my illness. While Parkinson's did have a direct impact on my ability to do my job, I was, for all intents and purposes, my own boss. So for me, decisions like whether or not to disclose my illness were not as fraught with risk. The anonymity of the Internet also allowed me to see the impact my disclosure had on other patients, their families, and the people they interacted with on a daily basis. I'm sure that the effect would have been the same had it been any number of other well-known people, but just that someone with the ability to attract so much public interest had shone a light on their predicament meant more than I could have foreseen. *Okay*, I thought, *so what do I do with that?*

Within a few months of my disclosure, I began integrating myself into the Parkinson's patient community and familiarizing myself with the various organizations and foundations that had reached out to me. I invited a few representatives over to my apartment to discuss their programs and lay out how I might fit into their plans. While they were certainly professional, dedicated, and committed, I was still looking for a more aggressive focus on research moving forward toward a cure. One contingent, a group from the Parkinson's Action Network (PAN) led by Joan Samuelson, a young-onset PD patient and activist attorney, touched on those issues right away, as well as the disparity between federal funding for Parkinson's research as compared with other diseases.

The Senate Appropriations Subcommittee on Labor, Health, and Human Services

had scheduled a hearing in Washington a few weeks later, and Joan presented a case that my testimony could bring attention to the issue and possibly move the dial on the support from Congress. Seeing a chance to make a difference, I agreed to testify.

What is now public record was little known at the time: I am a political junkie. As a preteen, I was inspired by Canadian Prime Minister Pierre Trudeau and frightened by President Richard Nixon. As a teenager, I volunteered for the British Columbia Liberal Party in the provincial elections, distributing my candidate's yard signs and redistributing his opponent's into the dumpster behind the liquor store. (It didn't help--my guy got thumped on election night.)

Throughout all those years, I followed politics avidly, and tried to stay informed about politicians and public policy. However, because I left Canada on my eighteenth birthday and was never a full-time resident again, and because I didn't become an American citizen until 2000, I had never cast a vote in any election. And without a vote of my own, I didn't feel I had the right to influence anyone else's.

By the time of the Congressional hearing, however, I was well on my way to becoming an American citizen. My papers were being processed, so I had no problem speaking my piece. By no means an expert on the current state of scientific research, I would speak to the effect this disease has on Americans, would share our hopes and hardships, assert our rights, and outline our expectations. Writing my congressional testimony was probably my first concentrated effort to communicate what I'd lived with for the last eight years. I didn't want people to walk away from my testimony muttering, "Poor bastard." Rather, I hoped they would be thinking, "Maybe we can do this."

The optimism that I carried into the hearings, my belief that any situation, given the right circumstances, can improve, was validated by the testimony of Dr. Gerald Fischbach, the director of the National Institute of Neurological Disorders and Stroke (part of the NIH). Dr. Fischbach postulated that with sufficient funding, scientists might be able to cure Parkinson's disease in five to ten years. If one of the congressional cameras had me in an isolated close-up, I'm sure I executed one of the finest double-takes of my career. I'd expected Fischbach to express confidence and lay down a challenge for researchers to match it and for Congress to support them in any way possible, but I wasn't expecting him to suggest a timeline. His testimony energized me. This was doable. I had been given the idea that a cure was possible, and I needed to act upon it.

I realized that I was ridiculously unqualified to contribute to this effort in any substantive way; I wasn't an MBA or a PhD--although a few years earlier, I had earned my GED. But my optimism had crystallized into definitive hope. And over the course of the next year, that hope became the inspiration for a streamlined private foundation, one that could galvanize the patient community and set up its own infrastructure to raise significant money, identify underfunded scientists, and provide the support they needed as quickly as possible.

Ironic that in order to do my life's work, I had to quit my day job.

Permanent Vacation

PEYPIN D'AIGUES, PROVENCE, FRANCE JULY 2000