

## Introduction

Amidst the muffled conversations of a quiet, softly lit restaurant, a man raises his voice. "Stop twitching! You're embarrassing me!" he snaps at a little boy. Diners near them turn puzzled stares their way. More quietly, but still irritated, the man finishes, "Every week it's some new habit with you!" The seven-year old squirms in his seat and looks down at a water circle on the tablecloth. He is trying for his very best table manners. The boy's right wrist jerks again, as if it were the wrist of a marionette, yanked from above by a string. This time the movement is so severe that kernels of corn fly from his fork through the air and become yellow dots on the brown-carpeted floor. This time they both look at the tablecloth and pretend not to notice.

\*\*\*\*\*

"Hey, Twitchy!" yells the classroom bully, jerking his chin up, then down, and then to the right. He is mimicking a teenager sitting three rows away, and he is making sure that every student occupying a desk within view will see his show. "What's the matter? You retarded or something?" The classroom fills with chuckles and giggles, and then with laughter. A sixteen-year-old head, object of the derision, jerks again. Another string is pulled, and the shoulder twitches violently into the chair back. He mumbles something about being nervous about the quiz. More laughter. Clenching his teeth, the student waits. His worry about the upcoming quiz is blanketed by his desperation for the teacher to appear, for the bell to ring, and for the 50 minutes of peace that will follow.

\*\*\*\*\*

Two college students cross a campus quadrangle on their way to a physics class, where a mid-term exam awaits them. "Whatcha got on your shoe?" asks the taller of the two. "Oh, nuthin', just a foot itch and no time to stop and scratch," answers the student on the left. He has intentionally positioned himself to the left of his walking partner, hoping to shield the involuntary movements from notice. As they continue their trek, his left knee bends again and brings his foot up, and his left hand reaches behind him to slap the left side of his shoe heel. His foot then slams the ground, yet he never breaks his stride. The companion is curious, but makes no further query. Eight more times, before they reach their destination, the shorter man slaps his raised left heel, jerked up by the puppeteer, and stomps the ground with his left foot, in an effort to simulate a normal walk.

\*\*\*\*\*

In a kid-theme restaurant, a father emits a barely audible grunt and tightens his lip muscles around his mouth to mute the sounds that want to get out. His little boy, about three years old, watches. The sound is followed by a subtle but noticeable head jerk, and the father bounces ever so slightly on his booth bench. As the man calculates the gratuity for the guest check, he notices his son begin to sway his head from side to side, slowly at first, and then with more force. The boy stops and smiles his delighted silly-smile when he notices his father is watching. The man looks at his son with wonder, returns the glee with his own silly-smile, and reaches for his wallet. Is the toddler just mimicking his daddy? Or has his own puppeteer picked up his strings and begun to work? Although the father may not always know what to do, he is glad that he knows what not to do. He gathers his son into his arms, and they stop to laugh together at the huge balloon clown near the door.

\*\*\*\*\*

These four vignettes span thirty-six years of one life. The little boy whose wrist jerks, the teenager whose head snaps up, down, and sideways, the young man whose hand slaps his up-drawn heel, and the father who remembers not to watch his son too closely. They are all me.

Tourette syndrome is the puppet-master. This highly misunderstood and misrepresented disorder pulls the strings that invoke this strange behavior we call "tics." These are not isolated incidents, but snapshots of a life lived with Tourette syndrome. They have occurred hundreds, if not thousands of times over the course of my life. But these experiences are not mine alone. They are shared by many others with Tourette syndrome.

This book of first-person accounts is intended to allow you, the reader, to walk along with many people who have lived their entire lives in a state of "trying not to tic," knowing as no one else can that there is nothing they can do to prevent it. The feelings of embarrassment, shame, disgrace, and deceit that go along with Tourette syndrome are ruthless in their consistency and indescribable in their depth. All of these feelings emanate from the lack of knowledge, understanding, and acceptance by a world that frames those who are different.

More than just an intent to invoke empathy with suffering, however, what will come as you read these stories will be a sense of warmth - a comfort with your own discoveries to be found in them. Compassion is not just empathy or sympathy. It is understanding that, for people who are different, all it takes to ameliorate the damaging emotions that so often accompany their differences is simple acceptance. If one college friend on one college campus can brighten a day with the ability to observe, know, and be honestly sensitive to his friend's "oddness," it follows that a world full of such friends, known and unknown, can make the fright of being teased and ostracized disappear. These stories are not just for those whose lives are affected by Tourette syndrome. They are for all - to entertain, inform, educate, and bring a sense of acceptance - for only when it is as "okay" to have Tourettic tics as it is to have a limp from a football injury, will the puppet master's enslavement end.

Copyright © 2003 by Michael G. DeFilippo. All rights reserved.