

"[A] small wonder. Unsentimental and unpretentious, it manages to hit all its marks effortlessly."

—THE NEW YORK TIMES

Thomas Graboys, MD

with Peter Zheutlin

Life in the
Balance

*A Physician's Memoir
of Life, Love, and
Loss with Parkinson's
Disease and Dementia*



“[S]ound advice for all seriously ill people: Live with grace; be honest with yourself; unburden yourself of anger; exercise; read the paper; and, if it suits you, reaffirm your faith in God.”

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“I was blown away . . . An eye-opening read . . . A remarkable book.”

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“[We] need the perspectives . . . in books like this, since our ability to evaluate the choices that patients and families make may be limited by our lack of experience.”

—*New England Journal of Medicine*

“He recounts his daily struggle to live a dignified life . . . A very moving book.”

—Leonard Lopate, *WNYC*

“In this stirring and chilling memoir, [Graboyes] takes an unblinking look at himself as his mind and body suffer unrelenting hits from those progressive illnesses. An unforgettable doctor-as-patient account, including reflections by Graboyes’ daughters, sons-in-law, and members of the family blended by his marriage.”

—*Booklist*

“Tom Graboyes was my student over many years. With *Life in the Balance*, he has become my teacher. This book is brimming with unflinchingly honest insights on how to confront a devastating illness. Each of us can learn much from this poignant memoir.”

—Bernard Lown, Founder of Lown Group,
Emeritus Professor Harvard,
Recipient of Nobel Peace Prize 1985

“[G]ripping . . . A must-read for anyone with a degenerative or dementing condition—and for any couple grappling with serious illness.”

—Judy Foreman, nationally syndicated health columnist

“A powerful story of Parkinson’s, from the inside out.”

—Tom Ashbrook, host of NPR’s *On Point*

“*Life in the Balance* is Graboyes’ heartbreaking account of his ongoing battle with Parkinson’s. It is the story of a doctor turned patient, of unrelenting challenges and even more unrelenting strength; a story that is at once sad, honest and poignant, but ultimately—and against all odds—hopeful.”

—*Parade Magazine*

“[A] profoundly moving experience. Physicians like Tom Graboys are rare, to be cherished and celebrated.”

—Dr. David Gree

Dean Emeritus Brown University Medical Scho

“This well-written memoir of a life shattered by Parkinson’s disease will give readers, patients, and their caretakers an honest account of life with the disease.”

—*Library Journ*

Life in the Balance

*A Physician's Memoir of Life, Love,
and Loss with Parkinson's Disease
and Dementia*

THOMAS GRABOYS, MD,
with PETER ZHEUTLIN



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Dedication

*This book is dedicated to
my wife, Vicki Tenney Graboys,
to my two indefatigable daughters,
Penelope and Sarah,
and to the memory of
Caroline Rigby Graboys*

*Never deny a diagnosis, but do deny
the negative verdict that may go with it.*
—Norman Cousins

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Author's Disclaimer

The events described in this book are based on memories of Dr. Graboys as recounted by him during and after the onset of his illness. Others, including colleagues, may recall these events differently.

Foreword

TO THE THOUSANDS OF PATIENTS who came under Tom Graboy's care over the more than three decades of his cardiology practice, Tom was much more than a doctor; he was a trusted adviser, confidant, and a friend. Rare was the patient who left his office not feeling better than when they came in, for Tom had a way of infusing hope and optimism about the future and easing the emotional burdens of illness. He used words with care. He reassured. He allayed anxiety. He listened attentively. He gave every patient his home phone number, and many used it.

I first met Tom in 1985, when I went to work for an organization cofounded by his mentor, Bernard Lown, called the International Physicians for the Prevention of Nuclear War (IPPNW), winner of the 1985 Nobel Peace Prize. Tom was active in both IPPNW and its U.S. affiliate, Physicians for Social Responsibility. It was hard not to be in awe of this very handsome, brilliant doctor with a strong social conscience.

In the 1990s, my father, a physician himself, had heart problems and was about to undergo a second angioplasty when I urged him to travel from New Jersey to see Tom for a second opinion. My father never had that second angioplasty; indeed, he might not have had the first had he seen Tom from the outset. Tom assured my father that his condition was eminently manageable without surgery, and this lifted an enormous burden of worry from my father's shoulders. From his first visit, and after every annual visit that followed, my father would remark to me that Tom was everything a fine physician should be. My father would know: He was a deeply beloved pediatrician with an extraordinary gift for endearing himself to children and allaying the anxieties of their parents with his quiet, unassuming, deeply human touch. He and Tom were cut from the same cloth.

In 1998, I accepted a position as Executive Director of the Lown Cardiovascular Research Foundation, associated with the Lown Cardiovascular Group, of which Tom was the director. There I saw for myself what an extraordinary physician he was, and how profoundly gifted in the art of interpersonal communication. Both before and after undertaking this book with him, I spoke with dozens of his patients, and I read the hundreds of deeply moving, heart-rending letters patients wrote to him when Parkinson's and the dementia associated with his Parkinson's forced his premature retirement from medicine.

Even in Boston, a city renowned for its legions of exceptionally skilled clinicians, Tom stood out. His clinical judgment was impeccable, his opinions valued by colleagues and patients, his meticulousness unparalleled. But what truly set Tom apart was his uncommon humanity, his intense concern for what ailed the hearts *and* the souls of his patients, and his unstinting generosity with his time. Despite the crushing workload he carried on his shoulders, no patient was ever rushed and no patient concern was ever belittled. A patient's annual follow-up with Tom always ran for an hour or so, unheard of in this era of managed care. After each examination, Tom would sit, knee to knee with the patient, on a small sofa in his office and talk. He never interposed his desk. He treated you as his equal. He was a full partner in your care, and you were glad to have him in your corner. A lot of doctors talk about the importance of the human connection between doctor and patient, but Tom walked the walk.

Tom believed that to be an effective physician, you must first and foremost be a skilled listener. He could learn as much about what ailed you by listening to you talk as he could by listening to your heart with his stethoscope. He understood, and believed in, the healing power of a strong doctor-patient relationship. He was never glib with his advice, whether to lose weight, to stop smoking, or

exercise. He knew that without his constant support and gentle, nonjudgmental follow-through, ninety-nine percent of such advice would soon be forgotten. He accepted gladly his share of the burden to ensure that patients did their best to get or stay well. He spoke easily with patients about subjects that many doctors avoid. He was at ease with discussions of sexuality, for example, and thereby put patients at ease discussing this most intimate of subjects. Many heart patients fear that sex might trigger a heart attack, but Tom believed that sexual intimacy with a loving partner was essential to a sense of well-being and happiness that is beneficial to the heart. He believed deeply in medical science, which he mastered, but he also believed in the power of the human touch, what Bernard Lovell has called “the lost art of healing.”

When you saw Tom Graboys, you were seeing the best. But Tom never conveyed arrogance. For Tom, each patient was a privilege, a window into the human condition, and he never took your trust for granted.

Though his specialty was cardiology, he treated the whole person. He embraced each individual's complexity. He eschewed pat answers and bromides. He exuded warmth and compassion. As I said, his specialty was cardiology, but really it was people. He was uncommonly generous and compassionate, and was truly beloved by his legion of patients.

When Tom first informed his patients that he had Parkinson's, in August 2004, and when he was forced to retire from practice a year later, he received an avalanche of letters and cards that bore eloquent testimony to Tom's extraordinary impact on the lives of many, many people. I want to let a few, whose sentiments were echoed repeatedly over countless letters, speak for themselves here.

Sal DeSimone was a patient of Tom's for almost thirty years; indeed he was one of Tom's very first patients. He, too, suffers from Parkinson's now. “You impressed me right from the beginning,” he wrote. “You have what Socrates called *arête*—the excellence of the soul.” The letter was signed “your friend and patient.”

“We have known each other for almost thirty years,” wrote Virginia Richardson, another longtime patient. “You gave me the hope to do what I've had to do, enjoy life when I could and overcome adversities. I am fully aware and appreciative of the time, thought, and care you have applied to me, as a person and patient.”

“So many people love you for so many reasons,” wrote patient Kenneth Wile, who is also a physician. “You have the rare ability to envelop patients, the families and their loved ones and provide them with a sense of comfort, confidence and hope. You exemplify the qualities that medical schools try to imbue in their students and that physicians work a lifetime to achieve. Thank you for your tender care over the past twenty-three years. You have helped redirect my paths in life and have added hope and joy to my journey.”

“I want you to know that the caring questions you always asked about my life's difficulties, which, without eliminating them, comforted me by the simple act of a doctor's caring enough to ask,” wrote Pamela Perry.

And, finally, this: “Your [retirement] letter has brought me what my Swedish ancestors called ‘soul sickness,’” wrote Raymond Kask. “It's deeper than being ‘heart sick.’ You were and are more to me than my cardiologist. You were my younger brother, my friend, and you had all the time in the world to care. It was your way of showing you care. Now I want you to know that I care for you.”

It seems especially cruel, both to Tom and to all those who came to depend upon him, that at the age of sixty-two, a particularly insidious form of Parkinson's disease, one accompanied by a syndrome called Lewy body dementia, forced him to retire from medicine. That someone as devoted as Tom to the health and well-being of others for all of his adult life must now endure the cruel and unremitting

trials of dementia is beyond reckoning.

When Tom asked if I would help him write this book, I knew it would be an experience like no other in my life. Unable to write, battling cognitive difficulties and progressive dementia, Tom needed someone who might, he hoped, be able to listen and then to communicate his most intimate thoughts and feelings. Aside from raising my children, never have I been entrusted with such an awesome responsibility. Like everyone who had known Tom over the years, it was painful for me to see what Parkinson's had done to him. And the task was particularly challenging because Tom's ability to organize and articulate his thoughts has been compromised. But knowing Tom as I have over the years proved invaluable in our collaboration. I knew something about the essence of Tom Graboys before we ever met to discuss this book; and that, I think, is what made it possible for us to communicate and collaborate effectively.

Working with Tom has given me the rare privilege that so many patients allowed Tom, a window into the human condition. I doubt I will ever see such grace in a human being again.

This book is one tough read, because what ails Tom is unrelenting and merciless. Every day is filled with extraordinary challenges and with terror about what the future holds. Yet, in spite of it all, there were plenty of flashes of Tom's dry, ironic humor. One day in December 2006, when we weren't quite halfway through our work on this book, I invited Tom to a Boston College basketball game, a short walk from his house. Tom had been telling me for months about how Parkinson's and dementia affected nearly every detail of daily living and his ability to navigate the world, but this was the first time I had a chance to see him outside the familiar environs of his home. During the game, he tried without success, to make sense of the numbers on the scoreboard. I introduced him to the people we were sitting with, but he had difficulty remembering who they were from one moment to the next. At halftime, we got up to head to the snack bar, and Tom faltered as a sudden drop in blood pressure had him groping for a wall for support. When that passed, I watched as he fumbled awkwardly with his money, not quite sure which bill to use while trying to pay for some M&Ms, and struggled to peel back the lid on his hot chocolate. Then, aware that I was watching him, he looked at me with the small smile that I had come to associate with his moments of self-deprecating humor and said, "This is like a field trip for you, isn't it?"

Tom has suffered two enormous tragedies in the past decade: the loss of his first wife, Caroline, to cancer in 1998, and the loss of much of himself to Parkinson's and Lewy body dementia. A lesser man would have curled up and rolled away long ago. Yet Tom, despite the anger, frustration, and sadness that have been visited upon him, remains a deeply sensitive person determined to derive from his life as much happiness and pleasure as he can, a resilience that is positively breathtaking. And he remains acutely sensitive to those around him—family, friends, and former patients he encounters in regular visits to the Lown Center, where he still maintains an office. No less remarkable was his determination to tell his story so that others might find some comfort—or inspiration or validation—in their own struggles, whether with Parkinson's, dementia, or another affliction of the mind or body.

It took enormous courage and fortitude, given the toll Parkinson's has taken physically, mentally, and emotionally, for Tom to write this book. But it is the logical continuation of a life devoted to caring for the world, one human being at a time.

When Tom and I discussed how this book—a book with more than its fair share of anguish and tragedy—should end, I suggested to Tom that he imagine what Dr. Tom Graboys the physician might say to Tom Graboys the Parkinson's patient if they were sitting knee to knee on the sofa in his small office, because Dr. Tom Graboys would find a way to convey hope, optimism, and an appreciation of all that it means to be truly alive in whatever time and space is given to us.

Preface

TO KNOW WHO I AM TODAY, losing control of my body and my mind to an insidious form of Parkinson's disease, you have to know who I was fifteen years ago.

In 1993, Boston Celtics star Reggie Lewis grabbed a rebound and was headed upcourt during an NBA playoff game against Charlotte when he slumped to the floor and blacked out for a few seconds before getting to his feet and making his way to the bench. When Lewis returned to Boston, the Celtics assembled a team of twelve Boston-area cardiologists with various specialized expertise to determine if Lewis's fainting episode indicated a cardiac problem. This team of top physicians was soon dubbed rather extravagantly, "The Cardiology Dream Team" by the Boston media. I was one of them.

Though the evidence was ambiguous, the team concluded that Lewis might have suffered from a particularly dangerous type of arrhythmia, an irregular beating of the heart, caused by a condition called cardiomyopathy, a disease of the heart muscle. If correct, that diagnosis meant Lewis's basketball career was over.

Based on a second, more favorable opinion rendered by another eminent cardiologist who is a dear friend of mine, Lewis resumed playing basketball. Then, in July of that year, Lewis, just twenty-seven years old and in his prime, collapsed while shooting baskets at a local gym and died.

I was forty-nine in 1993 when I was a member of the Cardiology Dream Team. I had a beautiful wife, Caroline, and two wonderful daughters. I was on the faculty of Harvard Medical School and the staff of Boston's Brigham and Women's Hospital. I had a thriving private practice with the Lowell Cardiovascular Group, led by the inestimable Bernard Lown, widely regarded as one of the most accomplished cardiologists of the twentieth century, and with whom I had trained after medical school. I was, to use a well-worn cliché, on top of the world in every way. I was blessed.

Today, I can no longer see patients or give rounds. My face is often expressionless, though I still look younger than my sixty-three years. I am stooped; I shuffle when I walk; and my body trembles. My train of thought regularly runs off the rails. Though I am remarried to a lovely, caring woman, Vicki Tenney Graboys (the former Vicki Baker), an accomplished interior designer, Caroline, the mother of my children, my soul mate for more than thirty years, is gone. She lost her life to colorectal cancer in 1998.

I have lost an awful lot in the past ten years: a spouse, a career, and, to a considerable degree, control over my body and my brain. Used to being a caregiver, a healer to a legion of patients, I have lost countless relationships with people I once cared for. For a long time, while I was in denial about the severity of my condition and the extent of my impairment, I expended extraordinary physical and mental energy trying to maintain the façade that I was the in-control doctor. My patients didn't want to leave me, but in the end I had to leave them—for their own good.

People always want to read stories of triumph over tragedy. But there is no sugarcoating Parkinson's and, as the baby boomers age and live longer, more and more of us are succumbing to the disease. There is no silver lining here. There is anger, pain, and frustration at being victimized by a disease that can, to some extent, be managed but cannot be cured.

While Parkinson's, which is caused by a chemical imbalance in the brain, is usually understood to be a disease characterized by loss of control over body movements, most people afflicted with the disease also experience difficulties with attention, concentration, problem-solving, concept formation, sequencing, vision, depression, and memory. But a significant portion of Parkinson's patients—and I am one of these—have an associated degenerative disease, known as Lewy body disease or Lewy body

dementia, which seriously impairs cognition and has other powerful side effects, such as hallucinations and violent REM sleep, that can result in injury to oneself or one's sleeping partner. Every night, I can suddenly lurch out of control; by day, I feel as though I have an on-off switch that controls my brain and I am not in control of it.

Named for the doctor who discovered them, Lewy bodies are abnormal protein deposits. When they form in a particular area of the brain stem, they deplete the neurotransmitter dopamine, which then results in Parkinsonian symptoms. In Lewy body dementia, however, these abnormal proteins are spread throughout other areas of the brain, including the cerebral cortex. Though Lewy bodies themselves are a factor in all Parkinson's cases, Lewy body disease changes the Parkinson's equation dramatically. Patients with ordinary Parkinson's can expect to live to their full life expectancy. Lewy body disease, the progression of which is variable and unpredictable, can cut life short and dramatically affect quality of life. Mine is not an easy life, and it is certainly not the life I, or my family, imagined for ourselves, nor did we ever think we would experience it.

Despite all that I have lost, I continue to derive pleasure from my life. Regular exercise and yoga have been indispensable in helping me achieve some sense of well-being and have helped me maintain some control amid the chaos inflicted by my brain. I still play the drums occasionally in a band comprising local doctors. Most importantly, I have grandchildren now and have been lucky enough to find love a second time with Vicki.

Writing this book, telling this story of a degenerative neurological disease from the inside out, is an act of defiance. I have good days and bad. On the best days, when I come out of the clouds, I have brief periods when I am sharp. But on others, I falter and am keenly aware of what is happening. Parkinson's has taken some of my eyesight, and I cannot sit at a computer and type anything longer than an E-mail—and even that requires considerable effort and concentration. My memory often fails, and trying to organize my thoughts is often impossible. To tell my story, I had to find someone who could bring some order to my thoughts and put them into words.

I have a great sense of urgency about this book. My disease is a degenerative one. I may not be able to tell my story tomorrow, or next week, or next year. I live with the knowledge that the theft of my mind may not be over and that this story would then be lost forever. Just as I am not the person I was fifteen years ago when I was a member of the Cardiology Dream Team, I may not be the person next year, or even next month, that I am today.

Why share this painful and tragic story publicly? Why go through the effort? Why summon up once again the various losses I have endured along the way? Why subject my family to the public sharing of the most intimate details of our lives?

Well, I am a doctor. I have spent my entire adult life caring for people. And unlike much of what the medical profession has become in this age of industrialized medicine, our practice at the Lown Group was a throwback to a time when doctors listened at length to patients and sought to treat the body and assuage the soul. My engagement with patients was deeply personal. Medical school trained me to care for the heart, an organ profoundly affected by the stresses, strains, and anxieties of daily living. But to be truly effective, I listened as people told me their life stories, their fears, and their hopes. Such deep engagement with patients is therapeutic for the patient and an invaluable aid to the doctor. From thousands of patients over nearly four decades, I learned much, for each patient is a window into the human condition. That is why a doctor should feel privileged by all patients who entrust themselves to his or her care.

Even though I am no longer able to engage with patients or to teach young medical students, this book is a logical extension of my medical career. Parkinson's now afflicts more than one and a half

million Americans, with sixty thousand more cases diagnosed each year; and an estimated 640,000 Americans *under the age of sixty-five* (not to mention the millions over sixty-five) are suffering from dementia caused by Alzheimer's and other causes, such as Lewy body disease. By sharing this story, it is my hope that others who suffer from serious disease, especially those struggling with diseases that steal control of mind or body, along with their loved ones, will find some comfort—that I may be able to articulate and, therefore, validate what they feel and experience but may not be able to express. This book is the only way I know to continue, in a sense, to be a doctor. This isn't an easy story to tell. But it is an important one.

—Thomas B. Graboys, MD

Life in the Balance

My Days

NOTHING IS SECOND NATURE to me any more. No task is too simple, no activity so routine that I can do it without forethought. Is the glass right side up, or will I pour orange juice all over the counter again? When I leave the kitchen to walk to the bedroom, how will I get there? At the party tonight, where will the stairs be, and how will I navigate them? Will I be able to join the conversation? Or will I be standing in a corner, nearly catatonic?

For social gatherings, I have what I call my cassettes: a repertoire of conversational riffs on various subjects that will allow me to enter the conversation and, with luck, appear to be a reasonable facsimile of the old Tom Graboys. Can I pull it off? Can I act the part and mask the reality of my dementia? One of my goals in social situations is to have people go away saying, “You know, Tom seemed pretty good.” It allays the anxieties of friends and colleagues when you look and sound good, even if they cannot fathom the effort it took to muster such a performance.

Without my cassettes, entering a group conversation is like trying to get on the freeway traveling twenty miles an hour while the traffic is rushing by at seventy. Slowness, an all-encompassing mental and physical slowness, has descended upon me. It is not going to lift.

★ ★ ★

Holding on. Much of my life, today and every day, is about holding on to what I’ve got—or, more precisely, holding on to what is left. There is still happiness in my life: my wife, my children and grandchildren, music, and, now that I can no longer practice medicine, the time to explore new interests such as indoor cycling and writing. There are even days when the “old Tom” emerges, usually briefly, and I feel like my old self, only to awake the next day and come face-to-face once again with the reality of life with a progressive neurological disease.

For now, I still see the light; but on the other side of this knife-edge ridge I walk, there is darkness, so I hold on. I have discussed this with my wife and adult daughters. There is a point beyond which I do not wish to go. That is the day I can no longer control my bowels and my bladder, a common problem for patients with advanced Parkinson’s disease. To me, this is the ultimate regression. I have been in too many hospital wards and nursing homes where patients with severe dementia are lying on the floor or sitting in their own urine and feces, oblivious to the world around them. I have seen the end of this road, and I won’t go there.

I am determined not to let Parkinson’s, which has stolen so much, steal my dignity. That is what I am really holding on to. Dignity. It’s why I exercise, practice yoga, and play the drums. It’s why I shave every day. It’s why I dress well and make sure I look my best. As a cardiologist with a predominantly geriatric patient population, I often noted in my files when a patient started looking unkempt, a look that signaled that he had surrendered, been beaten down, or no longer cared enough to pull himself together. I no longer save my best clothes for special occasions. Now, every day is a special occasion.

★ ★ ★

The daily struggle with Parkinson’s disease, especially in this form, is relentless. There is no reprieve, and the future is uncertain. Even on the good days, Parkinson’s lurks like an unwanted

shadow. On the bad days, my frustration boils over into anger and despair.

~~In my case, Parkinson's is a twenty-four-hour-a-day affair, because the associated Lewy body disease brings forth vivid nightmares and violent sleep on a weekly basis, nightmares so realistic that I am likely to act them out. I have dreamed of being attacked and, in an effort to fight back, have inadvertently struck my wife, Vicki. This is extremely abhorrent and sorrowful to me, but it is part of the picture of our daily lives.~~

★ ★ ★

In the mornings when I wake, or when I stir from the midday nap that has become as essential as functioning as my medication, I lie entombed in my own body for ten or fifteen minutes. The paralysis of mind and body lasts until enough synapses can spring into action to allow me to move.

As a young intern and resident, and later as an attending cardiologist, I was accustomed to being summoned suddenly in the middle of the night. I could launch myself out of bed, get dressed, and perform at my intellectual peak within moments. I could make life-and-death decisions within seconds of a nighttime phone call. Today, I wait for thousands of tiny cellular engines to start themselves so I can rise from the bed and begin another day, trapped in a body that no longer fully responds to my will and subject to a mind that spins at 33 RPM in a 78 RPM world. Neurological disarray affects every aspect of my life.

★ ★ ★

One small accommodation to my Parkinson's is our master bedroom, located on the ground floor of our home. This is where I begin my day, staring at the ceiling. We're on the ground floor because navigating stairs can be difficult for me. Stairs often appear fused together, navigable only by feel and with one hand firmly on the railing.

The tricks my eyes play on me are not a matter of focus. Objects sometimes appear strangely flat without dimension. Double vision is a problem. Minor hallucinations from time to time make it hard to trust my own eyes. Many patients with Lewy body disease experience frightening hallucinations often involving insects or animals. I have been spared such hallucinations so far, though I do sometimes "see" stationary objects move or mistake a pan of brownies for a loaf of bread. Sometimes while I look at a person or thing, the object of my vision is replaced, just for a split second, with the image of another. The hallucinations are subtle and transient, but disconcerting nonetheless. Wasn't that chair on the other side of the room a minute ago? The occasional auditory hallucination breaks into my day as well. I will hear an alarm, convinced it is sounding, but only I will hear it.

Once liberated from the bed, I head to the kitchen, though I sometimes get disoriented and find myself lost momentarily in my own house, or forget where I was going and why. I pause and wait for the confusion to pass. Such demoralizing mental lapses constantly punctuate my day and tear at my self-esteem.

In the kitchen, I have learned from experience to use my fingers to determine if the glass for my orange juice is right side up before I pour. I can see the glass, but I often cannot process what I see and translate it into an understandable reality. So I make one of what will be countless adjustments during my day to compensate. I move the tip of my finger to the top of the glass. If it strikes a solid surface, I know to turn the glass over. If my finger meets no resistance where the top would be, I know the glass is right side up. If my medication hasn't "kicked in," I concentrate as hard as I possibly can to pour the juice into the glass with trembling hands.

The common perception of Parkinson's as little more than body tremors is way off the mark. In his poignant and courageous memoir, the actor Michael J. Fox put a very public face to Parkinson's. Fox's predominant symptom, which is controlled with medication, is hyperkinesia—extravagant involuntary body movements and tremors. But in many cases, like mine, the symptoms are global. No major function of mind or body has been spared. From visual perception, cognition, and speech to blood pressure, body temperature control, and sexuality, Parkinson's permeates every aspect of my being.

I have the classic appearance of a Parkinson's patient. I often appear hunkered down, head bowed, shoulders slumped, my once-fluid body rigid, my once-graceful gait an old man's shuffle. This has been hard to accept, for I have a strong narcissistic streak. My looks have always been important to me. I always believed that my interpersonal skills and my attractiveness (attested to by my wife) were largely responsible for my success in life. So I am trying to hold on to my looks too.

The dyskinesia, or lack of body control, is especially pronounced as I dress. Indeed, it would be more accurate to say "I do daily battle with my clothes" than to say "I get dressed in the morning." The once-simple task of putting my arm through a sleeve can be exasperating, and Vicki will often turn to see me on the losing end of a wrestling match with my clothing. Buttons are a particular challenge—fine motor skills have become an oxymoron in my life—and I don't have the balance to put my pants on standing up. The simple act of dressing in the morning is a physical and mental challenge and a constant reminder of the regression wrought by Parkinson's.

This lack of motor control, along with my now-slurred speech, is the source of many embarrassing moments. People may sometimes quite logically assume that I am drunk. At the end of a recent airplane trip, I attempted to put on my overcoat while standing in the aisle and ended up looking as though I were frozen in a straitjacket. Temporary paralysis is yet another symptom of my Parkinson's. It was surely a strange sight to those watching me on that plane, but to me it was just another in a series of moments of public humiliation to which I have become more accustomed over time.

The simple act of carrying a cup of coffee to a cash register and trying to find the money to pay for it can be a daunting challenge, one made even more difficult because if people are waiting behind me I feel great pressure to perform. My trembling hands cause the coffee to slosh about, and I fumble for the change in my pocket, change that often ends up on the floor. Sometimes I cannot tell a nickel from a dime from a quarter, so I hand over my change like a child at a candy counter and wait for the clerk to sort it out. At the supermarket, I can never figure out which way to slide the debit card. More than once I have had a cashier snatch it from my hand abruptly, point to the people behind me, and say "People are waiting, sir!" Who wants to turn around and announce, "I have Parkinson's disease"? So you swallow the small indignities and humiliations and try ahead of time to think about each tiny step in the process of a task as simple as buying a carton of milk.

In my cardiology practice, I often discussed with patients what physicians call "ADLs," the activities of daily living. In assessing the toll of any disease, an important measure is how it impacts the patient's ADLs. By that standard, the toll of my Parkinson's has been great. The most routine tasks require a level of attentiveness and concentration that I once reserved for the treatment of seriously ill heart patients.

The physical manifestations of Parkinson's go well beyond tremors and involuntary jerks of hands and arms. Balance is problematic. Last year, I fell in the shower, hitting my head and drawing blood. As a result, I am more defensive and deliberate in my movements. I am always anticipating what obstacles—stairs, furniture, inclines, curbs—I will have to navigate in the places I go. I am constantly in a high state of vigilance that is draining, both emotionally and physically.

The impact of Parkinson's is so pervasive that even my thermo-regulatory system is out of control. ~~often feel too hot and too cold simultaneously. Hot flashes accompanied by sweats send me to the~~ shower two or three times a day. A hot bath is often the only way to get comfortable again.

My hands and face often tell the story. While my face may be perspiring uncontrollably, my hands can be clammy and cold. As a practicing physician, I always paid careful attention to my patient's hands, often beginning my physical exam there, for the hands often provide important diagnostic clues. Thickened tendons in the palm can indicate diabetes. Swelling of soft tissue near the fingertips, combined with nailbed changes may be a sign of lung cancer or cardiovascular disease. Painful lumps in the fingertips can suggest an infection of the heart valves.

But there was another, equally important, reason for beginning a physical exam with the hands: taking the patient's hands in your own invites intimacy and trust, a nonthreatening beginning to an exam that will involve physical contact between physician and patient. An examination of the hands can also yield clues to a patient's state of mind or tell you something about their life that can provide an easy entrée to conversation. Are the patient's hands moist with sweat? If so, the patient may be anxious. Do they tremble? If so, Parkinson's may be suspected. Are they yellow with nicotine? That's the patient smokes. Do they reflect hours spent in the garden? If so, the patient may be put at ease with a question about his or her garden. My hands, too, reveal much. They are often red, often cold, and they often have a life of their own. My hands tell you a lot about my Parkinson's.

Another "small" problem related to the hands is what doctors call "micrographia," which is typical of Parkinson's patients. No matter how hard I try, the amplitude of my handwriting gets smaller and smaller as I write because my hand muscles fatigue. This is, in fact, no "small" problem because with memory failing, I often leave notes to myself, ironically notes that I cannot later read. It's not unusual for me to write the same note six or seven times before I produce one legible enough to be read hours later. It takes me ten times as long to write a note as it once did. This is one of the daily frustrations that can quickly raise a high titer of anger. I have crumpled countless pieces of paper in frustration and thrown them at the wall. This is how Parkinson's chips away, bit by bit, at your humanity and the sense of normality that all seriously ill patients crave.

Sudden hypotension, usually lasting only a few seconds, is another symptom of my Parkinson's. Typically triggered by exercise or exertion of some kind, these sudden drops in blood pressure bring me to the brink of fainting. My peripheral vision disappears and narrows to tunnel vision as I begin to lose consciousness. Frequent hydration is a prophylactic, so I try to remember to drink six to eight glasses of fluids a day.

Eating is yet another ADL that has suffered the impact of Parkinson's. In addition to the messes I often make at my place, I have to avoid some foods that I once enjoyed because I can no longer manipulate my silverware well enough to cut a steak, for example, and I detest the notion that someone will have to cut up my food for me as if I were an infant or a senile old man. This can be especially embarrassing at a restaurant or dinner party. If it were not for the fact that Vicki has become a swift and very discreet monitor of the area around my dinner plate, it would often appear that a three-year-old child had been seated at my place. The more dramatic tremors associated with Parkinson's can be controlled with medications; yet the compromise of fine motor skills can turn a formal dinner into a management nightmare as I try to move soup from bowl to mouth without spilling it all over my shirt, or try to confine rice to the boundaries of my plate.

The rigidity of body and loss of physical control and fine motor skills have also interfered with some of my favorite activities. Though I still play the drums, a passion for many years, I can no longer coordinate my feet sufficiently to generate the rapid motion of cymbals needed for jazz, and imparting

rhythm—and drums are all about rhythm—is increasingly difficult. Drumming is becoming harder for another reason as well: Math is an essential part of music—whole notes, quarter notes, tempo—and I can no longer process mathematical relationships. Sheet music simply doesn't make sense to me as I once did.

Loss of physical control also means occasional drooling, sometimes when I am awake, but more often during sleep. When I wake up, I find that I have soaked the pillow with drool and the sheets with sweat. If I've had a good day the day before, waking up like this the next morning is an unwelcome reminder that Parkinson's is my constant companion.

Each of these manifestations of Parkinson's, no matter how trivial, erodes my sense of stability and my desperate need to feel that there is stasis—that I have battled Parkinson's to a standoff, at least temporarily. The appearance of any new symptom invariably leads to the inescapable conclusion that the disease is progressing.

* * *

Physical deficits are only one part of my daily battle with Parkinson's. My interactions with people are marked by a slowness of thought (called bradykinesia) that is as embarrassing as it is frustrating. It's more than losing my train of thought, though that happens a hundred times a day or more; it's having the words in my head, but being unable to move them from the part of the brain where thoughts are formed to the part that controls speech. The neural pathways are disorganized, like some fantastically complex highway system with overpasses and intersections, on-ramps and exit ramps, all leading nowhere. A thought forms, it gets sent down the pike, only to get lost in some cul-de-sac where it spins like a whirling dervish. The train of thought in such cases isn't lost; I'm well aware of the thought; but I cannot maneuver it to the place in my brain that will allow communication. Sometimes the thoughts will finally spin out of the cul-de-sac and find expression; often, however, they simply spin themselves out like a spent whirlwind, never escaping. The halcyon days when I spoke eloquently and with great confidence are gone. As I said, nothing, not even speech, is second nature any more.

It is this dementia, this progressive loss of cognitive and intellectual functioning, that is the hardest symptom of my disease to live with and the hardest to accept. I can no longer balance a checkbook or calculate a restaurant tip. The concentration required for two hours of often-halting conversation leaves me weary. A veil descends, like a night canopy over a birdcage, and I need to nap to recharge my diminished synapses. Many Parkinson's patients will tell you that having Parkinson's is like having a switch in your head, a switch that is not in your control; a switch that can be flipped up and down once an hour or ten times in a minute. Sometimes I simply shut down and wait out the power outage.

I have lost large chunks of knowledge that have dropped away like a glacier cleaving huge chunks of ice into the sea. It's still hard for me to admit to having dementia, because there are times, wonderful moments of lucid, clear thought, when I feel intellectually intact. I try desperately to hold on to those moments, or hours, but inevitably they pass. Am I an intellectually intact person with bouts of dementia? Or am I a demented person with moments of lucidity?

Predictably, this cognitive decline has led to a loss of intellectual and social confidence. Initially my social confidence was completely destroyed by Parkinson's. Because stress and a high volume of sensory input exacerbate the slowness of mind that frustrates me so, I resisted social occasions for a long time. But Vicki has rescued me from life as a recluse. She has always had an active social life with a wide circle of friends, and there are countless charitable functions on her calendar. Though

social events are challenging on many levels, they force me to engage with the world, as difficult that engagement can sometimes be.

When a friend of Vicki's recently graduated, as an older student, from Wellesley College, we were invited to a buffet dinner on Wellesley's magnificent campus. It was so crowded that you could hardly move, so noisy you could barely hear. My anxiety always spikes at such times. Sensory overload makes it harder to mask the symptoms of Parkinson's. The pressure to "perform" feels onerous and quickly becomes counterproductive. I couldn't muster the motor coordination to move food from the buffet table to my plate; conversation, for several reasons, was impossible. The verbal sparring, the quick give-and-take that is so much a part of daily life, no longer takes place on a level playing field for me. For one thing, Parkinson's interferes with voice modulation, so I often speak, involuntarily, in a near-whisper. The volume of my voice is one indicator of how I am feeling: On my good days, it can be close to normal; when I'm struggling, it can be inaudible. Competing with the background noise at a party when my voice is faint is arduous, and I am often forced to lean in and speak inches from people's ears. Gradually, I have grown more comfortable explaining to people, even those I don't know, why I may be hard to hear and telling them to feel free to tell me if they can't hear me. The playing field is also tilted because I am keenly aware that I am often well off the pace of the palaver. I often drop fancy words like "palaver" into my conversation to prove I still have "it," that I am not an intellectual shipwreck. Words I once thought pretentious I now use deliberately in conversation, to compensate for the loss of intellectual firepower.

When we return home from these occasions, I am always eager for a debriefing from Vicki. "How was I?", I want to know. This is a part of holding on: I am relieved when the report is a good one—that I may have started slowly, but picked it up by evening's end. When I'm off, it's terribly discouraging.

Because I am always on the alert for any sign of deterioration in my condition, when Vicki tells me that I seem confused, I am instantly thrown into a state of acute stress, wondering if this is the moment when I fall off, irrevocably, to the dark side of the ridgeline I walk. From years of experience listening carefully to patients and even listening between the lines for what my colleague Bernard Lown calls "the unarticulated ache," I have become quite astute at sensing anxiety in others. Often Vicki doesn't need to say anything: I know, just from looking at her, how the evening has gone.

* * *

Fifteen years ago, I taught a course at Harvard Medical School on heart disease and sexuality. Sexuality is a topic widely ignored by physicians for a variety of reasons, including the physician's discomfort with the subject. At the time, most cardiologists weren't even raising the issue of sexuality with their patients—yet almost every heart patient I saw would bring the subject up eventually, if I didn't. Most wanted to know if sexual activity was safe for them. And more often than not, my reply was that not only was it safe; it was necessary. The course of heart disease can be dramatically affected by stress and the strength of personal relationships. Patients in relationships filled with anger, resentment, and guilt are at greater risk than those in relationships that bring comfort, joy, and peace. For married patients, or those in a long-term relationship, a healthy sex life marked by intimacy and caring can impart a sense of wellbeing, reduce stress, and bring happiness.

The effect of Parkinson's on my own sexuality has been profound. But, similarly to heart disease cases, sexuality is the forgotten part of the Parkinson's discussion unless initiated by the patient. The issue of sex and Parkinson's is a complex one, in part because the medications used to treat the symptoms of Parkinson's, including the characteristic depression, can affect sexual function. Some

antidepressants and other medications can cause impotence, for instance. It's an example of how, in diseases like Parkinson's, or Alzheimer's, or multiple sclerosis—diseases of the central nervous system—everything can affect everything else. It's like an ecosystem—a change in one niche can trigger changes throughout the system.

When Vicki and I first met, we were in our mid-fifties and enjoyed an active sex life that brought great intimacy and closeness to our marriage. After my Parkinson's diagnosis, various medications were prescribed in a search for a combination that would bring my symptoms under control. As a physician, I was well aware of the complexity of "polypharmacy." I frequently saw patients on multiple medications for the treatment of multiple ailments, often with inadequate consideration given to how the individual medications would interact. At its worst, polypharmacy with inadequate consideration of drug interactions can be life-threatening. It took some experimentation until I responded favorably, but Zoloft, prescribed for depression, seriously depressed our sex life.

At one point, I became so frustrated that, without telling Vicki, I abruptly stopped taking the Zoloft. A good doctor is not necessarily a good or compliant patient. (Indeed, as we will see, though I was a good doctor to my patients, during the onset of Parkinson's I was a terrible doctor to myself.) Weeks later, I confided to Vicki that I had taken myself off the Zoloft, she was justifiably angry. She already felt that I had betrayed her trust, in the months before our marriage, when I had assured her that my fainting spells and other early warning signs of Parkinson's were under control and not serious. Winning back her trust was still a work in progress, and I had just dealt that work a setback. And quitting the Zoloft intensified my Parkinson's symptoms. It was a Catch-22, for Parkinson's symptoms themselves interfere with sexuality, and so do the medications used to treat it.

I resumed the Zoloft, and slowly, after much open and honest discussion, we regained some of our intimacy, though it has been inconsistent. But Parkinson's and the medications used to treat it continue to have profound effects and permeate every aspect of our lives.

I suspect that most neurologists who see Parkinson's patients see sexuality as incidental in the face of such a devastating disease, a bit like worrying about a cold in a patient with terminal lung cancer. But for the patient living with Parkinson's, the patient who has already lost so much, sexual intimacy can be especially meaningful and a vitally important quality-of-life issue. Ironically, in the 1990s, I served on the FDA panel that oversaw the approval of Viagra. Such drugs can play a critical role in giving back to Parkinson's patients—and to others who suffer from sexual dysfunction resulting from neurological disease—a part of their humanity.

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Every day, something happens—some event large or small—that triggers my anger at what has happened to me. The anger, too, is pervasive. I am angry over my losses, angry about the terrible pain and anxiety my illness has introduced into the lives of my wife and daughters, angry at the loss of so much of my sexuality, angry that my young grandchildren will never know "Pops" without dementia, angry that it takes me twenty minutes to change a lightbulb, angry that the disease has ripped apart the fabric of my life, and angry at being dependent. Parkinson's has foisted on me a dependence on Vicki that I resent, but one that has become absolutely necessary. Every day, she anticipates my needs even as she struggles with her own fears about what might lie just ahead.

Yet, though I chafe at my dependence, I know that I am far healthier for having Vicki in my life. Her own vigilance eases the road I travel. When I flew to California alone to visit my daughter a few months ago, I was filled with anxiety about the logistics I would have to manage. The ticket counter

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