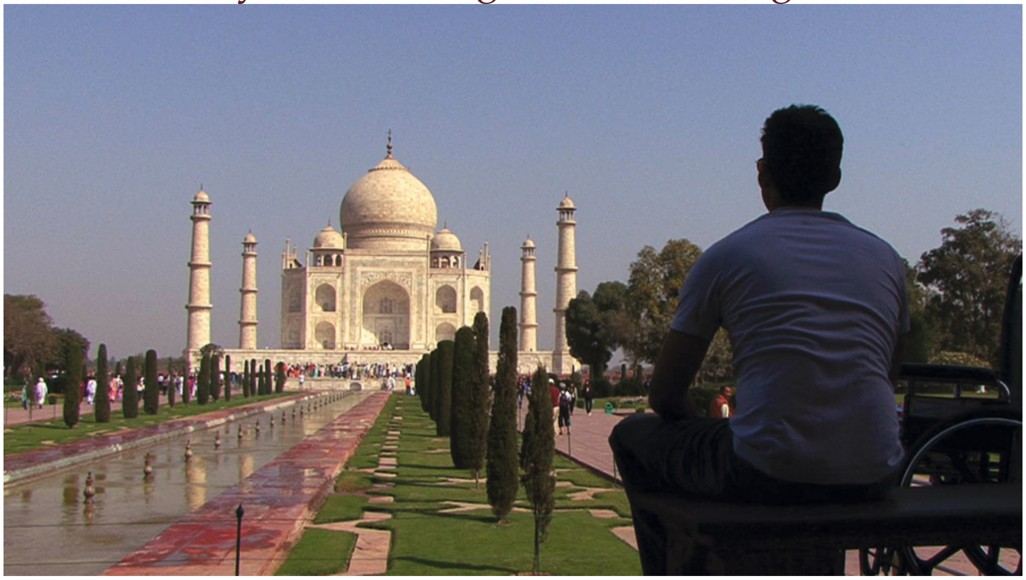
PROPOSAL

WALK WITH ME

The Heroic Story Of A Young Man's Race Against The Clock



By Jason DaSilva

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What matters most in life when you lose the unimaginable?

Overview

Walk With Me

Jason DaSilva

The Heroic Story of a Young Man's Race Against the Clock

In *Walk With Me,* **Jason DaSilva**, an Emmy-award-winning director, producer, writer, and disability-rights activist, makes his literary debut with a harrowing coming-of-age story, as he describes how his meteoric rise to prominence was cruelly interrupted by the early onset of primary progressive multiple sclerosis, a devastating diagnosis he received at age twenty-six.

Inspired by the author's celebrated PBS documentary *When I Walk* (lauded by the *New York Times* for its "uncompromising intelligence and unrelenting candor"), here is an uplifting story of courage, perseverance, and hope in the face of suffering and the ultimate threat of death.

In the tradition of *The New York Times* #1 bestseller *When Breath Becomes Air* by Paul Kalanithi, Jason's story traces a young man's fight against time as he battles an incurable disease that causes the rapid decline of his physical mobility. But the affliction does not prevent him from falling in love, getting married, having a child—and making a difference through the artistry of his many films and through his worldwide travels advocating for disability rights.

> "Sure, MS results in the loss of vision, muscle control, balance, and a whack of other problems," says the author, "losses and more losses. But there are gains too—an ability to totally appreciate what I *can* do and what I *do* have—creative work that consumes me, a family that embraces me, and the ability to make my own decisions. That's freedom."

As the author is faced with eventual paralysis and blindness, we witness his struggles with mortality; his fear of losing his ability to work; his loneliness and isolation; his frustrations with having to learn new ways to cope with everyday tasks; and his terror of one day losing his capacity to communicate at all as his symptoms worsen.

Throughout, we witness a continuing metamorphosis as a young man matures, gaining strengths he never were possible as he imparts invaluable life lessons to the reader.

No obstacle derails his determination not only to survive, but also live fully as he turns crises into opportunities, and pain into power.

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Cinematic in style, the 220-page memoir is punctuated with evocative anecdotes and succinct scenes, sweeping the reader from filmmaking locations in India, Africa, Cuba, and Iraq to international film festivals in Berlin, Venice, Cannes, and Toronto—and from one doctor's office to another.

We first meet DaSilva as a peripatetic 23-year-old, a strappingly handsome lady's man who divides his time between shooting independent films and working teaching jobs to fund them. Partying hard and traveling to film festivals, he drives himself relentlessly and sleeps four hours per night. His future seems limitless as his first film, *Olivia's Puzzle*, is shown at the 2003 Sundance Film Festival, where the author gets to meet Robert Redford, Philip Seymour Hoffman, Hilary Swank, and Spike Lee. The story about the daily lives of two eight-year-olds of Goan ancestry, one in India, the other in Vancouver, is ultimately broadcast on HBO, PBS, and on various networks worldwide. During this momentous time, inexplicably, his legs become weirdly weak and occasionally tangled, and he starts to trip. He squints his eyes as colors break apart and fade, and he struggles with blurry double vision.

Relentlessly ambitious and locked in youthful denial, he tries to ignore it and parties even harder to the end of 2004. Finally, after falling down a flight of stairs, and at the insistence of his mother, he undergoes a series of tests that reveal PPMS, a rare disabling neurological condition affecting 40,000 people in the U.S., 250,000 worldwide.

At first, paralyzed by fear and ignoring the ramifications of his illness, he neglects his health and refuses to rest, furiously pumping iron and becoming a version of *The Bachelor*, skipping from one date to another. But as time passes, he gradually accepts the reality of his situation and adapts to it.

Over the course of the next decade, we watch an energetic young man grapple with intense frustration and sadness, moving from denial to anger and depression as he

"Sometimes I ask myself: Why am I here, feeling as it I don't exist?--conscious but unable to move. Floating. Waiting. Life feels too quiet, like it's eroded. I try hard to fight off this massive and continuous existential crisis, but it's always there. Then I go back to work."

“progresses” from a cane to a walker to a motorized scooter and finally to an electric power wheelchair. He graphically shows us the horrors of being incrementally stripped of mobility, from his soccer-playing heyday to, years later, being confined to a wheelchair, with no use of his hands or legs, relying on an aide for even a sip of water, while maintaining the outward normalcy of life.

Through it all, the narrative captures the never-maudlin author’s sardonic humor as he manages to find light moments in the surreal reality that engulfs him.

We see him valiantly supported by his close-knit family (notably a fiercely candid mother who scorches any impulse for despondence), by a team of volunteers and aides, and by his wife Alice, all of whom function as his extra set of legs, hands, and eyes. He wills himself not only to “walk,” but to shoot films throughout the world. Eventually, he makes the decision to turn the camera on himself, setting off on an epic seven-year journey—producing an autobiographical documentary about his daily battle, the film that wins him an Emmy.

All the while, the resilient author fervently searches for a cure or an effective treatment. He becomes a vegan and then turns to a fully raw diet; he tries acupuncture, Reiki, IV steroid treatments, experimental stem-cell therapies, and chemotherapy. He travels to India where he tries yoga, meditation and ancient Ayurvedic treatments using herbal compounds. He even journeys to Lourdes to bathe in the fabled spring waters.

What did all those herculean efforts amount to? “Not much,” he quips “other than a lot of flyer miles. I felt like a sitting duck and was willing to try *almost* anything—though I did reject bee-sting therapy, blood-letting through leeches, hyperbolic oxygen therapy in a body chamber, and bathing in urine!”

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The charismatic 37-year-old, a charming raconteur who has appeared on such TV programs as *The Meredith Vieira Show*, fills the narrative with buoyant optimism, self-deprecation, and wit as he captures the irony of living a life "feeling old in a young body."

"Inside, I still see myself as that young guy racing around town with six things planned in a night. But my body isn't cooperating. But this is not a story of gloom and doom," he says. "It's about the love and support of my family, my no-nonsense mother, two brothers who are endlessly supportive, and a woman who was open-minded enough to date and then marry someone who brought her back up the aisle in a motor scooter!"

Throughout the story, the author defies limitation as he continues to cope in creative ways. We see how his 24-hour-a-day aides become an extension of his own body and how dictation software replaces typed e-mails, allowing him to work though he's legally blind and can hardly move. He continues to write screenplays and shoot documentaries, including his next film, *When We Walk,* a sequel to *When I Walk* that picks up the story after his wedding and includes the unraveling of his marriage. And most important, we watch his exuberance and immense frustration as Dad, talking and watching his son play, though he is unable actually hold him or participate in father-son activities.

"In many ways my son and I are on equal terms. We both need assistance from others and we both appreciate our wheels!—he in a stroller, me in an electric power chair. My fear, though, is that he's going to walk away from me."

For a young man faced with a potentially shortened lifespan, his worldview shifts from self-obsession and hedonism to self-preservation and contribution to others. Testifying on panels at the United Nations and giving keynote speeches at leading universities such as Princeton, Harvard, and NYU, he emerges as one of the nation's leading activists for disability advocacy and MS research. He travels to Berlin to a Google-sponsored conference on disability rights and hosts the National MS Society's "We Keep Moving" campaign. His photo is even beamed onto a Time Square billboard.

He also founds AXS Lab, Inc., a non-profit serving those with disabilities through the arts, media, and technology; and creates a unique mobile app called AXS MAP, which allows any disabled person to share reviews on the wheelchair accessibility of businesses, restaurants, and other public places.

All this he accomplishes despite the steady progression of the disease, which becomes a catalyst for growth. In the end, this is not a story about MS per se, or about any particular disease, but about how the human spirit can flourish even in the face of a monumental challenge.

Even though his physical strength deteriorates, he gains strengths he never knew he had—the ability to withstand pain, the maturity to accept loss, the patience to adapt to crushing circumstances, the courage to work no matter what the sacrifice, and the wisdom to value each moment.

The takeaway lessons are timeless, including the author's commitment to seize opportunities and demonstrate boldness; to use each day to the maximum, with no time wasted for fear or procrastination; to live beyond the expectations of others; to cultivate gratitude for whatever he does have and can do; to put trust in the innate kindness of others; and to believe he was put on this earth to serve a purpose, and that there is opportunity in every crisis, a reason to serve others.

Touching a universal chord, *Walk With Me* is an unforgettable story that will appeal to any reader struggling with a life crisis—an illness, an accident of fate, or a reversal of fortune. They will see in DaSilva that, with the right attitude, no challenge can destroy the spirit or weaken the resolve to live.

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<u>Los Angeles Times</u>: *"DaSilva hits the perfect balance.... extraordinarily accomplished, poignant, and wise."*

Jason DaSilva is an Emmy-award-winning director, producer, writer, and disability rights activist. He has acquired an international platform as an artist by creating ten celebrated films while simultaneously battling the severe physical limitations of primary progressive multiple sclerosis.

His meteoric rise as an independent filmmaker began at age 23, when his first documentary short, *Olivia's Puzzle*, was accepted and shown at the Sundance Film Festival. Over the next ten years, the New York-based filmmaker traveled the globe and mastered his "run-and-gun" documentary style, a spontaneous form of shooting in which he chased the action and recorded events in real time. Whether filming in India, Iraq, Africa, or Cuba, the 37-year-old repeatedly demonstrated a passionate social conscience, contrasting the underprivileged lives of children in underdeveloped nations to those in Western countries.

In 2007, as his PPMS symptoms worsened, he turned the camera on himself in a seven-year shoot that resulted in his prize-winning documentary, *When I Walk*, an unflinching portrait of a man and artist confronting an incurable disease. The film was screened at sixty film festivals worldwide, including Sundance, broadcast on PBS and on Netflix, and awarded a 2015 Emmy for Outstanding Informational Programming.

DaSilva has since emerged as a nationally known activist for disability rights. He has been the recipient of numerous grants and awards, and was a past spokesperson for The National Multiple Sclerosis Society. He has testified on panels at the United Nations and also given keynote speeches at such universities as Princeton, Harvard, and NYU. He created a mobile app called AXS MAP (www.axsmap.com), which allows any disabled person to share reviews on the wheelchair accessibility of businesses, restaurants, and other public places.

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Born in Ohio and raised in a modest household in Ft. Lauderdale, Florida, DaSilva was the eldest of three boys and was both athletic and artistic. He had a natural ability for creating story lines and drawing hilarious comics. His parents, both schoolteachers, were of Indian ancestry and born in East Africa. His mother is from Kenya and father from Uganda, with family roots traced back to Goa, India. For Jason, moving from Florida to

Vancouver at age 14 created a perennial "culture shock," as he had to make new friends and adjust to a new environment. He withdrew first into art, and in his teens, into photography and music, playing keyboard in a punk band.

Although he intended to become a visual artist and graduated from the Emily Carr Institute of Art and Design in Vancouver, the stellar result of a class project, his documentary *Olivia's Puzzle*, thrust him unexpectedly into the limelight. On a whim, after moving to New York to attend Parsons School of Art and Design graduate school, he submitted *Olivia's Puzzle* to The Sundance Film Festival, and from 3,000 applicants, he was one of the winners. Unexpectedly in the limelight at 23, he parlayed his Sundance fame into procuring multiple grants, which financed a string of his subsequent films: *Lest We Forget* (2003), a feature-length film drawing parallels between post-9/11 racial backlash and Japanese internment camps after Pearl Harbor attacks; *A Song For Daniel* (2005), a short comparing the lives of two Iraqi boys during the Iraqi War; *Twins of Mankala* (2006), a film comparing the life of an 8-year-old girl living in the village of Kilo, Kenya, with the lives of twin sisters of Kenyan descent in Lowell, Massachusetts; *Shocking and Awful* (2006), which investigated the U.S. occupation of Iraq; *From The Mouthpiece On Back* (2008), a feature-length documentary about the lives of members of a nine-piece New Orleans brass band separated after Hurricane Katrina.

Once the symptoms of MS became more noticeable, he produced *First Steps* (2009), which explored the beginning of his personal health crisis, followed by *When I Walk*. The filmmaker, who lives a stone's throw from Manhattan, in Long Island City, continues to search for effective treatments while working on his next film, *When We Walk*, a sequel that follows his life since his marriage to his wife Alice and the birth of his son Jase, now four.

Collaborator Biography

Bestselling author and veteran celebrity interviewer **Glenn Plaskin** specializes in writing memoirs, self-help, and inspiration-oriented books. His published work includes: *Horowitz: The Biography of Vladimir Horowitz; Turning Point: Pivotal Moments in the Lives of America's Celebrities*; *Katie: Up & Down The Hall: The True Story Of How One Dog Turned Four Neighbors Into A Family,* and *The Power To Change Today: Simple Secrets To The Satisfied Life,* and numerous ghostwritten projects.

His profiles have appeared in the *New York Times, New York Daily News, San Francisco Chronicle, Los Angeles Times, Chicago Tribune*, Family Circle, US Weekly, Ladies Home Journal, Cosmopolitan, W, and Playboy. His interview subjects have included Katharine Hepburn, Nancy Reagan, Calvin Klein, Senator Edward Kennedy, Audrey Hepburn, Elizabeth Taylor, Leona Helmsley, Barbara Walters, Diane Sawyer Donald Trump, Al Pacino, and Meryl Streep. His TV appearances include *Oprah, The Today Show,* and *Larry King Live*. He lives in New York City.

MARKETING & DEMOGRAPHICS

WALK WITH ME is targeted directly to:

- A demographic of 2.5 million who have MS, the most widespread disabling neurological condition of young adults worldwide
- An audience of 23.5 million Americans suffering from autoimmune diseases, one of the top ten leading causes of death in female children and women in all age groups up to 64 years of age
- A secondary worldwide market of readers who annually spend $693 million on inspirational books.
- A baseline audience of DaSilva fans, including 2.5 million U.S. viewers of the author's documentary, *When I Walk*.

The charismatic 37-year-old, a skilled public speaker, has appeared on such TV programs as *The Meredith Vieira Show*, and before the United Nations, at international conferences sponsored by Google, and at American universities such as Harvard and Princeton. He has also been featured in national “Move It” campaigns for The Multiple Sclerosis Society.

With access to the vast online community of The National Multiple Sclerosis Society and The United Spinal Association, he will promote the book on their web sites and in special appearances throughout the U.S.

Jason and his team maintain close relationships with the following media outlets that have contacted Jason previously, which would be used for book promotion:

- MSNBC’s *Morning Joe*
- *The Rachel Maddow Show*
- *Anderson Cooper 360*
- HLN’s *Robin Meade*
- *Fox & Friends*
- *Dr. Phil*

- *Steve Harvey*
- *The Meredith Vieira Show*
- *New York Times*
- *Los Angeles Times*
- *USA Today*
- *The Hollywood Reporter*
- *Time Health & Family*
- *CNN Health*
- *ABC News*
- *PBS*
- *New Mobility Magazine*
- *Time Magazine*
- *Parade*
- *New York Magazine*
- *Family Circle*
- *Woman's Day*
- *O*
- *Good Housekeeping*
- *Glenn Beck*
- *The Sean Hannity Show*
- *NPR*
- *Salon*
- *Slate*
- *Huffington Post*
- *Daily Beast*
- *BuzzFeed*

POTENTIAL TESTIMONIALS:

- Meredith Vieira
- Michelle Obama
- Deepak Chopra
- Michael J. Fox
- Robert Redford
- Robert De Niro

COMPETING & COMPLIMENTARY BOOKS:

Survival Inspiration

Tough as They Come**,** Travis Mills with Marcus Brotherton (Crown, 2015)

Shrinkage: Manhood, Marriage, and the Tumor That Tried to Kill Me**,** Bryan Bishop (St. Martin's Griffin, 2015)

My Stroke of Insight: A Brain Scientist's Personal Journey*, Jill Bolte Taylor (Plume, 2009)*

Blindsided: Lifting a Life Above Illness: A Reluctant Memoir, Richard M. Cohen (Harper Perennial, 2005)

The Diving Bell and the Butterfly: A Memoir of Life in Death**,** Jean-Dominique Bauby (Vintage, 1998)

Chapter Outline

-SAMPLE CHAPTER-

For No Reason At All

- On And Off The Red Carpet-

"We have no right to ask when sorrow comes, 'Why did this happen to me?' unless we ask the same question for every moment of happiness that comes our way."

-Source Unknown -

Thursday, January 16th, 2003, Park City, Utah, Sundance Film Festival, 7 pm [1]

It was exactly as I had pictured it.

The red carpet was lit up by beams of floodlights and by the flashes of the paparazzi, their curiously loud clicks like persistent castanets.

It may have only been 12 degrees that winter evening, but I felt the heat of the night around me. Just to my right was one of my favorites actors, Steve Buscemi, who stood there chatting with Spike Lee. Holy S—t!

And as I was walking into the Eccles Center for the Performing Arts, I remember thinking the woman ahead of me was cute. She turned out to be Minnie Driver, arm in arm with Philip Seymour Hoffman; both of them were there for *Owning Mahoney*, a Canadian film about gambling addiction.

For a 25-year-old, seeing Hillary Swank, Al Pacino, and Ben Affleck floating by in a blur of lights was like a mirage—everyone assembled to celebrate the festival's feature attractions. That year the lineup included *The Station Agent*, *American Splendor*, *Party Monster*, *Prey For Rock*, and the brilliant documentary *Capturing The Friedmans*, one of my favorites, which focused on the 1980's investigation of Arnold and Jesse Friedman for child molestation.

And there was I, a film world newbie standing in the middle of it all, being interviewed about my first movie, *Olivia's Puzzle*, a 12-minute short I'd made on a shoestring right out of art (not film) school, contrasting the daily lives of two eight-year-olds, one living in Goa, India, the other of Goan ancestry living in Vancouver.

For any young filmmaker, having your work shown at the nation's largest independent film festival was a little like making the top 20 on *American Idol*. For

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[1] The sample is a composite of Chapters 1, 2, 4, as referred to in the Chapter Summaries

me, it was a life-changing shock. Up until then, as always, I was hyper-energized, my time split between long days of filmmaking and the healthy pursuits of a healthy athletic New Yorker--out at galleries and nightclubs, playing soccer in the park, dancing and dating, and existing on almost zero sleep. Professionally, I was still straddling the lines between careers as visual artist, filmmaker, photographer, and punk band keyboardist. It was all up in the air.

But at Sundance, and in its aftermath, I finally reached a place in my life where I felt confident in myself as a man. Growing up, I'd had a lot of doubts about my own worth, especially when it came to dating girls. Every young guy goes through a wing-testing stage, taking on different personas as his masculinity evolves. For me, though I was always self-assured in my abilities as an artist, there was inner doubt about whether I was attractive enough to the opposite sex. I was a little skinny, but by the time I was in my early 20's, I had bulked up at the gym and had come into my own. Whether it was in coffee shops, nightclubs, or restaurants, I admit that my vanity was bolstered by the attention I was getting. I finally felt happy with both my ability to connect with women and with the work I was creating.

A few months earlier, when I had gotten the news over the phone, I impulsively quit the Master's program at the Parsons School of Design in New York City, figuring I would no longer need it. It was an expensive education that I was paying for on student loans. And my own professors were telling me to drop out and use the tuition money to make a film.

In fact, one of them, who had been a special effects designer for Hollywood films, was so impressed that on my last day in school, he pulled down the blinds and took out a big bottle of tequila to celebrate my acceptance at Sundance! At the time, I was so naïve that I didn't even know where Sundance was or who had founded it.

In fact, that year during our family's Christmas in Vancouver, when my Auntie Tamara was telling me how cool it was that I'd been accepted and that it was Robert Redford's festival, I confused him with "the guy on the salad dressing labels!" I never lived that one down. (I should have watched *Butch Cassidy and the Sundance Kid* more carefully.) To this day, she reminds me of my mistake.

So twenty-five years after Robert Redford founded the festival, I stood in front of a Sundance banner, amazed, and grinning before a mob of photojournalists, film aficionados, and that assortment of stars.

I spent the next days going to events and networking and saw as many films as I could. While the stars were all in rented houses in Deer Valley, or at fancy hotels like the Montage or the St. Regis, I stayed at the AAE Lodge, a dorm-style hostel with sixteen beds per room. Every night, filmmakers, support crew, and just regular filmgoers who loved movies, were all snoring or packing or unpacking their bags. It was impossible to sleep, but I really didn't care. I would wake up early in the morning with a stack of business cards and then network my ass off. I'd go from brunch celebrations for filmmakers, to panel discussions, to screenings, and then on to nighttime networking parties. It went on and on for ten days straight. (And because I had exactly $100 to my name, I tried to do all my eating and drinking for free at those events.)

One evening, I was at a party at one of the Sundance venues hanging out with the cast of *Thirteen*--Evan Rachel Wood, Holly Hunter, and Nikki Reed. And from that minute on, knowing how much fun all this was, and that there was a market for me in this world of movies, I knew I wanted to be a full-time filmmaker, and there was no turning back. My films were a proclamation to myself—each one endowed with a social message that rang true to me. In the blithe naïveté of youth, I felt unstoppable, though oddly enough, I wasn't feeling so great physically.

I'd been competitively playing soccer for most of my life and was in peak condition. Yet, on some days, I was walking like an old man, a little bit slower than usual, and at times, I even felt off balance. On several occasions I showed up late to my own screenings. "Maybe you're dragging," one of the program director's joked, "because Park City is 7,000 feet above sea level!" But that wasn't it. Sure, because of the elevation, I had been told to drink a lot of water and not to overexert. But even so, something wasn't right.

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Once I got back to New York, the experience of Sundance drove me relentlessly forward, fueling my ambition as a filmmaker. I was on a mission, determined to make use of all the networking opportunities I had to promote my work. In fact, with the stature of the festival, I saw how I could parlay that credit to getting larger grants, which would allow me to afford the rent in New York and continue making films. So for the rest of that year, I never stopped spinning. Sleep was an afterthought.

I marketed *Olivia's Puzzle* and worked hard to finish and prepare for the premiere of *Lest We Forget,* a feature-length film I'd begun in 2001 that drew parallels between post-9/11 racial backlash and Japanese internment camps after Pearl Harbor attacks.

The concept for the movie all began after the events of 9/11, when I got a daytime job as a disaster relief counselor at Ground Zero, interviewing the family members of victims who had died in the Towers. By night, I was an investigative journalist, astounded by the targeted discrimination of Arab, Muslim, and South Asians living in the U.S. These non-Americans, who had no responsibility for the attacks, were being rounded up, arrested and sent to detention centers by Homeland Security, based solely on their ethnicity! It was outrageous. I would interview people released from detention who would tell me horror stories about how they were stripped naked and forced to sleep in cells without blankets, or deprived of sleep entirely with the lights kept on, plus other forms of abuse. Here they had come to America for a better life—and this is what they got.

So on the heels of 9/11, the intense patriotism in the U.S. had created a backlash of racism, all of it revealed years later when we heard about the atrocities at Guantanamo Bay. I was incredibly excited by some of the interview footage I had gotten and felt passionate about reporting the inside scoop on what was really happening, a story that very few people knew.

That winter I worked non-stop to promote the distribution of *Lest We Forget*, and consistently got by with just four hours of sleep a night. But those weird physical symptoms I'd noticed at Sundance were becoming irritatingly noticeable. I occasionally lost my footing on stairs and tripped, and I'd have to stop and rest when my legs felt weak. Walking down into the subway, I'd grip the railings tightly for support.

Equally troubling was my vision, which was intermittently blurry. I had a part-time job twenty hours per week teaching teenagers about media, video, and film at SoBro (South Bronx Overall Economic Development Corporation). It was incredible to be part of this afterschool program, called "New Beginnings," for underprivileged high-school students interested in film, dance, photography, and poetry. I could lose myself as I taught, and I loved seeing that hopeful light in their eyes for a future career. As for *my* eyes, my memory is that everything around me was slightly discolored and blurry. Coming out into the light from the subway, colors were oddly muted. Bright red would be a pale shadow of itself. This really freaked me out, because my art and film career clearly depended upon my ability to see clearly.

Things came to an emotional head one wintry night in March of 2004, when I was out at a club in the East Village dancing with a very pretty ballet dancer. Rather abruptly, I uncharacteristically cut the date short and went straight home. Why? I felt sick, exhausted and overwhelmed by the changes in my body, which I kept a complete secret. It was rough for me to admit to anyone that I was now tripping over my own feet. To a strong young guy who'd been great at soccer and baseball the shame of losing ground seemed like a stigma, an affront to my masculinity. So I didn't want to talk to anybody about it. That night, I slept for ten straight hours, but by morning, feeling much better, I was back into my busy routine again. Though I continued to have bad days shuffled into the good ones, nothing was going to stop me.

As 2004 spun by, I hit more than ten film festivals in seven months screening *Lest We Forget*—including ones in Amsterdam, Glasgow, Mexico City, and the Canary Islands. Keeping to this frenetic schedule felt like a glamorous existence to me; after all, I was discussing my films with receptive audiences, then out nights drinking and partying with my fellow filmmakers. I would then race to get planes (that I sometimes missed). I was Mr. Absent-Minded-On-The-Go Guy who was burning both ends of every single candle, cramming too many things into a night, and then crashing into bed at 6 am.

I began to notice that I was slowing down even more physically, though I tried to mask it. It was a self-induced challenge. I'd walk along the street with other people, and then stop, casually pretending to curiously gaze at some scenic view, while my legs recalibrated. I knew my body was breaking, but I was determined to get to the El Festivalito International Digital Film Festival in the Canary Islands.

During my five-day stay in La Palma, the most northwesterly island, the tropical heat rolled in from the Sahara Desert and blasted the beaches like an oven, the temperature hitting 98 degrees. Ordinarily, I would have loved basking in it, but this time, I found it oppressive, and it really bothered me. I struggled climbing the rocks to the beach, and needed to stop frequently to regain my strength and balance. And once I got there, it was difficult for me to swim. At other times, I needed to sit to cool off and let my legs recharge.

One day, when my friends were trekking down to the beach, I couldn't go at all because it was too hot and I didn't trust my feet. So I just sat in the car and watched out the side window. It was so odd, adapting to something I didn't even understand. What was happening to me? I just sat there alone, pondering life, trying to comprehend what was going on. I wasn't particularly religious or very spiritual, so I was stuck in my head, defiantly frustrated and unsure of my future. It was as if a shadow had been cast upon me, like a demon that was lurking close by. But I didn't know what it was.

Once I got back to New York from that trip, I remember meeting up with friends or being out on dates and feeling a persistent imbalance and weakness in my legs. I spent the entire fall creeping along from object to object, leaning against anything I could to support me. As usual, I'd try to be subtle about hiding what was happening and was really good at it. I'd lean against a wall or hold onto anything in my path, so dates or friends wouldn't notice what was happening. If somebody met me for the first time, they would presume that I'd always had a slight limp. (Those green city garbage cans turned out to be a great prop to lean against before crossing the street, my own version of support rails.) At night, even though I hadn't even had a drink, bouncers at nightclubs would take one look at me and turn me away at the door because of my teetering gait, assuming I was drunk or on drugs. What the hell? There I was, swaying a bit, unable to walk a straight line, ambling on the diagonal across the street, feeling unsteady, my balance totally out of whack. At all costs, I tried to prevent my legs from crossing, which would make me trip and fall.

There was a strange disconnect between my intention to move correctly and my inability to do it. In fact, there were times when my leg just wouldn't move forward at all, even if I "told" it to.

What was going on? I had no idea. I kept telling myself that if could just eat right and exercise more, I could make it all go away. So I did a lot of strength training at the gym, though I couldn't use the treadmill, because I'd trip on it. When I casually mentioned a few of my symptoms to a friend, she said maybe it was shingles or Lyme disease. I even suggested to a concerned friend that maybe my leg arches had given out. In the end, I just wanted to ignore it and keep on going. And I admit I was too afraid to find out. Like any 25-year-old feeling indestructible, I had the motivation (and the ability) to plow through it in denial. After all, I could still function, and if I felt unsteady at a dance club, I'd just sit on the sidelines and watch for a song or two.

To state the obvious: Why didn't I see a doctor?! The main reason was that I didn't have any health insurance or the money to purchase it. As an independent filmmaker living off of grants, I really couldn't afford to see a doctor. Frankly, it was the last thing I wanted to do, my way to avoid bad news, or at least keep it at bay. I didn't want to even think about my health, much less talk about it. I simply didn't have the time. I was living life and enjoying it. That year, I took the $21,000 I got from grants and sunk it into my films, not into my health.

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During the summer of 2004, my home base was an East Village apartment at the corner of 11th Street and Avenue B in Alphabet City. It wasn't Park Avenue but it was cheap, especially with six roommates. We'd had at least 25 different people living there in the previous two years. All of us were poor artists, filmmakers, musicians, and writers, including our new roommate named Alexandra, a 23-year-old online-magazine editor with dreams of her own start-up. She was a blonde, blue-eyed Irish girl with a fantastic smile. And although I guiltily thought, I shouldn't date a roommate, I couldn't resist. She was funny, smart, gorgeous, and could really dance. So against my better judgment, our relationship quickly progressed from platonic to romantic.

One night we were out at a club for a friend's birthday, sharing a flask of Glenfiddich 12 year. We got pretty drunk and went to the dance floor. Our moves became closer and more intimate and we ended up kissing for an entire dance. And that was the start of our love affair.

At first, Alexandra didn't say anything about my limp and assumed it was nothing serious. She just assumed I'd pulled a muscle. After all, we were in our twenties, didn't think about going to doctors, and we had no insurance. So even when I got off balance and spilled my coffee, she just held the cup and we kept on walking. No problem. After all, my limp wasn't keeping me from going out. In fact, she'd say that she couldn't keep up, calling me a typical New Yorker who could go out until 6 am.

But as our relationship developed, much as I wanted to ignore my physical symptoms, my limitations were becoming more noticeable. Sometimes, it seemed as if I had to stop every ten feet to regain my balance.

One night, when we went out dancing salsa, I tried to dip Alexandra and pick her back up, but I *dropped* her and then fell on top of her! She and I both laughed about it, but we were both getting worried. I had certainly never dropped anybody on the dance floor before. All the little accidents and falls were adding up. But that December, when I headed home to Canada for Christmas, I was still determined to ignore and mask the problem.

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Hosting our family's holiday celebration that year was Mama, my energetic maternal grandmother Irene, who whipped up her spicy Portuguese and Indian food, with lots of seafood and curries, all of it generously seasoned with chili pepper. Our

Mama was born in India, then moved to Kenya for an arranged marriage and ended up raising her five children in a western suburb of Toronto.

She was a tornado of energy, such a blur of motion that my mother always joked that maybe she had Attention Deficit Disorder. She'd skip from subject to subject, asking questions and then butting in with a new question before you had the chance to answer the first. I'd call her fiery and spontaneous—much better than being lethargic.

During the trip home, from the minute I got there, Mama, my mother, and I had been walking through malls and around the streets of Toronto, shopping and doing errands, while I lagged behind. I saw the worried look on my mother's face, but was determined to avoid any discussion of my health. As she later told me: "I knew something was wrong because you were limping and walking weirdly across the street, crossing it at an angle and with a tilt. Months earlier I thought that you just needed to tie your shoelaces tighter or get new shoes. If only that could have been the solution."

It was true, of course, that I was wobbly and that everyone around me noticed it, but said nothing. On the other hand, Mom wasn't going to put up with my avoidance or denial much longer. The third night into the trip, she'd had enough: "Jason," she exclaimed sternly. "How come you haven't got this checked out yet?" At first I just shrugged her off. "I'm fine, Mom, I'm fine."

"No, no," my mother insisted, "you're *not*. But if you're so fine, why don't we do a test. You walk up the stairs and just run down them fast. Let's see what happens."

"OK, OK," I said, "Fine, I'll run down the stairs," something I'd done my entire life. This was the first memorable game of *So You Think You Can* that MS would play on me. The house is narrow with a steep stairway of ten steps, with a turn to the right of four steps more. I had no problem getting up them by holding onto the railing. In my head, I was counting them—ten up, and four to the right. When I got to the top, my mom seemed like a sentry waiting at the bottom, while my two brothers, Daniel and Leigh, were engrossed in their computers in the kitchen.

"Go!" my mother shouted, and I started to bound down the stairs. I immediately felt unsteady, got two steps down, and then fell, tumbling down as I was forced to make the turn. I slid the entire way down on my ass. I was physically unhurt and felt embarrassment more than anything, disheartened that I couldn't perform such a basic task.

My mother was ashen. "So now I've proven to you that's something's wrong," she said, walking over to her computer. "Let's see what it is." She googled *reasons for falling down stairs and lack of balance*, and all these articles about multiple sclerosis and Parkinson's disease popped up. "I knew this was something neurological," she told me, as she paged through dozens of articles and videos of people having trouble with their balance and falling.

When she pulled away from the computer, she announced: "Jason, I think you have MS. You've got to go see a doctor right away and find out what's happening." I felt exasperated by her insistence and embarrassed that I had fallen down the stairs. I didn't like being pushed into seeing a doctor, even if something was wrong. It was my business and my life—and I was not interested in disrupting the status quo.

"But you're got to go!" she shouted, giving me a look that left no room for discussion. My mother was tough. But she was also right.

Beyond my walking, I couldn't deny the odd changes in my eyesight. I felt like I was looking at the world through a strip of Super 8 film. Everything was grainy, with contrasts sharper than they should be. Colors were either too bright or missing altogether. So it was the instability of my vision that finally convinced me to get a checkup, even though I thought it *couldn't* be multiple sclerosis.

So I said: "Okay, Mom, I'll go and get tested." And that's where we left it. On the flight home, I resolved that this would be one of the priorities for the New Year.

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When I got back to New York, as if I'd forgotten that I'd been having physical symptoms for two years, I felt oddly optimistic and pretended that everything was still okay. This had to be temporary. So I continued to hide the symptoms. I was too embarrassed to tell my friends, or even Alexandra, about falling down the stairs in Toronto, much less about my Mom pushing me to see a doctor.

In mid-February, I finally took the plunge and saw an internist who, already suspecting MS based upon the way I was walking, immediately sent me to a neurologist. Based at Roosevelt Hospital on West 59th Street, he was an overweight professorial type with a gray beard and a detached, business-like demeanor. I had read that his specialties included Parkinson's disease, epilepsy, MS, and peripheral neuropathy. What a great combo.

He examined me, observed my gait, questioned me in detail about my symptoms, and then sent me for a battery of tests. Ah, the memory of my virgin MRI experience. It was claustrophobically spooky being dollied into the tube, putting in earplugs, then being closed up into the quietness until the bombardment of pinging sounds began, like piercing radio waves assaulting you. I liken it to being tossed into a garbage can and having a pipe hitting it over and over. In subsequent MRIs, though, I'd be more relaxed and the sound of it became almost a Zen ritual.

Next was the Visual Evoke Potential test, "designed," the exam tech told me, "to measure the electrical activity in parts of the brain used by light, sound, and touch." There were nodes and wires attached all over my scalp while I sat before a screen on which an alternating checkerboard pattern was displayed. It was weird, but painless.

The hours of testing seemed surreal to me—sitting there in those sterile exam rooms, walking through the drab hallways of a hospital, talking to someone who wasn't very personable. This was a world alien from filmmaking, Sundance, and happy nights with Alexandra dancing in the East Village. It was all a bad dream, especially the spinal tap, which turned out to be incredibly painful.

On the day it happened, I was terrified inside, lonely and estranged from my regular world. I hadn't been prepared for how excruciating it would be and how completely it would zap my energy. The doctor made the 45-minute procedure seem so simple: "We'll just insert a thin, hollow needle between the two lower vertebrae, through the spinal membrane, and into the spinal canal." Ho hum.

As the technicians hovered over me, I felt eerily disembodied, unsettled at the idea of yielding control to a team of strangers. It was a violation in a way, which is exactly why I had been fighting the idea of medical testing for more than a year. I hated the idea of being *the patient*. I was the kind of guy who was always juggling six things in a night with a reservoir of energy that defied sleep. I felt as if I'd been spinning happily in space for years, the hand of fate now knocking me off my game. It was a horrible feeling of helplessness for someone who had everything to look forward to.

The anticipation of the procedure was actually much worse than the reality of it, at least at first. Because of the anesthesia, the long needle wasn't so bad, as long as you didn't look at it. Lying down on my side in the fetal position, with my eyes closed, I felt oddly minimized, though little pain. But the aftermath of the test was horrible. I had been warned to have someone drive me home, but I blithely hopped on the subway, determined to save money and convinced I'd be immune to side effects.

Instead, I was incredibly nauseous and threw up all over the subway car. Hardened New Yorkers staring back at me with practiced detachment couldn't quite mask their disgust. I was mortified. It was as if I was looking at myself from above and couldn't believe the sight of it. The discharge nurse had told me to lay down as much as possible to avoid a low pressure headache which was supposed to be worse than the spinal tap itself. She also told me to drink plenty of water and do nothing for a few days. But I carelessly defied most of that good advice too. So the day afterward, when I stood up from bed, I had an excruciating headache, as if nails were sandblasting their way into my brain. I later found out that the neurologist had neglected to administer any saline solution, which would have dissipated the blistering headaches I had over the next three days.

The throbbing in my head activated a kind of terror I'd never known. How could a healthy guy have turned into such a wreck overnight? I could barely stagger into the bathroom to relieve myself before collapsing back down into a heap. So there I was the next morning, lying on the couch in my little apartment—a five-floor walkup in Harlem that I had just moved into. Although I felt like crap, I had scheduled meetings at HBO and PBS, both of which were interested in broadcasting my documentary, *A Song For Daniel*, a short film comparing the lives of two Iraqi boys during the Iraq war, one living on Long Island, the other in Baghdad.

I had no time to be sick—not today. But I was momentarily hypnotized that early morning, staring up at the ceiling fan spinning against the bright sunlight and cutting through the air with its rhythm. I'd never really noticed it before. But, then again, I had never had to lie horizontally for so long, other than when I slept. I'm usually face down, my forehead against the pillowcase. I never looked up at the ceiling. But today, I was immobile, feeling lethargic, but forced to work full force.

I'd been on the phone since 8:30 am, creating a small bidding war between the executives of HBO and PBS/POV, the latter being the winner. But the one caveat was that I had to go down in person to their Wall Street office and sign the deal that very day, plus do a filmed interview about the movie.

I looked like shit and had that brutal headache and felt so weak I could hardly stand. I was grateful that my good friend, Karin, a filmmaker, showed up at my apartment with a strong coffee and a helping hand, just in time for me to tell her that we had to head downtown to PBS—now.

So even though I was nauseous and had a fever, I hobbled down the stairs to the subway. I then lay down across a wooden bench on the platform, hoping that the ungodly migraine would go away. It seemed like an eternity before the train finally arrived. Karin helped me stand, and then I threw up all over the platform, with people staring all around me. I wiped off my mouth and stumbled toward the doors and into the car, and off we went. The motion of the train wasn't helping my stomach, and I now lay down across the seats inside the car. To my fellow passengers, especially the group of doe-eyed elementary school students, I must have looked like a crazy person.

When we got to the PBS/POV office, I somehow kept it together, even though I looked terrible and was sweating profusely. Taken to a separate room, I was actually lying down on a couch and getting the contract read to me by a PBS lawyer before I signed the contract. Then I moved to the studio where I sat for what must have been a nonsensical promotional interview about my film. Right afterward, with Alexandra at my side, I vomited in the elevator—and again on the street as we left. After I got home, I was in bed for two days. It was a big eye opener.

A few days later, I returned to the hospital for more tests. I kept telling myself: You have to do this. I had told my Mom I would. So I went through the motions. Although the tests were depressing and alienating, I knew I could push it all away and return to my regular life as soon as I left the hospital. Although I'm not by nature an optimistic person, I've always had this ability to compartmentalize my emotions, blocking things out that are traumatic or upsetting. I guess it's a form of self-protection. I just shift gears. Even as a teenager I'd be upset about something, and within about 15 minutes, I was singing a song and sketching a cartoon--and life went on.

So I would finish a test, then go out with Alexandra to a happy hour with friends--and then it would all be better. The world wasn't stopping because of an MRI. As Alexandra remembers it, I was actually quite comedic in conveying my impressions of the tests to friends. Having gotten through the trauma of a spinal tap, I made a parody of it by comparing it to the spoof movie about a rock band—*This Is Spinal Tap*. So every time we were walking around with friends and I mentioned spinal tap, I'd make a little guitar twang with my voice and do a pantomime, to dissipate the scariness of it all. And I didn't think twice about any of the test results. Not until the day my entire life changed—on March 4th, 2005.

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"You're late!" my neurologist exclaimed, with his usual brusque lack of charm. Alexandra and I were running twenty minutes behind schedule, dreading the visit. "But OK, you're here," he continued. "Good. Come to my office." As I entered that room, my heart started to pound. He opened up a folder and got right to the point. He looked me straight in the eye and said, "I have the tests back and we have a diagnosis." Time, it seemed, was suspended. Everything slowed down. I was hardly breathing. "Okay," I said. "What is it?"

"You have primary progressive multiple sclerosis."

Silence.

There was no warmth, no "I'm sorry," no use of my first name. No nothing. Just those words.

And then he got up from his desk and went over to the examining table. He began to explain that PPMS is an autoimmune disease--the body attacks itself, stripping away the protective coating around the nerves of the brain and spinal cord. “Many patients get progressively worse, eventually losing the use of their arms and legs.” He then went on to explain the potential loss of vision, the fatigue and pain, bladder and bowel issues, and difficulty breathing, “though thinking, memory, and intellect are relatively spared with primary progressive,” he said. He even demonstrated the tremors and spasticity I might feel by shaking his own leg. Huh? Eccentric. (On the way out, Alexandra and I had a fun moment and laughed about it, imitating what he had done, comparing him to the Mad Hatter.)

But as I sat there, staring out the grimy window of the doctor’s office, I was in shock. I don’t think my brain could process what the doctor had been saying. It was as if his voice was coming at me from outer space. When he was all done talking, I took a long pause. I felt like I was in front of an audience waiting for a reaction. It all felt surreal. In a dark and sardonic tone, I just quipped: “As long as I can still play soccer.”

That’s what I said. And I had nothing more to ask. MS was a huge monkey wrench that threw me for a huge mental loop. I had wanted to live in a state of denial, where I felt everything was going great and nothing was holding me back. But now, he had just given me horrendous news, and there was nothing else to discuss. He handed me a bunch of color pamphlets on MS and off we went. Rather than being diagnosed with the Relapsing-remitting form of MS, with symptoms easing or going away, primary progressive MS would be unrelenting, and in the worst-case scenario, ultimately leaving me unable to care for myself.

As Alexandra and I walked up Tenth Avenue, I was silent. It was a weird kind of introverted shock, becoming super-withdrawn, and totally still. I didn’t know how to deal with what had just happened, so I felt numb. Alexandra, who really knew how devastated I was, was bowled over too.

She stopped me as we were walking, took my face in her hands, and said: “Jason, I love you.” And then she gave me a big hug in the middle of the street. It was so tender, so sweet, but I didn’t react. I didn’t reciprocate by telling her I loved *her*. I think it was an expression of my shame, my brokenness. I felt embarrassed and defeated. I was in my own head and I couldn't even talk to her about it, though I knew she was an incredibly empathetic person.

She may have experienced my withdrawal as rejection, but it wasn't. I was just shut down. As I look back on it now, maybe I wasn't ready to accept the level of commitment she seemed able to provide. I wish that we had had more time together before after any of this happened, that we had had the money to take a vacation and have some fun and just relax and evaluate our lives.

But instead, we were both under-the-gun young New Yorkers, working and playing too hard. That day, she went off to her job, I went back to work, and that was the end of it—and the end of my life as I knew it. Nothing would ever be the same again.

In the next year, I worked harder than I ever had before, creating three new films, and basically doing anything I could to keep my mind off the diagnosis. By the end of that summer, I shipped all my things in boxes, broke up with Alexandra, left New York, and hid—moving back in with my family in Vancouver, where nobody could see me. I wanted to leave everything in New York behind. It was the saddest time.

The words of that doctor kept reverberating: "There is no cure. And there are no treatment options." I was terrified. For two years, I'd been holding a house of cards together. But the house had now collapsed. And the possibility of being carefree had abruptly vanished.

I became fatalistic in my thinking. I thought to myself: *Everything that happens from here on will be painted with a ticking clock.* And it would just keep on ticking, as I only got worse. In just a handful of years, I'd no longer be able to travel to India, and shoot films across the subcontinent, or hop from one random hotel to another, or spend the night dancing with a pretty girl. It would all disappear. And the only freedom would be from the memories that I could conjure beneath my closed eyelids.

In search of a second opinion, another doctor at the University of British Columbia Hospital reconfirmed the prognosis as hopeless. I was now considering different models of wheelchairs. And for the first time ever, I put my head in my hands and cried.

I was 28, and I had just been given a life sentence.

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Three Years Later: Maho Beach, St. Martin, Saturday, December 29, 2007, 12 p.m.

Tucked between the Atlantic Ocean and the Caribbean Sea, the island of St. Martin, our spunky grandmother announced, would be the perfect destination for an end-of-the-year family cruise. She had recently sold her house in Toronto and decided to splurge—and take all 21 of us on an all-out escape from the brutally cold Canadian winter.

Late in December 2007, she booked a 7-day Christmas getaway from San Juan on Royal Caribbean's *Serenade of the Seas,* a sleek, sunlit ship containing nearly three acres of exterior glass. Talk about panoramic views. I had never been on a cruise before and the whole thing seemed cheesy to me. Everybody in the family was excited—Mama, my two younger brothers Daniel and Leigh, my mother Marianne, aunts and uncles, and thirteen assorted cousins. We all flew from Canada to Puerto Rico, then boarded the ship, whose ports of call would include St. Martin, St. Thomas, Antigua, St. Lucia, and Barbados. At the end, we'd all ring in 2008 with the other 2400 guests (and a crew of 884) at an onboard party.

As we got onto the huge ship, with its thirteen decks, I was glad to learn it had nine elevators, because, as usual, I was limping. It had been almost three years since my MS diagnosis, and at this point, my walking was erratic—reliable some days, but often tentative and unsteady. Sometimes it seemed as if I was moving in slow motion, through glue. My mind attempted to direct my uncooperative legs, but I couldn't control them. There I was trying to walk around like a normal person, while my body was literally at war with itself. Whereas a healthy person's immune system attacks bacteria, my immune system was attacking nerve endings in my brain and spinal cord. I could no longer navigate stairs at all. And even on a flat surface, every ten minutes my gait would change from upright to tilted, like a tree bending in the wind. On the worst of days, my feet would get tangled up—and down I'd go. At least

I could always get back up myself, which gave me the certainty of independence, though I found myself taking every excuse I could to sit down.

A few months earlier, I had gotten my first cane, a dreaded "milestone," but since I was still able to walk, I much preferred to hold on to things and periodically stop to gain my balance. It was a strange and awkward to navigate the world—holding onto walls and railings, resting, then moving on, never sure if my equilibrium would get me from one place to another, much less on the expansive decks of a ship. But the last thing I wanted was anything to do with a cane, though I did bring it along with me. No cool person, I thought, had a walking stick when they were 28 years old, unless they were hiking in the mountains. I suppose it was a combination of pride and shame that kept me from accepting my increasing need for help.

Sometimes when I shared my frustration or sadness to my mother, she expressed her tough-love approach briskly: “You’re always whining and sighing,” she’d say to me. “Think of people in other countries, very, very poor people living in shacks by a river with floating garbage in it. You only have one life, and I know I’m Miss Practicality, but we don’t know how long we have to live. We could be dead tomorrow. You mollycoddled North American kid. You are so fortunate, so privileged.”

As I look back on it, it was so true that I had much to be grateful for. I had already made six films, I had an incredibly supportive family, and I still had complete, if very imperfect, mobility. But a guy in his twenties isn’t always mature enough feel thankful for what he can do. In fact, ever since I’d moved back to Vancouver with my family, I had been attempting to come to mental grips with the diagnosis. It was incredibly challenging to accept the inevitability of losing my mobility and vision. At first, I just ran away from confronting the reality of it. And I made sure that I was not on-screen, in front of the camera at all. But by the time of the cruise, I was already in the initial stages of planning a film about my experience with MS, and had decided to turn the camera on myself and actually face what was happening, the images on the screen a reflection of the truth.

And on this trip, the truth became quickly apparent: I wasn’t walking very well and navigating myself around such a large ship would be impossible. So to get from one far-flung location to another or to disembark for excursions, I used a wheelchair, which was pushed by my Mom or by one of my brothers. And when we were all having dinner together on the ship, and I didn't use the wheelchair, I needed someone to walk with me to the bathroom, usually Mom. Otherwise, without help, even the slightest movement of the ship made my walking unsteady.

While my mother fully understood the seriousness of my diagnosis, my brothers were less focused on it and not really worried about my health, at least outwardly. Meanwhile, my cousins and other family members pretended to be nearly oblivious to it, more comfortable not recognizing the elephant in the room. I realized, later, that they were probably all worried about my health, but chose an outward show of nonchalance. I understood their denial—it was one of mankind's greatest coping mechanisms. I had become a master of it.

So on the cruise that December, while everybody knew I was struggling physically, we all ignored it as much as possible, and I was able to throw myself into the cruise, though I almost winced at the forced gaiety of it. If I hadn't been with my family and I didn't have MS, you might have found me in dark sunglasses, lying on a deckchair popping Quaaludes and drinking Manhattans! That, and sarcastic jargon, would have been my strategy for passing the week of social conformity on a boat. I would have made some snide remark about the 70-year-old woman walking by me in her flowered swimsuit. But that lady happened to be my own grandmother. So I was a good boy and just went with the flow. I watched movies and saw live shows in the ten-story glass atrium. On the physical side, I used the leg-strengthening machines in the gym and enjoyed spa massages—a treat from my grandmother. Also, of course, I was packing in lots and lots of food. And through it all, I was armed with my new high definition video camera, a Sony FX7, which shot with mini DV tapes in HDV format, which allowed me to document everything in crisp and colorful high resolution.

On Saturday afternoon, the 29th, the entire family was revved up for our shore excursion from Philipsburg, our port in St. Martin. My mother was, as usual, the drill sergeant and caretaker, scouting out a wheelchair for our departure from the ship.

Off we went to Maho Beach, situated precariously close to the runway at Princess Juliana International Airport. This was the rollercoaster of all beaches, its main attraction gigantic blasts created by the departing and arriving jetliners, seemingly on top of vacationers who dared to withstand these gusts of wind that could throw them into the ocean or down into the sand.

But my family reveled in it. My cousins were in the ocean and my mother was laughing hilariously, dancing around the beach with my brothers and all our relatives as the warm jet blasts blew sand into the air like a mini-tornado.

As for me, shirtless in green combat shorts, I was swaying in the wind, laughing along with everyone else, though struggling to stay upright. I wanted to be part of the family fun, with my video camera in hand, barely able to retain my balance as a Boeing 747 flew above me, the force of its exhaust was like a sonic boom.

And then, with the dazzling noonday sun of the Caribbean nearly blinding me, a gargantuan gust of air enveloped us. Although I tried to brace against the wind, I lost my footing and fell backwards and was thrown onto the warm sand. I had known, of course, that if you had MS, a beach was the last place you wanted to be. I had handed my camera to my brother Leigh—to continue filming planes—and laughed, dismissing my fall to clumsiness, a momentary lapse in balance.

Leigh then focused the camera on me and egged me on, urging me to get back up. “C'mon, c'mon, get up, get up!” The footage shows an almost comedic series of unsuccessful attempts to regain my footing. Inside, I wasn’t laughing. Although I tried to suppress it even from myself, I was instantly alarmed by my inability to get up. The soft sand provided nothing to lean onto. In fact, for the first time *ever*, I couldn’t get myself upright—as the message sent from my brain to my leg went unanswered. I had always been the smiling guy, someone who made the best of anything, but this time, I didn’t know how to react.

Like the beginning of a play that foreshadows a sign of trouble, I knew my life had changed in that instant. After two years of coping with a diagnosis I wanted to deny and ignore, the reality of it slammed into me. This was the first time I felt helpless.

At first, I started crawling on all fours like a crab, trying to push myself up by using my right leg. But I didn't have the leg strength or balance required, so I fell back onto my butt. Next, I tried to get a grip on the sand with my right hand as I pushed up with my leg.

Leigh, who kept filming, later reflected: "You have an older brother your entire life who's always stronger, faster, and bigger than you, so seeing him in that moment of weakness was shocking, something I couldn't really believe."

My mother panicked and called on my cousin David to help. He ran over and attempted to pull me up with both hands. But struggling against me, he failed, and I fell back into the sand. Finally, with Leigh still filming, my brother Daniel came over to help. Pulling with both hands, David and Daniel finally got me upward and standing.

I was covered in sand, feeling embarrassed and really mortified. It was a disturbing moment for everybody involved. I'll never forget the expression on my mother's face, a combination of shock and sadness. As for me, I knew this was the beginning of a new era and that things were going to get worse.

I struggled to get back onto the cruise ship, stumbling up the gangway since no wheelchair was waiting. I was so out of it that I fell again. People looked at me like I was drunk. And from that point on, I became a lot more self-conscious and cautious and would only tour around the ship in a wheelchair.

I wondered if this was the beginning of the end. Where was I heading? I had had two years to cope with a diagnosis that I still was unable to fully accept. Our family trip, intended for relaxation, turned out to reveal the stark horror that my life would never be, and could never be, the same again.

I now knew that I was going to live a life filled with wheelchairs, helping hands, and medical treatments. I also realized that I couldn't handle this alone, not anymore. I was going to need my Mom, my brothers, my family, and all the help I could get. It was a humbling epiphany, something I would have done anything to avoid. It was very hard, and sad, for me not to be able to be the same person that I had been, with everything in my body working. Unlike that guy who felt 100% invincible, I now felt defective and inadequate, somehow diminished as a man. Yes, I still had my film work and my desire to excel, but my body was working against me, slowly destroying itself from the inside out. In short, the time scope of my life was now compressed—my physical body no longer in synch with my chronological age.

I now saw that I had never appreciated my independence until I began to lose it. For years, I had used my arms and legs effortlessly, the miracle of movement just an automatic assumption. So it wasn't until I began to fall, and then not walk at all, that I viscerally appreciated what I used to have. While gratitude is not an attribute of youth, it was a lesson I was learning. In that way, MS was a gigantic wake-up call, a reminder to be thankful for what I still had, while fully aware of how much I still had to accomplish in my race against the clock.

CHAPTER SUMMARIES

With the eye of a master filmmaker, and using his personal diaries and film archive as a guide, DaSilva captures the tumultuous events of his life in succinct, colorful vignettes as he moves almost continuously across countries and continents as a documentarian and social activist.

Following the style of the sample chapter "For No Reason At All," all chapters in ***WALK WITH ME*** *feature dramatic narratives that highlight DaSilva's journey as an artist along with his struggle against a terrifying medical condition, a balancing act that molds his character and future.*

Each step of the way, life lessons are crystallized: We witness DaSilva's maturation from an artistic high-energy teenager in a punk band--fascinatined by cartoons, photography and movies; to an up-and-coming filmmaker, a Sundance star at 23 who leverages this triumph to make the most of his bachelor days; to a disoriented 25-year-old overwhelmed by a devastating medical diagnosis; to a maturing artist who simultaneously wrestles with the complexities of making films while functioning as a husband and father; to a disability rights advocate who finds meaning in life in the face of near-total paralysis.

DaSilva delivers a powerful message--that each of us has been put on this earth to serve a purpose that we must follow, even in the face of a crisis. He believes that we can be productive and prevail over any adversity, including the threat of immobility. In doing so, we can create an invincible spirit that fuels a life of purpose and contribution.

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CHAPTER SUMMARIES

Chapter One: On and Off the Red Carpet

On the red carpet at Sundance, as he debuts his film *Olivia's Puzzle*, the naive 23-year-old describes his first-time exposure to the Hollywood big-time, meeting Robert Redford, Philip Seymour Hoffman, Hilary Swank, and dozens of other stars. He's euphoric but oddly exhausted, puzzled by a strange weakness in his legs, an intermittent imbalance in his gait. He ignores it and returns to New York feeling invincible, his newfound mini-celebrity fueling his ambition, without a clue how the reality of his life is about to change. As events unfold, he'll come to believe that he's been put on this earth to serve a purpose, to follow his own unique path, to trust his intuition and follow his convictions.

Chapter Two: For No Reason At All

Over the next two years, as Jason travels to film festivals worldwide to promote his films, he's no longer able to ignore the weakness and imbalance in his legs or the deterioration of his vision. He's often mistaken for being drunk or on drugs, though he attempts to hide his fears and symptoms from friends. On a film festival trip to the Canary Islands, he's uncharacteristically sensitive to the heat, collapsing on the beach. Yet he remains locked in avoidance and denial until a fateful Christmas visit to his family in December 2004. One night, in a moment forced upon him, his mother dares him to bound down a steep stairway. He collapses and falls down the entire flight of stairs. He's pressured by her to see a doctor, and he reluctantly agrees to do so.

Chapter Three: Painted With A Ticking Clock

Jason enters the surreal world of hospitals and extensive medical testing, the process leaving him disoriented and alone. After a painful spinal tap, he collapses on the subway, painful headaches nearly obliterating his abilty to work. Then, in a chilling scene at the neurologist, he finally gets the grim news that he has primary progressive multiple sclerosis, a degenerative disease that will gradually destroy his mobility and vision, leaving him a quadraplegic.Terrified, and too ashamed to reciprocate the sympathies of his girlfriend, he sinks into despair, and believes he's been given a life sentence. Everything now, as he thinks to himself, is "painted with a ticking clock."

Chapter Four: Not Denial: Just Selective About Reality

In the spring of 2005, after Jason's diagnosis, it's the saddest time, demoralizing and terrifying. Entering a period of despair, he breaks up with his girlfriend, leaves New York, and moves back to Vancouver to regroup, "hiding where nobody can see me." Is he going to allow MS to stop him from filmmaking? "Hell no!" he declares. Instead, he defies the disease and travels to Kenya for a grueling shoot, the 90-degree heat and jungle environment making his vision and muscle fatigue worse. Yet the resulting documentary, *Twins of Mankala*—comparing the life of an 8-year-old girl living in Kenya with the lives of twin sisters of Kenyan descent living in Massachusetts—is his most visually stunning film to date. More than ever, he's learning to seize opportunities and follow his vision no matter what, knowing that he’s racing against the clock, unable to predict when his ability to work might end.

Chapter Five: Jet Blast Into The Sand

Two years after his diagnosis, in the winter of 2007, Jason and twenty-one of his relatives embark on a Caribbean getaway. Although he’s now using a cane and, at times, a wheelchair, he’s still mobile, though increasingly dependent on his family. More and more, he’s learning to trust in the innate kindness of others when he most needs help. In a climactic scene at St. Martin’s Maho Beach, he’s blown down into the sand by a gigantic jet blast from an airliner, a pivotal event foreshadowing the challenges that lie ahead. For the first time ever, he can’t get himself up.

Chapter Six: Will Anything Work?

After the family cruise of 2008 though his emotional strength and physical independence are furhter compromised, Jason produces another film. He’s learning to exercise caution without suffering from *analysis paralysis*, getting stuck in his own head. Instead of becoming impotent and unable to take actions that move himself forward, he vows to win the battle against MS, and to confront it head-on. We follow his travels from France to India and beyond as he searches for treatments and cures, from becoming a vegan and eating a fully raw diet; to taking high doses of Vitamin D and turmeric; to acupuncture and Reiki; IV steroid treatments; experimental stem-cell therapies; CCSV (chronic cerebrospinal venous insufficiency); to yoga, meditation and herbal compounds; and to the fabled spring waters at Lourdes. Nothing works.

Chapter Seven: Escape Route

Suffering from increased instability in his walking and vision, DaSilva is feeling defeated and consumed with worry about his health. While studying for a graduate degree in Vancouver, he gloomily studies a 1941 German film *Ich Klage An*, the first portayal of MS, used by the Nazis as a propaganda film to promote their euthanasia program. Meanwhile, in a poignant scene at a local hospital, after a neurologist reaffirms his dim prognosis, he collapses in tears, but his resilience briskly returns as he picks up the camera and to tell his own story in *First Steps*, a short point-of-view documentary exploring his personal health crisis. He's learing to appreciate whatever independence he has—especially his ability to think, to talk, and to walk or be mobile in any way. These are freedoms to be grateful for, and never to be taken for granted.

Chapter Eight: 400 Hours and Counting

Back in New York, his life is back on track as PBS gives the green light to fund the sequel to *First Steps*, a film to be titled, *When I Walk*, a grueling seven-year shoot documenting the emotional trauma of his daily life as his symptoms slowly worsen. From Puerto Rico, Antigua, Saint Lucia, and Saint Martin, to shoots in India, France, and Canada, we witness DaSilva's dismay at the rapid progress of the disease, his boredom mixed with sadness on weekend nights as he finds that "the girls disappear" –until the lucky day he meets his future partner, Alice. Meanwhile, *When I Walk* screens at the Sundance Film Festival and is the season opener for 2014 PBS POV, earning him an Emmy and multiple accolades.

Chapter Nine: A Girl Named Alice

Flashback: In 2010, five years after his diagnosis, DaSilva is no longer able to walk, having transitioned from a walker to a motorized scooter. Living with six rommates, he feels deep frustration at the lack of accessibility to transportation in New York. The isolation cuts deep for the 32-year-old who once could so easily slip into relationships. He feels unlovable and invisible. Encouraged by his mother to attend an MS support group, he meets a girl named Alice. The two strike up an unexpected friendship, start dating, and are soon passionately in love, marrying a year later. Life has taught him to be prepared for anything, "which is another way of saying you can't be fully prepared at all." When things fall apart or come together, he recognizes that changing the things you can and adapting to what you cannot are essential parts of successfully navigating through life.

Chapter Ten: For Better Or Worse

By 2012, now settled in Williamsburg, Brooklyn, DaSilva feels more imprisoned in his wheelchair than ever, intensely frustrated that he can't get a taxi, and that subways are inaccessible to him. He creates AXS Map, a mobile app that will aid people with limited mobility to finds stores, restaurants and other destinations that can accommodate wheelchairs. He has learned not to take anything personally (even if you're in a wheelchair and subject to judgment or prejudice.) Meanwhile, Alice is pregnant, suffers a miscarriage (with Jason unable to find transport to the hospital), and gets pregnant again, giving birth to a son named Jase. DaSilva is ecstatic but worried about how his disability will impact the life of his son. Through the maze of his worries, he learns to you must pick your battles carefully, and not waste hours of time on needless brushfires and tangents, reacting to everything around you. Instead, pick a worthy battle and move forward.

Chapter Eleven: When It All Falls Apart

Now living in Long Island City, DaSilva continues to feel deeply frustrated that he can't physically interact with his son without the help of a nanny or Alice. Meanwhile, the DaSilva marriage is crumbling, the couple sleeping in separate bedrooms and arguging about the minimal amount of time Alice allows DaSilva to play with Jase. Raising a toddler and the demands of a relationship with a disabled husband weigh heavily on Alice, who decides to leave Manhattan and accept a tech-industry job in Austin, Texas, taking Jase with her. DaSilva is devastated, more isolated than ever before. But he forges on, working on his next film, *When We Walk*, which picks up the story after his marriage and the birth of his son.

Chapter Twelve: Beyond The Losses

Without the use of his arms or legs, and now legally blind, DaSilva plows relentlessly forward, hoping that new stem cell treatments might reverse the damage of MS. He's also shooting his new film while expanding his AXS MAP initiative by partnering with the UN. On the personal side, existential questions loom large ("Why am I here—feeling as if I don't exist—conscious but unable to move.") He has profound regrets too, including his inability to be physically intimate. (*Am I forced to accept not being loved? Being touched?"*) Yet his adaptability is remarkable and he persists with the hope that he'll find a cure and a new mate, putting a personal ad online, as he continues to travel the world, screening his films and worked for the disabled. He’s learned to excel beyond his own expectations, and avoid making assumptions about himself. No matter what, he wants to live, and so he will.

- Seize opportunities and follow your vision for yourself no matter what, as you only have one life. And you never know how long it’s going to last.
- Believe you’ve been put on this earth to serve a purpose, to follow your own unique path. Trust your intuition and follow your convictions.
- Demonstrate boldness and show no fear, even when you feel it, which enables you to accomplish more than you thought you could. If you fail, even if you have to literally pick yourself up (or have someone else do it), there is no harm in that or in trying again and again.
- Appreciate whatever independence you have—especially your ability to think, to talk, and to walk or be mobile in any way. These are freedoms to be incredibly grateful for, and never to be taken for granted.
- Be prepared for anything, which is another way of saying you can’t be fully prepared at all. When things fall apart, recognize that changing the things you can and adapting to what you cannot are essential parts of successfully navigating through life.
- Pick your battles carefully, as we waste hours of time on needless brushfires and tangents, reacting to everything around us. Instead, pick a worthy battle and move forward.
- Exercise caution but don’t suffer from *analysis paralysis*, getting stuck in your own head. This leaves you impotent and unable to take actions that move you forward
- Trust in the innate kindness of others, which allows you to rely on people when you most need help. Give others the benefit of the doubt.
- Live beyond your own expectations, and avoid making assumptions about yourself or others. Just when you think something can’t happen, it can.
- Refuse to take anything personally (even if you’re in a wheelchair and subject to judgment or prejudice.) Everything that people say and do is a reflection of their own needs and emotions. Nothing other people do is because of you.

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