Without Hesitation

Speaking to the Silence and the Science of Stuttering

Gerald A. Maguire, MD
with Lisa Gordon Wither

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The National Stuttering Association is a 501(c)(3) nonprofit organization, founded in 1977 and dedicated to bringing hope and empowerment to children and adults who stutter, their families, and professionals through support, education, advocacy, and research.

All profits from sales of *Without Hesitation: Speaking to the Silence and the Science of Stuttering* will be used to further the educational, clinical and research endeavors of the National Stuttering Association and Kirkup Center for the Medical Treatment of Stuttering at the University of California, Irvine School of Medicine.

First edition

His name was Demosthenes.

A child of ancient Athens, born to wealth in the year 384 BC, but orphaned young. A youth betrayed by the guardians charged with protecting him. And a young man possessed of both intellect and fearlessness yet cruelly mocked for a severe speech burden that presented in uncontrollable hesitation and word repetitions.

For solace, he escaped to the seaside, walking and resting and – always – listening to the thunder and whisper of the waves. And it was in these hours that Demosthenes slowly improved his speech. He learned to breathe in concert with the surf, to recite poetry to the rhythm of the ocean and the song of the sea winds.

Demosthenes would become known as one of the finest and most compelling orators and statesmen of his era, challenging the injustice forced upon his nation by men of war and unscrupulous politicians, at last dying by his own hand in 322 BC. And, despite the speech burden of his early years, Demosthenes' words would resound throughout ancient Athens and, one day, history – for he had learned to speak with clarity and commitment.

To speak without fear.

To speak without hesitation.

Member of the Club

Rare is the book about stuttering that doesn't reference Demosthenes and how he overcame his condition to rise to greatness. And why not? The anecdote is one of operatic proportion, resounding with all the elements of grand storytelling: persecution and perseverance, tragedy and triumph. People who hear the story can't help but respond.

As a physician dedicated to healing, I, too, am moved by the story of Demosthenes – but as a psychiatrist who spends the bulk of my practice time treating patients who stutter, I recognize the limitations within the narrative.

Seeing the complete picture and recognizing its restrictions: such is the life of the contemporary physician. Our time is spent merging sound science with common sense, reading between medicine's occasionally indistinct lines, integrating information from multiple sources and accepting that we can be thwarted by unforeseen limitations.

But, as all physicians learn, only certain limitations are necessary or unbreakable. Some exist merely because no one has yet pressed beyond them.

Medicine, you see, is about promise as well as purpose. Medicine's purpose? To heal. But moving beyond seemingly fixed limitations to give patients a chance at better health? *This* is medicine's promise.

I strive to communicate these concepts to the patients and medical students I see almost every day. The University of California, Irvine (UC Irvine) School of Medicine employs me as an Associate Professor of Clinical Psychiatry and Senior Associate Dean of Educational Affairs, for which I oversee the medical school curriculum and student affairs in addition to my role as a clinician, researcher and academic instructor.

In 2007, my role at UC Irvine expanded to include a position that may resonate with many people reading this book. That year I was appointed as the Kirkup Endowed Chair in Stuttering Treatment and the Director of the Kirkup Center for the Medical Treatment of Stuttering at UC Irvine – currently the only facility in the world dedicated exclusively to this specialized area of medicine.

The hundreds of emails and phone calls I receive each month, from residents of Southern California and from people living on the other side of the world, illuminate the profound need for a resource like the Kirkup Center. These communications are usually enthusiastic, occasionally poignant and always hopeful about developments in of Clinical Psychiatry and Senior Associate Dean of Educational Affairs, for which I oversee the medical school curriculum and student affairs in addition to my role as a clinician, researcher and academic instructor.

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I know this, too: before the end of my first interaction with these patients I'll have disappointed them. Each new patient – *every* new patient – asks me the same question: *Dr. Maguire, can you cure me*?

My answer is always the same: *No, I can't – because there is no cure for stuttering.*

Having a stutter is like belonging to a club that you wish would revoke your membership. It's a medical condition that shatters one of those fundamental expectations we have as human beings. People reasonably expect to converse with the same degree of ease required to blink. With stuttering, communication suddenly becomes an obstacle of significance rather than an action free of effort.

It's especially frustrating because stuttering is furtive in its appearance. Like a baby crying for no visible reason, stuttering presents in language without warning or expectation. Some people block – they freeze on the first sound of the first word. Others are affected by what we call bouncing, which is an inability to proceed past the initial sound of that first word.

Someone who stutters may have no trouble with articulating words of three or four syllables only to be stopped cold by the most uncomplicated of terms. Imagine being unable to say *thanks*. Or *Happy Mother's Day*. Or your name.

Imagine saying *the spoken word is my enemy*. People who stutter don't need to say it – but they think it almost without pause every day.

Imagine, too, being told *speak more slowly and you won't stutter*. Or learning you've been assigned to a remedial language-arts class because someone noticed your disfluency and thought *can't talk, probably can't read*. Imagine hearing the whispers that you never quite manage to avoid and the face-to-face comments like *why don't you try harder?* Remarks like these are among the gems often found in the *Illusory Dictionary for Those who Stutter* under the heading: *Stuttering, bad advice for*.

Sometimes, new patients will tell me how hard it is to live with stuttering – that I can't possibly understand how they feel or empathize with the reality of their pain. And my answer surprises them – if they haven't already recognized *my* reality. You see, I, too, am a member of the club.

I have no memories of a life without stuttering – of a time when words weren't a stumbling block, when I didn't have to choose my words with care or pause and consider which terms would roll off my tongue with the greatest fluency. On a scale of one to 10, I'd place my stuttering firmly at five – not so bad that I can't occasionally get by but bad enough that I've never been able to ignore its unwelcome presence in my life.

Stuttering has enormous and extended psychological impact. Parents may blame themselves for their child's speech difficulties and feel at a loss as to their role in managing the condition. Siblings can feel torn between resentment and protectiveness, establishing an imbalance within the family relationship. Strangers and recent acquaintances respond with impatience (most people who stutter can recall stories of service personnel whose exasperated facial expressions made it evident they were thinking *would you please get to the point?*) Even teachers may confuse fluency issues as a sign of substandard intellect and delayed development, although this is less of a concern as most contemporary educators recognize stuttering for what it is and are proactive in encouraging families to seek therapy.

And the person who stutters often feels ashamed – because if the hesitations and repetitions and the seemingly infinite silences that are inherent to stuttering weren't present then none of this would be an issue.

Do you stutter? If so, perhaps that sentence about educators erroneously linking stuttering to intellect or ability is not entirely unfamiliar. I experienced this in 1989, when I received instructor feedback during a medical school patient-interviewing session stating that my stutter caused people discomfort – a comment without

resolution as the feedback neglected to reveal who had expressed discomfort: patients, colleagues or administrators.

Several years later, while interviewing for my psychiatric residency at UC Irvine, one member of the selection committee asked why I thought I could become a psychiatrist as the field relies heavily on communication. I reminded him that listening is a greater virtue than speaking.

After completing my psychiatric residency and joining the UC Irvine faculty, I examined my application file and discovered that, despite what I thought had been a successful interview, this particular committee member had recorded a single comment. Actually, it was a single word: "stutters."

I'm sharing this history not as a plea for sympathy but to demonstrate the rather shocking lack of knowledge about stuttering that can exist even within the academic community, and how crucial it is for educators to ensure that a scholastic analysis of stuttering be part of the curriculum.

To what degree stuttering affects people varies. For some who stutter, the struggle to communicate poses little concern. They learn to work around their disfluency (this is particularly true with individuals whose stutters are relatively minor and who receive medical intervention at a young age), ignore it and, in some cases, find humor in it.

Others employ a variation of the disorder known as covert stuttering, during which certain feared or difficult terms, sounds and situations are avoided. In theory, this might seem like an effective way of managing disfluency; in practice, it may become an overwhelming process that dominates one's life with every statement requiring extreme forethought. Covert stuttering can lead people to suppress essential elements of their personalities resulting in the same dysfunction and despair that those with more severe outward symptoms experience.

And some who stutter simply shut down. They withdraw, making a painful choice to separate themselves from the disparagement and pity that stuttering often attracts and live at a standard that doesn't meet their true intellectual and social abilities.

I was lucky – I had an extremely supportive family, which made a colossal difference in how I perceived myself. Even so, I searched endlessly for solutions that might improve my speech, including a period of what I thought was divine intervention – something that occurred every Sunday morning when I was age eight and seated in the pews of St. Thomas Moore Church. I'd begin the litanies,

which consisted of my repeating certain phrases in rhythm and my stutter would vanish. I later learned that people who stutter often find their fluency improves temporarily when they repeat things in a chorus-style manner; then, it seemed miraculous. I conceded defeat only when I realized that my stutter reappeared as soon as the litanies were finished.

Of course, it wasn't a cure. Nor was it anything over which I could claim control since I had no comprehension of the process that drove my unexpected fluency. I was too young to understand anything more than my stutter would temporarily disappear – but the joy I felt in those too-brief moments never left me.

. . .

What is stuttering? Five million voices can speak to this.

A disorder that has defied physicians for centuries, stuttering claims as its own grade-school students and senior citizens, captains of industry and kings of nations, politicians, performers and professional athletes. It causes confusion in families, contempt in the uninformed and anguish in the approximately five million individuals in the United States who find it impossible to speak without effort.

There are no cures but there are solutions. And there is hope because of significant advancements in pharmacotherapy – the clinical treatment of stuttering with medication.

Without Hesitation: Speaking to the Silence and the Science of Stuttering explores the history, the heartache and the hope for this medical condition from an insider's perspective: a physician who has stuttered since childhood and knows how it feels to struggle with words and to express himself with ease.

Gerald A. Maguire, MD, is an Associate Professor of Clinical Psychiatry, the Kirkup Chair in Stuttering Treatment and the Senior Associate Dean for Educational Affairs at the University of California, Irvine (UC Irvine) School of Medicine. He serves as the director of the Kirkup Center for the Medical Treatment of Stuttering at UC Irvine – at present, the only facility in the world devoted wholly to this specialized area of medicine.

Dr. Maguire is a Diplomate of the American Board of Psychiatry and Neurology, Distinguished Fellow of the American Psychiatric Association and serves on the research advisory board for the National Stuttering Association. His research has been featured in many leading medical journals and he has presented at numerous conferences and symposia throughout the world. Dr. Maguire is the principal investigator in the clinical trial for pagoclone – the first medication developed specifically for the treatment of stuttering – underway at research centers throughout the United States.

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