Good Talk, Dad

The BIRDS and the BEES... and other CONVERSATIONS we FORGOT to have

Bill Geist and Willie Geist
Chapter 14

Parkinson’s: The Denial Treatment

BILL

There’s never been a good time for me to deliver bad news, especially not to you and your sister. As you know, I’m a private person. I was raised to suppress the whining and keep things sunny-side up. For the past twenty years, only your mother knew that I have Parkinson’s disease. She says the only reason she finally told you and Libby was that you thought when I took long naps every afternoon—Parkinson’s drains you—it meant that I didn’t want to do what the family was doing, or maybe that I just didn’t like being around you two. That was crushing to hear.

When I finally did discuss it with you at a Rose Bowl game a few years back, I told you I didn’t want to be the subject of pity. You said no one could pity a man who had just walked five miles to and from the Rose Bowl! I lived in denial, which had always worked for me. I didn’t want to think about Parkinson’s, didn’t want to let it into my life, into my house, didn’t want it to be the first thing people thought of when they saw me. I didn’t want my office to know, didn’t want to disqualify myself from moving up, although certainly my field producer, Amy, who traveled the country for fifteen years with me and saw me taking pills, knew something was up.

Moreover, I didn’t want you and Libby worrying about it: my having it, your inheriting it. Undoubtedly you saw that I was walking funny. And squirming. Holding my hands in awkward positions. People notice, especially when five or six million of them are watching you on TV. They’d see a twitch and send me an e-mail or put it on Twitter, at first as a question: “Does he…?” “Is it possible he…?” Then it becomes the first several items on your Google search (which I haven’t checked now in five years). I thought I was hiding it pretty well, but when I looked at video of myself, I knew I wasn’t fooling anyone.
Unfortunately, denial doesn’t work so well with disease. You try to keep it out of your head, but it keeps reminding you it’s there. There are symptoms. They worsen and multiply. You can tamp them down with drugs but they keep popping up.

I withdrew, holing up in my office with the door closed, working more at home and not seeing old friends because I wanted them to remember the old me, not the new whoever-I-had-become me. In public I make a concerted effort to look “normal,” but my movements don’t flow easily, and at times neither do my thoughts. Sometimes my feet stick to the ground.

Parkinson’s is weird. In addition to all the physical ailments, it causes depression and flattens your emotion. The old sparks become wet matches.

The last thing I want to be is a drag. I’ve always been the one to cheer everyone up. Make them laugh. Fans would write to me: “They were reading your column on the radio and I had to pull off the highway I was laughing so hard”; “People on the bus thought I was nuts I was laughing so much”; “I fell to my knees in front of the TV laughing and pounding the carpet.”

It was at a book signing event in Richmond in 1992 that I first noticed my signature getting tighter and smaller and sometimes illegible.

“Sorry,” I’d say to the signees, “I’m recovering from a broken wrist.”

“That’s too bad,” they’d say. “How’d you do it?”

My answers were whatever came to mind: “Skiing…in France” or “Playing football with the kids.” My mending broken wrist was the excuse I used for years. In more recent signings I finally went so far as to say, “Sorry, I’m having a little neurological problem with the hand.”

I visited a neurologist who said I was experiencing writer’s cramp. She did all manner of tests: hand, foot, eyes. There was an MRI, an EEG, an EKG, and a series of tests in the examining room that involved pricking my hands, feet, and thighs. She repeated this with electric shocks. She put me on a couple of drugs. She said I had mild Parkinson’s disease. I told the doctor that we were moving to New York and she gave me a referral. Her final words to me: “Good luck.”

Six neurologists, twenty years, and about a dozen different medications later, it’s still pretty much “Good luck.” There is no cure, just trying new combinations of somewhat effective and promising new drugs, one to six times
a day. The next approach might be drilling a hole in my head, which always causes me to think of Black & Decker.

The uncertainty haunts you. You don’t know what will happen to your body, nor how soon. And how much of this is owing to Parkinson’s and how much to what one MD diagnosed as my “rotten” back, and how much to the fact that I’m getting really, really old? I’m in denial about that too. Several of my high school friends are six feet under.

I go for appointments with my Parkinson’s doctor (as distinguished from my battery of other doctors: skin, back, eye, heart, etc.), and I see patients in the grip of the late stages of the disease. At first I think, “I have nothing to complain about. I shouldn’t even be here.” Then I think, “That’s me in a few years.” I go home and we plan the trip to Africa we’ve thought about forever.

Deep down, beyond the realm of rationality, I somehow feel that it’s all still temporary. I am always a little disappointed and angry when it takes ten minutes to button my shirt. I yell “Fuck you!” at the disease. I hope your kids haven’t overheard me.

**Willie on Parkinson’s**

I’ve told you this before, Dad, but the day you announced to the world on national television that you have Parkinson’s disease—Sunday, July 1, 2012—was my proudest as a son. The star on the Hollywood Walk of Fame was pretty badass, and I don’t mean to diminish your third-place finish at the Illinois State Fair Bake-Off, but admitting to so many people what you’d denied to yourself for so long was a hell of a brave thing to do. We sat in the living room together that morning—you, me, Mom, and Christina—watching, applauding, and crying a bit. It had been a long time coming.

I agree we were better off not ever having the “birds and bees” talk, but the Parkinson’s conversation definitely was one we should have gotten around to sooner. When your early, mild signs began to show, Mom told us you had a “neurological thing” as if it were something that would pass. I look back now and wonder why I didn’t ask more questions—of Mom and of you. You were trying to protect us, I guess, hoping the disease somehow would go away and we could get on with our lives as normal. I can’t remember the moment Mom told us you had Parkinson’s, maybe because it was so unsurprising. We knew by then what our eyes had been telling us.
I do remember the first time I noticed you slowing down. We had a white Jeep Cherokee in the early and mid-nineties with an automatic sunroof. Don't ask me why, but it registered with me one day when you guided your hand slowly up to press the button to open the roof. It was a strange thing for me to store away in my mind, I know. Like a lot of little things that followed—the naps, the occasional reach into a pocket for medication, the subtle social withdrawal—I chalked it up to Dad just getting older and slowing down.

Except you were only in your early fifties. I should have known something was up. But I didn't. Hereditary denial, I guess.

Once you told Libby and me the World’s Most Obvious Secret, we encouraged you to tell everyone else. That took some time. Then one summer morning in 2012, I woke up to a bunch of e-mails and tweets containing well-wishes from friends and strangers about “your dad’s news.” What the hell were they talking about? Turns out you’d decided to let the world know you have Parkinson’s disease in a late-night Facebook post—a response to an inquiry from a virtual “friend.” Social media, insomnia, and, I’m guessing, a little Scotch conspired to get the word out. Whatever it takes.

Whether or not you recalled making the announcement in the wee hours, the outpouring of love and support you got from the people who have watched and read you for decades vindicated your decision to “come out.” Then there are the millions of PD patients who drew inspiration from the fact that you’ve worked full-time for years with the disease—appearing on television, no less. They told you as much in thousands of letters and e-mails.

And still today, nearly two decades into your fight against Parkinson’s, you’re working like a thirty-year-old, traveling the country, telling stories, and making people laugh. Doing your thing.

In case anyone reading this wonders if you have a sense of humor about all this, a quick story. The fall after you made your announcement, you and I were invited to speak at the gala for The Michael J. Fox Foundation, the phenomenal Parkinson’s group. In a hushed Waldorf Astoria ballroom full of New York’s most famous and glamorous people, you talked about living with a disease that, among other things, causes tremors. The audience was waiting for something sentimental and reflective. You began with this: “I thought at times about ending it all.” The room went silent, the group stunned by what sounded like a dark confession. I knew better. You continued, “But I was afraid if I tried to shoot myself, I’d miss.” The room erupted in laughter.

A little sick, Dad, but funny as hell. Just like you.