

Playing His Hand

After being diagnosed with focal dystonia of his right hand, professional musician Billy McLaughlin relearned how to play the guitar —with his left.

BY TODD FARLEY

When Billy McLaughlin finally first heard the term “focal dystonia,” he had already been suffering from symptoms of the condition for more than two years. By that time—due to severe muscle spasms in his right hand—the world-renowned, classically trained guitarist had lost the ability to play his own music. He had dropped out of the public eye, “humiliated,” he says, by the loss of his profession and disheartened by the fact that no doctor could identify the problem.

Unfortunately, McLaughlin’s difficulties being diagnosed with dystonia are not the exception but the rule.

According to Stanley Fahn, M.D., professor of neurology and director of the Movement Disorders Division at the Neurological Institute at Columbia University in New York, NY, the term “dystonia” refers to sustained (and unwanted) muscle contractions and twisting movements. Focal dystonia involves the same type of muscle contractions but only in one specific part of the body. Most focal



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dystonias involve an abnormality with a relatively small part of the body, such as the face, neck, eyelids, vocal cords, or, as in McLaughlin’s case, the hand.

ON THE ROAD AGAIN

McLaughlin’s symptoms first became noticeable to him in 1998, shortly after he completed his second recording for Neurota records. It was a project that entailed new and extremely complicated finger techniques. “I started to notice some finger confusion,” McLaughlin says. “It was really baffling.” Adding to his puzzlement was an earlier slip and fall that resulted in two dislocated fingers. “Something was out of balance,” he says, “but I attributed it to swollen knuckles from the dislocation. I thought it was an orthopedic problem, not anything bigger than that.”

The fact that McLaughlin’s focal dystonia affected the hand he depended on to play music does not surprise Dr. Fahn. “People believe that overuse of the affected area creates more of a risk factor,” he says. “Musicians in general can be affected, usually in the important part of their body involved with their instrument.”

The misfiring of neurons in the brain seems to lead to the contractions of focal dystonia, while the overuse of certain muscles can increase the risk of the disease. However, the cause of the condition is described by doctors as “idiopathic” (of unknown cause). Mark Hallet, M.D., of the National Institute of Neurological Disorders and Stroke (NINDS) explains: “The focal dystonias are multifactorial. There’s not going to be a single cause. There isn’t any doubt that repetitive use is going to be a factor in a musician’s dystonia or hand dystonia in general. But it’s probably not the whole story.”

The road to diagnosis was a long one for McLaughlin. Though he knew his symptoms were real, the orthopedists, chiropractors, and acupuncturists who examined

him could find nothing wrong. “I set out on a two-year odyssey trying to figure out what was going on with me,” he recalls.

According to neurologists, focal dystonia can be difficult for some doctors to diagnose, because the diagnosis is purely clinical, and the condition is relatively uncommon. According to Dr. Hallet, “Many doctors—for example, general practitioners—probably wouldn’t see but one case every 10 years. Things that aren’t commonly encountered are hard to recognize, and you have to recognize the signs and symptoms of focal dystonia to diagnose it.” Focal dystonia of the hand may look like carpal tunnel syndrome or tendonitis. As a result, patients often go through a series of misdiagnoses before their symptoms are correctly identified.

THE DENIAL SONG

Coupled with McLaughlin’s frustration at the absence of a correct diagnosis was a growing sense of anxiety stemming from the fear that he was losing his ability to do the thing he loves most. He also worried that his fans had begun to notice a change. “As a solo guitarist, there’s no place to hide on stage,” McLaughlin says. “If you begin to hit wrong notes, everybody knows.”

“Pretty soon I couldn’t trust my fingers to repeat the motions necessary for my pieces. I had to omit certain songs from my shows,” McLaughlin says. As his symptoms worsened, the guitarist began to entertain the possibility of giving up his career. “I couldn’t face the audience, because they were expecting a high level of skill and craftsmanship,” he says. He describes this difficult time period as one in which he felt “disconnected.” He withdrew from music, from his fans, and from his social life.

“I began to think I was going crazy,” he recalls. “I felt utterly alone.”

Two years after his symptoms first began, McLaughlin finally visited a neurolo-



gist. Five minutes after he described his symptoms to the doctor, she diagnosed him with focal dystonia. “My first response was ‘What’s that? I have to play music!’” he says. Though the doctor cautioned McLaughlin that a heavy performance schedule would likely worsen his symptoms, he continued to perform and to practice between eight and 10 hours per day, hoping the symptoms would somehow disappear. “I was in a deep state of denial,” he says. “I didn’t have any other options for income.” Sure enough, the more he played, the worse McLaughlin’s symptoms became.

CROSSROADS

Although there is no cure for focal dystonia, certain medications aimed at balancing neurotransmitters help some people. Often the first drug administered belongs to a group that reduces the level of the neurotransmitter acetylcholine. Some people benefit from physical therapy, including the use of a brace on an affected area. Outside of the U.S., surgery and/or deep brain stimulation have proved beneficial.

In many cases, the most effective treatment is through botulinum toxin injections into the affected part of the body. However, these injections work to different extents in different people. Dr. Hallet explains: “These injections work less well in professional musicians. Even if they can get better, they can’t necessarily improve enough to go back to professional-level performance.”

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When botulinum toxin injections failed to reduce McLaughlin’s symptoms, he went to another neurologist for a second opinion. The diagnosis of focal dystonia was confirmed almost immediately, and McLaughlin’s attitude toward his condition changed. Faced with a crossroads in his life, he decided to meet his illness head on, referring to his “emergence from denial” as a “paradigm shift.” First, he decided to share with his fans the truth about his struggle.

“I went all those years without telling anyone in my fan base. I hid my problem because I was humiliated at losing my ability to play,” McLaughlin says. When he finally shared the words “focal dystonia” with his fans, they were overwhelmingly supportive. “The flood of encouragement was dramatic. I was receiving e-mails from people all over the world.”

McLaughlin also changed his focus. “I stopped concentrating on what didn’t work, and started focusing more on what *still* worked.” What still worked was his left hand. The musician set out to achieve the seemingly insurmountable goal of retraining himself as a virtuoso left-handed guitarist. While McLaughlin describes this grueling period as “a challenge in managing frustration and anxiety,” he ultimately succeeded.

COMING BACK ALIVE

Then, McLaughlin set another goal: to perform with an orchestra in front of a live audience. “It was such a test for me to see if I could handle all that,” he says. At that time, in 2004, some of McLaughlin’s fans approached him about documenting this comeback concert. Soon a documentary crew joined him on his journey back to performing.

“They wanted to see if I could pull it off,” he says. “At the point when they started shooting, I was awful. It was crazy.”

In late 2005, McLaughlin felt confident

enough to attempt a first performance. The concert, aptly named “Coming Back Alive,” consisted of a mixture of pieces, many composed by McLaughlin after his struggle with dystonia. (Go to billy-mclaughlin.com for CDs and DVDs.) Of his piece “Don’t know How to Die,” he says, “It’s a song about not giving up, about not knowing what to do with yourself if you aren’t doing what you know you’ve been put on earth to do.” He describes the piece as “deeply emotional,” and one he would not have written had he not gone through his struggle to keep playing music.



For this first concert performance, McLaughlin received high accolades from musicians and fans alike. The orchestra members, after completing their performance segment, remained to hear the second half of the show. “It meant a great deal to me because it said that the quality and the level of music-making were really high,” he says.

But the most important feedback, for McLaughlin, came from his longtime fans, whom he refers to as the “scholars” of his music. “They know where the music should go. They’re able to compare my performances at every level,” says McLaughlin. “Most of them said, ‘Billy, you looked more nervous than we’ve ever seen you, and we know why, but by the second or third song you were back to yourself, and the show was incredible.’”

In the back of McLaughlin’s mind is the fear that his condition will spread to his left hand. This is unlikely, according to Dr. Hallett. “Focal dystonia often remains focal,” he says. “The possibility of it spreading to the other hand is about 10 to 15 percent.” For McLaughlin, this possibility serves as a reminder for him not only to appreciate every performance he gives, but also to feel a “healthy sense of urgency” as far as his career is concerned.

These days, McLaughlin is committed to helping find what he refers to as “a cure for the lack of awareness” about dystonia. “I always talk about dystonia at my concerts,” he says. “I’d never heard the word until I was diagnosed with it, and I don’t want others to end up in the same scenario.”

McLaughlin began working with the Dystonia Medical Research Foundation (dystonia-foundation.org) by doing event-based volunteer work. He was soon invited to be their first “ambassador for awareness” (a position he refers to as “a wonderful role, a perfect fit”). His volunteer work, he says, has created for him a much-needed feeling of community. “I can explain to other people with dystonia what I’ve been going through and feel a connection based on our similar experiences.”

McLaughlin has also come to realize the dire need for greater awareness in the medical community. “I hear stories about kids whose pediatricians don’t recognize the symptoms, whose parents think they’re faking it. It’s a nightmare for these kids, to be trapped in an undiagnosed space.”

The guitarist is optimistic about the new therapies that are being researched, such as deep brain stimulation. He hopes they may help him regain his ability to play music with the hand that made him famous. If not, Billy McLaughlin will continue to make beautiful music with his *left* hand—and to tell the world about focal dystonia. NN