



STONEWALL
STRONG

*Gay Men's Heroic Fight for Resilience,
Good Health, and a Strong Community*



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Contents

	Acknowledgments	xi
	Introduction	1
PART I	Growing Strong in My Broken Places	
	Overview: Part I	13
Chapter 1	Why <i>Not</i> Me? A Medical Diagnosis Upturns My Life and Launches a Journey of Self-Discovery	15
Chapter 2	Survivor: The Roots of My Resilience	21
Chapter 3	Normal: My Gay Liberation	27
Chapter 4	Destiny Calling: How a Lonely Boy Became a Professional Outsider	33
Chapter 5	The End of Innocence: How AIDS Became My “Beat”	37
Chapter 6	Tribulations: Perpetual Grief Fuels My Budding Activism (and Self-Defeating Sexual Behavior)	43
Chapter 7	The Cruellest Month: Watching the Man I Loved Die	49

Chapter 8	Hard Ways to the Stars: Romantic and Professional Rejections to Overcome	55
Chapter 9	Struggling Writer: Trying to Stay Balanced as Losses Mount and Risks Increase	63
Chapter 10	Wounded Warrior: How AIDS and a Shame-Filled Man Taught Me to Value Myself	73
PART II	The Heroic Legacy	
	Overview: Part II	83
Chapter 11	Subversives: How “Gaydar” Helped Gay Men Survive in the “Old Days” Before Stonewall	85
Chapter 12	Gay Power! Seizing Control of the Discussion About Gay Lives	93
Chapter 13	Out and Proud: A Community and Movement Emerge	101
Chapter 14	Love in Action: Showing the World What “Community” Looks Like in the AIDS Epidemic	109
Chapter 15	Claiming Our Power: AIDS Organizing Proved Our Ability to Create Change That Benefits All	115
Chapter 16	Love (and America) Won: Our Successful Push for Marriage Equality Moved America Closer to Fulfilling Its Promise	125
PART III	A Home in the World	
	Overview: Part III	137
Chapter 17	How to Raise a Gay Son: Straight Parents Become Staunch Allies After Son Comes Out to Them at Fifteen	139
Chapter 18	Husbands and Dads: Pioneering Massachusetts Couple Finds Resilience in Marriage and Fatherhood	145
Chapter 19	Becoming Their Story’s Hero: Helping At-Risk Gay Youth Find Strength in Their Resilience	151

Chapter 20	Invincible City of Friends: From Drag Houses to Community Centers, LGBT Americans Take Our Communities Seriously	161
Chapter 21	God Loves Us, Too: The Inside Truth About Religion and Homosexuality	171
PART IV	At Home in Ourselves	
	Overview: Part IV	185
Chapter 22	Integration: The Power of Authenticity in Our Work Lives	189
Chapter 23	Doubly Different, Twice as Strong: Gay Men of Color or Different Ability Show How to Find Resilience in All Their “Identities”	207
Chapter 24	To Our Health! Building Upon Our Resilience Is the Key to Good Health	221
Chapter 25	Defining “Old” for Ourselves: The Open Secret Is That Most of Us Already Do	241
Chapter 26	Stonewall Strong: Life Is Good When We Are the Heroes of Our Own Life’s Story, Standing Firmly on Our Community’s Proud History of Resilience	257
	Notes	273
	Bibliography	289
	Index	299
	About the Author	00

CHAPTER ONE



Why Not Me?

A Medical Diagnosis Upturns My Life and Launches a Journey of Self-Discovery

I'm a reporter.

For more than three decades I've written newspaper and magazine stories, and a book, about HIV-AIDS as it has robbed the health and lives of millions of people worldwide. Many were my friends.

I decided this would be my beat back in 1986, when I was still in journalism school. By then I had already lost two friends, men in their twenties like me. It was the year that Bill, the man I loved, found out he was positive. I was afraid I might be infected myself.

All around me, I saw a terrifying event unfolding. My role would be to tell the stories of the people the pandemic touched.

I started informing myself on every aspect of HIV-AIDS, reading the literature and interviewing activists, scientists, and people living with the virus. And I reported the terrible physical and emotional suffering, the extraordinary acts of bravery and charity, and the amazing spiritual transformations I witnessed.

But despite all I knew, I never truly *knew* what I was writing about.

As a gay man, I wasn't a completely detached observer, because HIV-AIDS affected so many people close to me and in my community.

Yet the stories I told were always "their" stories. I could watch and listen and share with readers what I saw and heard. Being HIV-negative myself, though, I had only a limited understanding of even my closest friends' experiences.

Until October 27, 2005, that is. That's the day I found out I have HIV.

Now I'm not just a reporter. Now I'm a reporter living with the same lethal microbe that unleashed so much fear, sorrow, and heroism in the world—and killed so many of my friends.

I am also still a reporter who recognizes an unusual story when I see it. I knew that “Veteran AIDS Reporter Learns He Has It” was such a story. I emailed my editor at the *Washington Post* “Health” section, and shared what I started calling “my news.”

“Oh, shit,” he replied. That summed it up pretty well. He put me in touch with the *Post*'s “Outlook” section. They wanted the story.

My HIV “coming out” story ran in the *Washington Post*'s Sunday “Outlook” section on May 14, 2006, including a 1991 photo of Bill and me.¹ I never expected that year to mark the twenty-fifth year of the HIV-AIDS pandemic, and the twentieth anniversary of my own first articles on AIDS, by describing how my perspective has shifted, from observer to participant.

The shift took place exactly three weeks after my forty-seventh birthday, on my close friend Rich Rasi's October 27th birthday. My doctor called with the results of the blood work from my annual checkup. For all the years I'd been seeing him, our annual phone call began with pleasantries and the latest readings on cholesterol and such. This time was different. I could tell from the tenseness I sensed in his voice over the phone.

“I have bad news on the HIV test,” he said.

I felt the ground fall out from under me. I'd probably written about this in other people's lives hundreds of times—people talking about a time before and a time after their HIV diagnosis.

Now I knew that words—the words I'd wielded like a shield against the reality of what I was seeing, hearing, and reporting—truly can't describe this moment of sickening self-awareness.

I didn't know what to think. It was when I thought of Glenn, the man I was beginning to love—and the thought “now he won't want me” hit me—that I started to cry.

I flashed back to the night I had reported on the protest at President Ronald Reagan's first AIDS speech, in 1987, when he stressed teaching “values” rather than methods of preventing the spread of HIV. That was the night my friend Gregg in Chicago told me he was positive, the night he called himself “damaged goods” that no one would want. All these years later, I felt the real weight of his words descend upon me.

When I went to my doctor's office later that afternoon for more blood work, he advised me that it was pointless to try to pinpoint exactly how “it” had happened; better to focus on dealing with this new reality, he told me. But that reality seemed surreal because I felt so well. I had no warning

signs—such as night sweats or swollen lymph nodes—to tell me something was wrong. I had no clue at the time that I was one of the estimated 13 percent of Americans living with HIV who don't know they are infected.²

“Suddenly,” I wrote in my journal, “it’s all as personal as personal gets—my very person, my body, my health, my life, my sense of security, my fears of illness and death.” I wrote that, but I was only beginning to grasp it. Part of me was still the dispassionate observer, looking on, writing about somebody else’s life.

Then, a week later, I received more shocking news. My tests revealed a relatively low viral load, suggesting a recent infection. But the T-cells, the white blood cells that HIV infects and destroys, were also very low—only 198, compared with 600 to 1,200 in a healthy person.

I knew what that meant. It was a fact I had cited in so many stories. A T-cell count below two hundred indicates a damaged immune system and risk of life-threatening infection. I also knew that the Centers for Disease Control and Prevention (CDC) at the time considered a T-cell count under two hundred an AIDS diagnosis.³

I was floored. “This is so 1980s,” I said to my doctor. “This isn’t supposed to happen to gay men in the U.S. who get tested regularly.” I thought that was exactly what I had been doing with each of my annual checkups. It turned out my doctor hadn’t tested me for HIV for at least the three previous years. I was frank with him about my sexual behavior, and neither of us considered it particularly risky; perhaps that’s the reason he didn’t ask for the HIV test, and I didn’t ask for one either.

My doctor said to forget all the images of suffering and death I had witnessed because there is effective treatment today. He assured me that living with HIV in 2005 was a very different experience than when Bill was diagnosed in 1986. He said my counts would improve once I began medication—and that if I took it properly, I could expect to lead a healthy, even long, life.

But a parade of faces passed before my mind’s eye: once-handsome faces covered with lesions, atop the wasted shells of formerly muscular bodies. I had cried for so many young men as I chronicled their stories. Their stories that were now *my* story.

I recalled the last weeks of Bill’s life, when I visited him at the hospital each day after work. I watched as his mind and his life slipped away in April 1994—two years before “combination therapy” and new drugs finally brought hope of living with HIV rather than dying from AIDS. I didn’t think any pill could help me manage such a painful memory, or other memories like it, of friends taken by AIDS—Gregg, Ron, Allen, Fred, Bob, Louis, Billy, Eric, Michael, and Jim, to name a few.

I was afraid of the potential side effects of the medication I would now have to take for the rest of my life. I knew they could range from insomnia and diarrhea to much more serious problems, such as diabetes or heart and liver disease. I was terrified of developing the gaunt look—another possible side effect—that Gregg had the last time I saw him alive in 1998.

Despite everything I knew about HIV, I found myself rereading the most basic information, remembering what others with HIV had said about how information is power. This time I used my reporter's ability to ask questions and gather information for the biggest assignment I would ever have: staying alive.

My individual insurance policy limited prescription drug coverage to a mere \$1,500 a year; the medications I needed cost \$1,700 a month. Now, with a major "preexisting condition," I was locked into this insurance policy, and no other insurance company would cover me. I searched the Internet and emailed friends in Europe looking for lower prices. When I found nothing, I scoured the websites of organizations that serve people with HIV-AIDS, feeling a new gratitude for their work. Suddenly groups such as the National Association of People with AIDS didn't seem like just sources of information for a story, but sources of the kind of hope I badly needed.

I contacted several people I knew from my years of reporting to see what they could suggest about getting the treatment I couldn't afford on my own. Cornelius Baker, former director of D.C.'s Whitman-Walker Clinic, was a friend and someone I had interviewed a number of times. He suggested I look into a clinical trial at Whitman-Walker. I enrolled in a study that would provide regular checkups and free medications for ninety-six weeks.

After only four months of treatment, the medication had already suppressed the virus to the optimal "undetectable" level. My T-cells remained troublingly low. My triglycerides shot through the roof—which meant another pill to treat that particular medication side effect. But the nurses and doctor at Whitman-Walker assured me that my immune system was rebounding.

In March 2006, I asked my doctor for a sleeping pill for the insomnia that had been the main side effect of my meds to that point. I also asked for a referral to a psychiatrist to find out why I was always on the verge of tears. As a medical reporter—and former AIDS training coordinator for the American Psychiatric Association—I was comfortable with the possibility that I could have a psychiatric issue, perhaps an anxiety disorder. I was willing to take medication if necessary. My only objective was to function at my highest level.

The psychiatrist said I didn't need medication. Instead he told me I was feeling sad because my HIV diagnosis had challenged my understanding of who I am, my place in the world, and my sense of where I'm going in life. He said I was suffering, and it's natural to feel sad in the face of suffering. He told me I am extremely resilient. He also told me I was entering an "exciting" time in my life because it offered an opportunity to examine so many things and redefine what I wanted for myself going forward.

I shared my news with close friends, who affirmed my view that HIV should not define me. AIDS had overshadowed my entire adult life and all the years since I came out the summer it first appeared, in 1981. I was determined not to let it *re-define* me as I know myself and present myself to the world. I instinctively eschewed any idea of being a "victim."

Yet the thought of telling my family, particularly my beloved mother, tore me up inside. I felt as though I had let her down in some way. Clearly I wasn't immune to the shame society expected me to feel for having the misfortune of getting HIV.

I have been open with my family for years about being gay, and they have always loved and accepted me. But I am the only son, the oldest child, my two sisters' big brother, my mother's Rock of Gibraltar. Since my father's death in 1989, I felt I had to be the *paterfamilias*, always strong for others. I never learned—in fact I was taught the exact opposite—that it's okay to admit I'm frightened or that I need to be loved. I think this is the biggest reason why I was able to be detached and clinical for so long in reporting on a subject as painful as HIV-AIDS, even as it broke my heart repeatedly.

When I finally shared my news with Mom in April 2006, she said to me, "Be brave, John." I've learned that brave people—like the many I have known and interviewed—are not without fear, but they do the right thing despite their fear. I'm able to be brave, and tell my story, because I have the love and support of family and friends.

I know too well that even approaching four decades into the HIV-AIDS pandemic such openness can still get a person killed in some parts of the world. And I know there are gay men in this country who will resist believing that my story could ever become their own.

I, too, resisted believing the stories I reported would ever become *my* story. I told myself I was smart, cautious, perhaps even "spared" so I could bear witness as a reporter. But my perspective has changed. Now I understand what I've seen and heard from others. And I can only try to make those without firsthand experience understand—not by writing as a detached observer, but by writing straight from the heart.

Two weeks after the article appeared, I was a guest on Tom Ashbrook's National Public Radio *On Point* show marking the twenty-fifth anniversary of the first reported AIDS cases. Ashbrook asked several times how I got infected, "knowing all you do" about HIV. If I could get infected, was there hope for anyone else? he asked.

Alone in the NPR studio inside the Christian Science Church building at the corner of Sixteenth and I streets in downtown Washington, I squirmed. I didn't care to discuss my personal sex life on live national radio. I certainly didn't believe I was responsible for others who got infected. I was also brand new at speaking publicly about having HIV, so didn't have a response thought out ahead of time.

Ashbrook reframed his question a couple of different ways. Finally, one of my fellow guests on the show came to my rescue. Dr. Helene Gayle at the time was executive director of CARE, the global humanitarian organization. She was formerly the director of the Centers for Disease Control and Prevention's national HIV prevention program. I felt intimidated, to say the least, not knowing what she would say. But she simply explained that "knowing" the right thing doesn't mean we always do it.

The next time Ashbrook asked, I simply said I got infected because "I'm human."⁴ It seemed hard to make that simple admission. I had to eat my words after saying that men my age who got infected "should have known better." I had to finally admit, at least begin to, that my sexual behavior wasn't *always* 100 percent safe.

Simply acknowledging my own human frailty launched me on a journey that eventually led to writing this book. It set me looking back through my life, sorting through my memories and journals, trying to fathom the challenges and choices that led me to become infected with the deadly virus that had already caused me so much sorrow.

I asked myself many questions: Would I have gotten infected if I hadn't lived in D.C., with its high prevalence of HIV? Would I have made different sexual choices if I had learned from boyhood that I am worthy of love and that I could marry *anyone* I love? Would I have been settled down with the man I loved if AIDS hadn't disrupted our relationship when we were so young? How deeply *have* I been affected by watching most of my closest friends die while we were in our twenties and thirties? *Why me? Why not me?*

I *never* questioned whether I would take my medications faithfully, go for blood work, see the doctor every few months, and do whatever I had to do to stay healthy and well. I am a survivor, after all.