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A Jangling Journey: Life with Tourette Syndrome

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“It is Tuesday, now, and a very calm morning. I am pretty sure I haven’t had a tic in 45 minutes. If you were sitting here with me, you would probably ask: Was I kidding about this Tourette thing yesterday?” Neurobiologist Hollenbeck is not kidding, but he hints at the paradox of Tourette syndrome, which defies our standard concepts of voluntary and involuntary behavior. What is brain science learning about this disorder, which often begins in childhood and often frustrates, infuriates, and humiliates its sufferers?



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by Peter J. Hollenbeck, Ph.D.



A Jangling Journey: Life with Tourette Syndrome

What is it like to be bombarded by inner sensations that overwhelm your best efforts at control, forcing you to make movements or sounds that can be unpleasant, even startlingly inappropriate? Although not diagnosed until adulthood, neurobiologist Peter J. Hollenbeck, Ph.D., has lived with Tourette syndrome since he was a boy.

After diagnosis, came (eventually) an effective treatment—one that Hollenbeck recently decided to discontinue. Brain scientists, geneticists, and immunologists are beginning to unravel the causes of this intriguing condition. But, asks Hollenbeck, is “ticcing” a disease, a gift, or a social problem?

The most common neuropsychiatric illnesses command our attention and challenge our imagination so deeply that they inspire popular metaphors. There is the dismal gray cloud of depression, the debilitating fire-and-ice of bipolar disorder, the waking nightmare of psychosis. But off at the edge of public awareness, out in the satellite parking lot of clinical attention, sits my personal affliction, Gilles de la Tourette syndrome. If it requires its own metaphor, I suggest something like “the car alarm” of neuropsychiatric disorders.

The sounds of this alarm, the outward symptoms of Tourette, consist of abrupt, repetitive physical movements and the production of sounds that in rare cases rises to the blurting out of words. From the moment in childhood that these movements, called tics, arise, their nature, frequency, and intensity vary in a bewildering progression. The less apparent, internal symptoms involve the buildup of sensations and urges that precede and impel the tics. Tourette is odd enough that some writers have afforded it an idealized, vaguely romantic treatment; it is startling enough that stand-up comics and B movies present it in ribald caricature. This abrupt, twitchy, bone-rattling condition has been my constant companion for as long as I can remember.

If you were sitting across from me now, you would probably not recognize that I am having a bad Tourette day. But there is a great deal going on here besides typing. Once or twice each minute, premonitory urges build up like a crackling background noise in my brain until they burst forth and manifest themselves as outward tics.

My current repertoire of tics is broad, but this Monday morning I am suffering just a small subset. My neck cranes to the right, then the muscles of the left side of my face and neck contract, squinting my left eye and tilting my head briefly forward. My left arm rises until my hand halts directly in front of my face. I am frozen for a moment; I emit a tiny—almost inaudible—whoop. Then I go back to my writing for half a minute or so, until the whole collection repeats itself.

If you were watching me through a one-way mirror in a movement disorders clinic, these movements would all be obvious to you. But I am in a university library, surrounded by strangers, and so I painstakingly sublimate these tics, disguising them as stretches, glances around the room, and

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throat clearing. So far this morning, everyone is fooled. This subterfuge takes a lot of energy, but I have had 40 years of practice and can pull it off because most Tourette tics—certainly most of mine—look like voluntary behavior. Indeed, it is useful to think of them as small cassettes of normal behavior, vignettes that play out unbidden from the basal ganglia, a region of the brain where movements are regulated. It may seem hard to believe that they are all involuntary: a blinking eye, rotating head, flailing arm, a sniff, a whistle, a phrase muttered under the breath, a halted stride, a little hop. But they

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are. Don't ask me to stop ticcing right now. I am a disciplined person who can run 30 miles, shovel snow for hours in the bitter cold, or go without eating for a couple of days. But on a morning like this, I cannot halt my tics, at least not for long.

Yet Tourette is a little more complicated than that. Three times a week, lecturing on cell biology to 400 university students, I forge through an intensely focused hour in the spotlight without a single tic. But throughout the lecture my premonitory sensations build up steadily, urgently, like God's own sneeze. So I must follow this period of submergence by climbing the stairs to the privacy of my office, a dolphin coming up to breathe, there to tic, tic, tic ad libitum until the need subsides. Like a terrible itch you can ignore, for a little while, Tourette tics call into question our

glib definitions of voluntary and involuntary behavior. Still, there are tics that invite suspicion, even from me. In the course of speaking at a program for young Tourette patients, their families, and teachers, I heard a mother describe her son's most annoying tic: "He spits on people," she said, "but only on people who make fun of his tics."

A DISEASE OF THE ONLOOKER

The fun-making brings us to the crux of Tourette syndrome. After all, Tourette is far from the worst disorder nature can visit on you. It does not weaken or destroy your muscles, your mobility, your senses, or your mind. It is not fatal. It is not even progressive; in fact, it usually gets significantly better with age. A mild-to-moderate case like mine does not grossly impede my day-to-day life, although it makes many things



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harder. Tourette differs from other neuropsychiatric disorders in one simple way: It is largely a disease of the onlooker. When I tic, I am usually not the problem. You are.

In large part, the discomfort, annoyance, and intervention of onlookers are what make me a Tourette sufferer. If I have a tic and there is no one there to mock me, is it a tic? It will distract me a bit, briefly disrupt my concentration, drain away a little energy, but I am well accustomed to this. Tourette has taught me to weather my tics and plow ahead. The dismay of others can be a heavier burden. To be mocked every day at school or on the playground is hard on a young boy. But I understood, even as a child, that most of my classmates and teachers were not mean-spirited. As I ticced, they simply could not help but stare at me, ask me what was wrong, imitate me, or even tell me

to “stop it, stop it, now!” These things were hurtful, but not unexpected. I was a disordered body in their field of view, and they could not resist the urge to establish order.

But there was also a wonderful, ongoing surprise in my childhood and adolescence: those closest to me remained outwardly unperturbed by even my most baroque tics. If I have succeeded in life despite having Tourette, it is in large part because I had the good fortune to be a ticcing young boy who had some compassionate onlookers—a loving family and friends who simply let me tic—and a marvelous, intuitive doctor who convinced me that everything would be OK.

THE MISFIRING BRAIN

A clinician or a Tourette patient will notice people on the street who display tics too

subtle or well disguised to attract the attention of the average passerby. Tourette is a developmental disorder of the brain, a disturbance in the flow of information that stimulates or inhibits movements. It typically emerges during early childhood when the wiring patterns of the brain are being extended and modified.

Many of the children are already being pestered by classmates and grown-ups and are learning to disguise their tics as voluntary movements. Most of these tics will vanish within months as the children, and their brains, mature.

Walking into an event at my son's elementary school—and so placing myself among hundreds of developing basal ganglia—I can easily pick out a dozen or more children with tics. Some have a single, simple tic, such as eye blinking or neck jerking, others more complicated repertoires. Many of the children are already being pestered by classmates and grown-ups and are learning to disguise their tics as voluntary movements. Most of these tics will vanish within months as the children, and their brains, mature. But some of these children will continue to experience tics as they grow, and in a very few (perhaps 1 in 50) the severity and complexity of the tics will increase until their parents seek help from a physician. When they do, those children with Tourette will have a good chance of receiving an accurate diagnosis. They and their parents

will be greatly relieved simply to hear an explanation of their disorder from an empathetic clinician. And, although there is no cure for Tourette, not even a robustly reliable treatment, many patients will benefit from medication or behavioral therapy.

The longer view is better still: recent advances in our understanding of the neural mechanism and causes of Tourette are likely to bring major improvements in treatment in the lifetime of today's newly diagnosed patients. Altogether, it makes an encouraging picture, but, as I have reason to know, this has not always been the case.

UNDERSTANDING “LA MALADIE DES TICS DE GILLES DE LA TOURETTE”

Georges Gilles de la Tourette, like Amerigo Vespucci, has had his name attached to something he did not, strictly speaking, discover. During the late 19th century, Gilles de la Tourette, along with a young Sigmund Freud, pursued medical practice and advanced study in Jean-Martin Charcot's clinic in the Salpêtrière Hospital in Paris. There, a colorful historical case of severe tic disorder was brought to his attention and may have stimulated his own work with a handful of similar patients. In 1885, he published his groundbreaking description of the disorder, marking a starting line of sorts for a century of clinical investigation.¹ Later in the same year, his mentor Charcot assured Gilles de la Tourette a place in history by naming the disorder after him.

Unfortunately, Gilles de la Tourette's own organic, neurological view of his eponymous syndrome did not immediately set the pattern for future studies or treatment

of tic disorders. For most of the 20th century, Tourette syndrome was considered so rare that it captured the interest of relatively few clinicians or medical researchers. Although some disorders spawned turf wars between the specialties of neurology and psychiatry, not so Tourette, which was so far under the radar of the average clinician that one prominent psychiatrist told me, “There was no turf war over Tourette, because there was no turf.”

During my youth in the 1960s and 1970s, neurologists largely abandoned the Tourette turf to psychiatrists, who at that time had neither the tools for nor the interest in treating disorders with obvious organic origins. But during this time, neuroscience

High-resolution neuroimaging, molecular neurobiology, and detailed genetic studies, along with the full elucidation of the human genome, are leading us to a time when drugs and treatment protocols can be designed specifically for Tourette, or even for the varied needs of individual patients.

was producing an explosion of knowledge about brain chemistry. This increased knowledge helped spawn a rigorous, scientifically oriented psychiatry that began to seek biological explanations for disorders of the brain and mind. In this milieu emerged the first effective treatment for severe Tourette, the antipsychotic drug haloperidol.

Just as important as those advances was the formation of the Tourette Syndrome Association (TSA)² by a group of patient families. In three decades of existence, this organization has managed not only to carry out a successful program of service for patient families but also to dramatically increase the awareness of both clinicians and the public about Tourette. More remarkable—and perhaps more important—TSA has used a modest research fund to catalyze the growth of a whole community of active researchers and clinicians working on the causes, courses, and treatments of Tourette.

The 21st century begins with medical researchers pursuing working hypotheses about the anatomical, physiological, embryological, and immunological bases of Tourette.³ Recent studies have focused our attention on particular brain circuits, those involving the thalamus, corpus striatum, and cortex that play a role in coordinating and controlling psychomotor behavior. Either excessive stimulation or disinhibition of some of these circuits, caused by defects in how some of the nerve cells in these circuits use the neurotransmitter dopamine, may underlie the production of tics. But altered properties of other classes of nerve cells that use different neurotransmitters may also be involved in tics. Thus, it is no surprise that detailed genetic studies of Tourette indicate that it cannot be attributed to variation in a single gene. It also seems possible that environmental factors, such as perinatal environment or autoimmune responses to infection, play a role in the development of some cases of Tourette.



Like all people afflicted with chronic disease, we Tourette sufferers become experts on our own condition. The nature of the Tourette brain gives each of us who lives with it an exclusive seat to observe our condition.

Clinical treatment is moving forward as well, with an expanding tool kit of useful drugs. These drugs are mainly “off-label”: medications that were developed for other purposes and have been found, fortuitously, to ameliorate Tourette in some patients. Other, better treatments will yet be found in this way. But it requires little imagination to see that high-resolution neuroimaging, molecular neurobiology, and detailed genetic studies, along with the full elucidation of the human genome, are leading us to a time when drugs and treatment protocols can be designed specifically for Tourette, or even for the varied needs of individual patients.

But progress includes more than drugs and neurotransmitters. Behavioral treatments such as habit reversal training show the potential to reduce Tourette symptoms. Indeed, of all the recent advances, perhaps the most

important is the realization that Tourette is not an obscure movement disorder, but rather a model neuropsychiatric condition. It is an impairment of integrated brain functions that manifests itself with highly variable character and severity; it has an important but complex genetic component; it has a complex life history that requires multimodal treatment; and it requires a highly engaged clinician who can take a complete, profound view of the patient.

LEARNING FROM THE INTERNAL EXPERIENCE

Much of the structure of Tourette lies deep within the patient. Like all people afflicted with chronic disease, we Tourette sufferers become experts on our own condition. The nature of the Tourettic brain gives each of us who lives with it an exclusive seat to observe our condition, a perspective missing

from most (but not all⁴) popular depictions of the disorder.

Clinicians and researchers have gained a great deal from careful descriptions of the internal, premonitory urges and sensations of Tourette provided by patients. One remarkable layman, Joseph Bliss, wrote an acclaimed paper in the *Archives of General Psychiatry*⁵ that convinced clinicians that they must understand the patient's experience of Tourette. He cataloged the sensations preceding his tics in exquisite detail, describing them as "irresistible, calling for an *almost* inevitable response." He even addressed the research community directly, stating: "There is uncharted territory here waiting to be explored. The signposts are few, incredibly subtle...."

Understanding the internal experience of Tourette is important not only for treating the whole patient but also for making an accurate diagnosis in the first place. Until and unless a laboratory test is developed to diagnose Tourette, clinicians will continue to be hampered by the capacity of these patients to drop the curtain between the premonitory urges and the outside world, to experience the discomfort but temporarily suppress their tics. If a clinician does not have enough time to sit with a patient, to listen to his story until the patient relaxes and begins to tic—perhaps even to try again the next day or next week when the patient's tics are worse—then that clinician does not have enough time to diagnose Tourette.

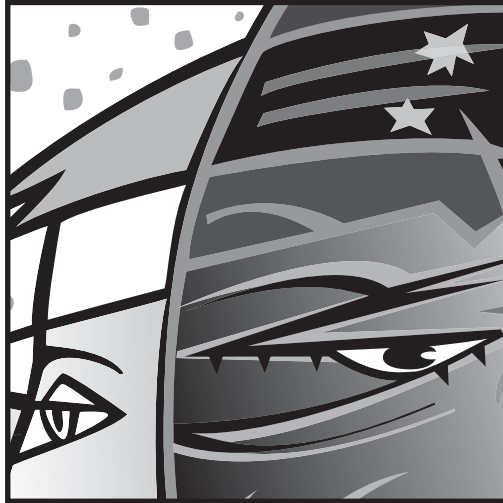
A small irony here: I am glad that my Tourette was not diagnosed in the 1960s. The only treatment available in my youth would have been the powerful antipsychotic

drugs that were used to great effect for the most severe and debilitating cases of Tourette. These drugs would have been inappropriate and unnecessary in my case, and I hope that

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hours; during each month, good
and bad days.*

no responsible clinician would have prescribed them. In the 1960s, a diagnosis would have provided me with a label and little else: no ideas about the disorder's etiology, no prognosis, no literature from the TSA. In fact, my childhood neurologist, in the absence of diagnosis, flatly rejected labels for my condition and cheered along my progress very effectively even without ever offering a medical solution. Of course, it would have been nice for me to have the good news that is available now: that the chances are better than even that the condition will improve. For young patients, and their parents, it is no small comfort to know that within 10 years or so the tics are likely to be greatly reduced, or even absent. The problem is what to do in the meantime? Waiting out Tourette can be made very difficult by the waxing, waning, and mutating of the tics.

Twelve years ago, after decades of living on the tic roller coaster, I came roaring down the slope of a very bad year. On the advice of a well-meaning and observant friend, I landed in a Boston neurologist's office, there to be diagnosed at last

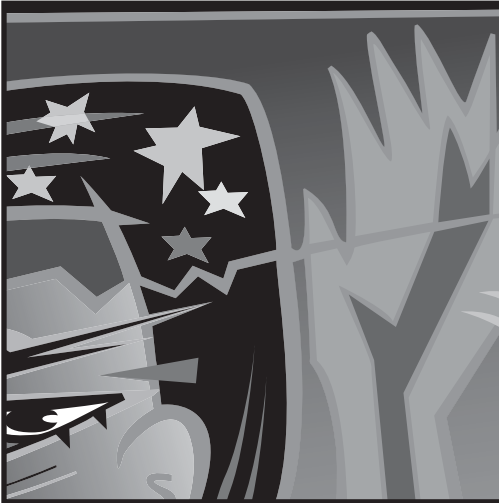


FRACTAL PATTERNS AND THE SEARCH FOR A CURE

It is Tuesday now, and a very calm morning. I am pretty sure I haven't had a tic in 45 minutes. If you were sitting here with me, you would probably wonder what happened to my tics. Was I kidding about this Tourette thing yesterday? But like so many things in nature—snowflakes, global climate, heartbeats—tics follow a fractal pattern. Their frequency and intensity fluctuate, rising and falling over time, so that during each hour I have good and bad minutes; during each day, good and bad hours; during each month, good and bad days. My lifetime with Tourette has had good and bad years, even decades. For many Tourette patients of my generation, diagnosed only in adulthood, it took not only advances in medicine, but also a very bad year, to finally send them to

a neurologist or psychiatrist. Twelve years ago, after decades of living on the tic roller coaster, I came roaring down the slope of a very bad year. On the advice of a well-meaning and observant friend, I landed in a Boston neurologist's office, there to be diagnosed at last.

But, once diagnosed, how was I treated? The fractal nature of Tourette, like that of many other chronic diseases, not only makes diagnosis difficult but also hinders the analysis of its causes and the discovery of effective treatments. If the frequency and severity of tics wax and wane in a complex pattern on several time scales, how will you determine whether an intervention has helped? Is the medication working, or is this just one of those good days? If it works, how much to take? Be careful here: a dose that covers my bad days may leave me sleeping through



It is difficult to draw the line between Tourette as my disorder and Tourette as an architect of my personality. Would I be the same person if my basal ganglia were normal?... Was I the same person when my tics were medicated away?

the good ones. It requires a finely tuned partnership of clinician and patient to get it right and keep it right. This fractal variation not only confounds the judgments of clinicians and researchers but also frustrates the parents of Tourette kids in their hunt for something, anything, that will relieve their child's tics. A quiet room? A change in diet? Herbs? Biofeedback?

My own brain chemistry was kind to me, and the first course of medication I undertook after my own diagnosis changed everything. It not only eliminated most of my tics but also, more important, quelled the constant drumbeat of premonitory urges. For several years, I lived, happily medicated and with few side effects, relieved of nearly all the static, the tension, the itches that had been with me since early childhood. The result was a kind of epiphany, an appreciation

of the calm and peace possible in the brains of all of you who do not tic. At last I was able to run workouts without holding my breath periodically, to walk without hopping, to stand in a crowd without twitching. I was at long last a calm man with almost no tics.

But I was also a man on psychoactive medication, who occasionally forgot to renew my prescription just before a three-day weekend, and, thus, a man who sometimes suffered the wild mood swings that accompany unplanned withdrawal from powerful drugs. In addition, the medication added an hour to each night's sleep and perhaps 30 seconds to my time for the 10,000 meters. And so, after seven years on your side of the looking glass, I took my cue from a long period of relative quiet in my Tourette brain and weaned myself off the wonder drug.

I am glad to have spent part of my life

on effective medication. It smoothed out what could have been some very bad years and also allowed me an accurate assessment of the full range of phenomena that for me comprise Tourette. Having lived with Tourette

Imagine being faced with an otherwise well-balanced patient whose brain compels him to do things that he does not want to do—sometimes even the opposite of what he desires: to twitch in front of an audience, avert his eyes from a beautiful painting, shout out in a quiet church service.

and nearly without it, and with it again, I know what it is and what it is not. I think that I understand the fascination that the world of Tourette holds for some, and why it is sometimes interpreted in idealized terms.

TOURETTIC ENERGY, TOURETTIC STRESS

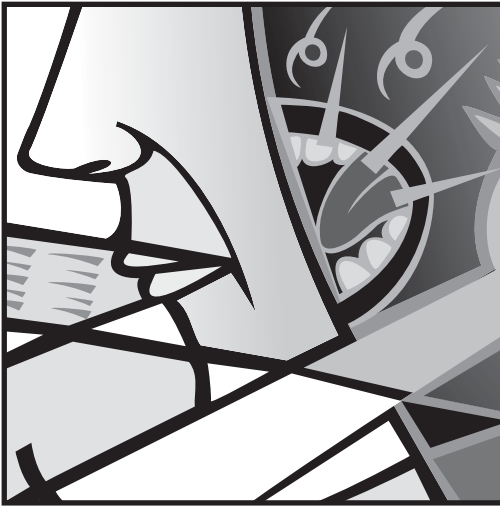
The romanticized view of Tourette derives in part from the fact that it is exotic, and, to the clinician, quite interesting. Imagine being faced with an otherwise well-balanced patient whose brain compels him to do things that he does not want to do—sometimes even the opposite of what he desires: to twitch in front of an audience, avert his eyes from a beautiful painting, shout out in a quiet church service. Observe a gentle soul who pokes and punches himself, a beautiful girl who contorts her face into a scowl, a cautious child who must nonetheless hop

into the street. But to observe the exotic and to live it out are quite different. A giraffe looks like a strange and dreamy creature. Yet, when I am gazing at one in the zoo, I always think the same thing: “I’ll bet that neck is nothing but a king-sized pain.”

An idealized popular view of Tourette also arises from the observation that many patients appear bracingly edgy, physically vigorous, with abundant intellectual and creative energy. But, although some perceive this energy as a compensatory gift, for me it feels like little more than the frank inability to sit still. When tics disrupt my attention constantly while I am reading, am I really compensated by having enough energy to read everything three times?

Clinicians who treat children with Tourette frequently comment on their almost uniformly positive outlook and joie de vivre. This is one of the places where it is difficult to draw the line between Tourette as my disorder and Tourette as an architect of my personality. Would I be the same person if my basal ganglia were normal? Would I be possessed of the relentless optimism that has guided all of the important decisions in my life? If not, would that be a good thing, or a bad thing? Was I the same person when my tics were medicated away?

My track coach warns me regularly that I must manage all of the stresses in my life. “Your body,” he says, “can’t tell whether you’re under stress this morning because you have a cold, or had an argument at work, or because you ran those 800-meter repeats at the track yesterday. It’s all just stress, and you have to accommodate it.” As I get older, my edginess, my balance



This disorder is an accident of birth, a pebble in my shoe. Although I am glad that it is not a larger one, I often dream of removing that shoe, shaking out the pebble, and walking away from my Tourette.

between Tourettic distraction and energy, becomes less of a tool to get things done and more a source of mental and emotional fatigue by the end of the day. It is becoming just another stress, to be placed on the scale alongside those 800-meter repeats. I ask myself, as must anyone with a chronic disorder, “How much of this is Tourette and how much is just getting old?”

To manage our tics, Tourette sufferers learn to reduce stress, to avoid the triggers that make tics worse or render them more apparent. Few of my coworkers have noticed I rarely communicate with them by telephone. Thanks to e-mail, the dodge has become easy. Before e-mail, I wrote reams of paper notes and letters and hiked many flights of stairs for a face-to-face chat in one office or another, all in order to avoid the phone. On the phone, I have a frequent and

often infuriating tic. During the course of a conversation, I pause sporadically and simply cannot initiate speech for a time, just a few seconds, but long enough to drive me and my listener to distraction. The more I want to speak, the more I have to pause, phone in hand, bon mots trapped behind a dam of silence. This is a diabolical tic because it rarely surfaces during face-to-face conversation, and, if it does, the visual cues that govern close interactions usually save me. This is a tic elicited by the only form of communication it can fully disrupt.

Bright, shifting lights against a dark background exacerbate many of my other motor tics, so I go to great lengths to avoid driving at night. When this event is unavoidable, I stay off main streets where the noxious stimuli of streetlights and headlights await me. Some Tourette sufferers

avoid specific postures or particular environments. Like athletes in training, we function best when we stick to a program like clockwork. These elements of mental hygiene can be personal or quite general. Fellow patients who notice my lifelong devotion to running or the lack of junk food in my diet ask whether these things can ameliorate their Tourette symptoms. What can I say, except, “Of course”? What chronic illness would not be helped by good nutrition and sound personal habits?

There is so little of the grand or noble about my condition that, were it in my power to wave a wand and banish Tourette from humankind, I would be tempted to do so. Yet, I have to wonder whether this action would take something out of the world.

A PEBBLE IN MY SHOE

Now we are at the point in the essay about chronic disease in which you expect me to tell you that I am a better person for having met this challenge. What a load of nonsense! Adversity can make me empathetic and compassionate, or it can make me angry and mean-spirited. I am not particularly proud of having to overcome Tourette. Beethoven composed *Symphony No. 9* from his silent, deafened world; Churchill fought depression and a learning disability as well as leading the West against fascism. They were extraordinary characters. I am just a guy with tics, a

bit like a tightrope walker wearing galoshes.

Tourette is frustrating, annoying, occasionally humiliating, but it is hard to imagine others finding inspiration in my paltry battles. There is so little of the grand or noble about my condition that, were it in my power to wave a wand and banish Tourette from humankind, I would be tempted to do so. Yet, I have to wonder whether this action would take something out of the world. Perhaps it would expel from life a small measure of optimism, a load of joie de vivre generated by a group of children who have been challenged by their lot but who, by and large, refuse to mope.

Although I speak regularly about coping with Tourette to these children and their families, I feel only a fleeting sense of collective identity with other Tourette sufferers and urge these children not to seek it themselves. We live in a society in search of role models, but I am no more proud of having Tourette just like Samuel Johnson did than I am of having white skin like Mozart. Most children will benefit from less fretting about their inborn imperfections and more attention to their developing strengths. My own parents and boyhood doctor attended much more closely to my latest math exam or foot race than my newest tic, and from that I learned what mattered most.

This disorder is an accident of birth, a pebble in my shoe. Although I am glad that it is not a larger one, I often dream of removing the shoe, shaking out the pebble, and walking away from my Tourette. But for the present I cannot walk away, nor can anyone else with this ticcing disease.



For now, we cannot cure Tourette, we can only try to make it unimportant.

I remind myself of what I have told countless Tourette kids and their families: do all that you can to make your condition better. Know yourself, exercise good mental hygiene, seek and demand the best medical care available. And until a cure for your tics can be found, do what you can to cure your onlookers. Throughout their lives all those with Tourette will face moments when they must gird up their loins and explain themselves, educate those around them in school, on the playground, in the workplace. When they do this, they will probably make the pleasant discovery that most of their onlookers are people of goodwill, able to understand and ignore the tics, that many can be made into allies, a few into partners on the jangling journey of life with Tourette. For now, we cannot cure Tourette, we can only try to make it unimportant. ■

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