

Encore!

Billy McLaughlin's Remarkable Comeback



For more than three decades, world-renowned acoustic guitarist and composer Billy McLaughlin has dazzled audiences with his virtuosity and unique style, releasing 17 albums, winning five Minnesota music awards and recently earning an Emmy. But in 1998, a bizarre accident left him with an injury that began to affect his performances and ultimately threw his life into a tailspin: he lost his recording contracts, his agent, his income, his marriage and his home. McLaughlin would eventually be diagnosed with the incurable neuromuscular disease focal dystonia (FD), which causes muscles in the body to contract and spasm involuntarily. Though doctors urged him to find another career, the Minnesota-native took matters into his own hands—literally. He did what most musicians consider unimaginable: he re-learned the guitar, one note at a time, using his non-dominant hand. Since then, he's staged a successful comeback as a left-handed guitarist.

At a recent live streaming concert sponsored by the Dystonia Medical Research Foundation (DMRF) at San Diego State University, McLaughlin's unorthodox technique of placing both hands on the fretboard produced a unique and surprisingly big sound, as if there were multiple guitarists on stage. His music was deeply rhythmic and fluid, his new age compositions intricate and uplifting. Recently, *ABILITY*'s Paula Fitzgerald spoke with him about his long journey back to center stage.

Paula Fitzgerald: Tell me about the accident that changed your life.

Billy McLaughlin: In 1998, I was on my way to a photo shoot for the cover of my second album for Narada Records when I fell on an icy sidewalk: I dislocated the middle finger and ring finger on the hand I used to play my fretboard. When we finished the shoot, I needed immediate physical therapy because I was leaving in just a couple of months to start a back-to-back, 50-city tour to support the release of my new CD. This tour included a lot of television and radio performances, as well as interviews. I managed to rehab in time so that I didn't have to reschedule any of the dates, but I still noticed stiffness in my fingers that I associated with the injury.

After the second leg of the tour, the swelling had gone down and my fingers felt normal, but I started to feel something was out of balance. I was still struggling with a couple of my more virtuosic pieces. When you're playing solo guitar concerts, it's very embarrassing to have a slip-up here and there. After talking with colleagues and mentors, everyone said, "Gee, Billy, you're the hardest-working guitar player out there. Take a break. Take a couple months off and let your hands rest."

Fitzgerald: Did you heed their advice?

McLaughlin: I took two months off, but when I started to play again, the symptoms were dramatically worse. I

started experiencing a curling of my pinkie and middle fingers, leaving them inoperable and me unable to perform. I struggled with it. Musicians always depend on one thing to help them get better, and that's practice. You practice and practice until you fix the problem.

I went to a hand specialist and also an orthopedic specialist, thinking it might be carpal tunnel. After the X-rays and MRIs came back, they said, "There's nothing wrong with you. Maybe you need to see a psychologist," which I found to be very offensive. I knew something was wrong with my hand. So I spent the next two-and-half years going to chiropractors, massage therapists, Rolfers, acupuncturists and acupressurists.

Fitzgerald: Were you still playing through this period, or did you stop altogether?

McLaughlin: I continued to play what I could play. I left out the very difficult pieces. I would tell my audiences, "I'm sick of that song; I don't want to play it any more," to their disappointment. Eventually I started canceling the higher-profile concerts—where I made the most income—to play club gigs. I went back to being a singer-songwriter and to performing everything from Bob Marley to Jimmy Buffett to Peter Gabriel, just to make a living. Those guitar parts are not as demanding as what I usually played, but I needed to continue to work, because I've only ever made a living as a performing musician.

In 2001, I went to Dr. Jennine Speier at the Sister Kenny's Musicians' Clinic [now the Courage Kenny Rehabilitation Institute] in Minneapolis. Because of her vast experience with orchestral musicians who also push themselves to the highest level of dexterity, she took one look at my hand and said, "I know just what that is," she told me. "It's called dystonia, and it's not in your hand, it's in your brain, and it's not going to get better, so you'd better think about what you want to do with the rest of your life." I had never heard of dystonia, and little did I know that with all the practicing that I was doing, I was probably intensifying the onset of the symptoms.

Fitzgerald: For a musician, that must have been a shocking diagnosis.

McLaughlin: Initially I was relieved to have a diagnosis and to know that I wasn't going crazy. There was so much discussion and whispering, "What's wrong with Billy? Does he have a drug or alcohol problem?" That's the first thing you think of with a musician, right?

Fitzgerald: That's certainly the stereotype.

McLaughlin: For me to understand that it wasn't in my hand but the way my brain was feeding messages from my nerves was an important revelation. I learned that there weren't any viable therapies and that my condition





McLaughlin playing guitar in his adapted unorthodox style.

was going to get worse, and it did. It continued to progress to the point where I couldn't even play club gigs anymore.

Fitzgerald: Had you been diagnosed right away, do you think you would have done anything differently?

McLaughlin: No. Even if it had been diagnosed earlier, I was still faced with a tough situation, which is, "Gee, music is my identity, my passion, my livelihood." Honestly, I went home from that initial diagnosis and made up my mind that my neurologist was wrong. I went into denial, and for about another year I tried to practice my way out of the problem. I sought a second opinion at the Neurology Department and Movement Disorder Clinic at the Mayo Clinic, and they confirmed the dystonia diagnosis. They said, "You got an excellent diagnosis. Dystonia is exactly what we think you have."

From there, I reached out to [classical pianist and conductor] Leon Fleisher. I had of course immediately gone on the Internet and found the Dystonia Medical Research Foundation (DMRF) and realized that there was a community of people who understood what I had, who lived with it. Many of them suffer more than I do, but it's certainly affected my life to the core. But interestingly enough, one of my guitar students came to me and said, "My uncle is a piano player, and he's got what you have. You should call him." I said, "What's

your uncle's name?" and he said, "Leon Fleisher," who I'd read about in the DMRF's *Dystonia Dialogue* newsletter!

Fitzgerald: (laughs) Oh, my!

McLaughlin: I said, "I'd love to call him." And he said, "Let me call him today and make sure he's home," and he called back and said, "Yeah, Leon wants to talk to you. Call him tonight after dinner." Leon Fleisher is a very kind-hearted, generous person. I only spoke with him once, but he talked at length about what to expect. He described the treatments that helped him play again, and I took up the same course of therapy, which involved attending the National Institutes of Health's Botox clinic. Dr. Barbara Karp, who also treats Leon, treated me. I went through three rounds of Botox treatments, which is supposed to reduce the symptoms. But over the course of 18 months, I never noticed any change.

At that point, I was just burnt out on therapy and tired of being disappointed. That's when I decided to go the adaptive route. My story doesn't include any kind of cure for dystonia. My symptoms are as bad today as they've ever been, but because the skill set is so different from one hand to the next on the guitar, I've been able to recapture—at a very high level—a certain percentage of my compositions, which is enough for me to resume my career. And I've been writing music again,



using the skill set that I do have. So I'm living with my dystonia in the most positive way that I can, until maybe some new therapy comes along that leads to a cure.

Fitzgerald: I was recently on the Musicians with Dystonia bulletin board, and a few people wrote about having some success with slow-down exercises, which is practicing movements that are below the threshold at which dystonia first starts. Did you try anything like that?

McLaughlin: I did, and it didn't work for me. I am aware of one or two musicians who had some positive results from that but not many. And the main person I'm thinking of is very, very clear in describing that he can still feel that the dystonia is there, and he has to be very careful in how aggressively he plays.

Fitzgerald: What else did Leon Fleisher say to you?

McLaughlin: He said, "Billy, with Botox and Rolfing, you can regain some of your skills, but it's never going to feel the same." In his experience, he echoes what this violinist friend of mine says, which is, he can tell it's always there, and he's compensating for it. He was encouraging me to look at other ways to stay involved in music, if it turned out that I didn't have success with my conversion to playing with my left hand. He said, "Music is still there to be enjoyed, whether you're performing or not." He got into conducting for years, of course, and was very successful at that and enjoyed it. That was the gist of our conversation.

Fitzgerald: So when did you make up your mind to relearn everything using your other hand?

McLaughlin: Before the diagnosis, the idea popped into my head that I might have to learn to play left handed, and I just dismissed it because it's a mortifying prospect. In fact, I would love to approach different musicians or professional athletes, such as Tiger Woods, and ask: What do you think it would be like to have to re-learn your sport as a left-handed player, stay competitive enough to support your family and achieve your dreams? I'd love to hear their answers. Tiger is so passionate about his sport that his experience of trying to relearn golf would be similar to what I've been through. You start practicing with the other hand, and it's just so frustrating; I quit many, many times because I was overwhelmed by the challenge.

Fitzgerald: I'm fascinated by the fact that you successfully re-learned all your music. You had your right-handed guitar adapted for left-hand use, right?

McLaughlin: Yes. Now my healthy hand is up on the fretboard doing all the movement across the strings, and I play in an unusual style that I've developed. But I still haven't re-learned all my music. There's a good 65 percent of my compositions that I still cannot play properly. There's a certain body of my work that involves an

unorthodox technique, and luckily I had developed that as a healthy right-handed player, and those are the pieces that I feature in my work now.

Fitzgerald: How did you support yourself through years of not performing?

McLaughlin: I was passionate about being a small-business person and realized early on that I was responsible for my own future. I was lucky enough to pay attention to accounting and to know how revenue came in and went out. I built up great credit prior to the onset of my dystonia, and I subsequently went into a deep hole with credit thereafter. I directed music programs at churches, which was a great opportunity for me to teach experiential music to students from preschool through 4th grade at a Montessori school, where my son was going to school. It didn't pay a lot of money, but it kept the lights on. I was also a consultant and manager for another artist here in Minneapolis, but quite honestly, I amassed a tremendous revolving credit debt that I continue to work out today.

I wasn't willing to declare bankruptcy as my accountant suggested, and I've never been on government assistance. I'm self-employed, and I don't know what's going to happen next. It's very much like pro sports; that's part of the reason I enjoy the distraction of watching professional athletes, because they're in the same boat that I have been in, where you're only as good as you were in your last game. I had to invest in myself, and I continue to believe there's a better tomorrow ahead. I have to believe 2014 is going to be the best year I've ever had, but I have to show up, do the work and uphold a standard of excellence in everything I do.

Fitzgerald: Does it feel completely different or awkward to play on the opposite side, so to speak?

McLaughlin: Not anymore! It feels so comfortable. But it took a long time. I found myself having to practice what I preached as a teacher and go through the steps, because nobody can practice for you. Nobody can make you a better musician. A lot of hard work goes into it. It was a long, lonely road there for a while.

Fitzgerald: I'm sure it was. I have focal hand dystonia, and as a writer, it has deeply affected me. Fortunately, I type well, but some days, even writing my address is a challenge.

McLaughlin: Oh, my gosh!

Fitzgerald: I wasn't falling apart in front of thousands of people like you, but I have found dystonia to be a very isolating experience, especially since so few have heard of it. Do you find that some days are inexplicably less symptomatic than others?

McLaughlin: Yes, so I haven't completely given up on





playing the guitar right-handed. I've adapted and found some different ways to tune the guitar so that I can continue to play right-handed with the limited set of two-fingered arrangements, which are still lot of fun to play. I've not given up hope that I'll be able to play with my right hand again. I've had some encouragement from overseas musicians, particularly in Spain and Argentina; they're encouraging me to spend some time with brain remapping, like the slow-practice method.

I'm hoping at some point, as my income and finances stabilize, that I'll have the time to really devote myself to exploring that because there are some folks who are claiming that there is a way to get past it. Classical guitarist David Leisner has dystonia not in his fretboard hand, but in his plucking hand, and he has been able to re-establish healthy movement in it. So there are some options out there. I find so much joy in what I'm doing now that I guess I'm taking a little time to revel in what I've accomplished. I'll tackle that next challenge when I feel ready for it! *(laughs)*

Fitzgerald: Sure, I don't blame you.

McLaughlin: To win an Emmy after dystonia affected my life is something I never would have expected. I'm indebted to so many people who believed that there was importance in the story and in the music. To have an Emmy on my mantelpiece right now is quite a surprise and very humbling, and I'm very proud of it.

[McLaughlin won in the category of Musical Composition/Arrangement for "Billy McLaughlin: Starry Night with Orchestra Nova," produced by KPBS San Diego].

Fitzgerald: Congratulations! That's quite an achievement.

McLaughlin: It took a big team of talented and dedicated people, and I'm proud of the hard work that everybody put into it, especially conductor Jung-Ho Pak and producer Maura Daly Phinney. I'm so lucky.

Fitzgerald: Do you think anything in your past helped prepare you for this uphill battle?

McLaughlin: Yeah. My dad was a straight commission salesman in the specialty chemical and metallurgical field. He grew up without a father because during the Depression his father had been murdered. The people who killed him knew his payday was on Friday, so they mugged him. My folks just really impressed upon all nine of us kids that there's nobody who can make a bigger difference in your life than you can.

As a musician you really connect with that truth, especially when you teach music. You realize that the people who have the most fun learning music are the ones who actually invest in themselves by practicing. So the work ethic example that my dad and mom shared with me is that you never know what's going to happen, so you have to be self-reliant. If you're going to be good at guitar, then you have to play the guitar. There's no middle ground.

Dealing with focal dystonia took me back to the beginning. I continue to love the guitar, and there's no substitute for practice. But you have to be kind to yourself because it takes a while, and you can't look for that immediate gratification. With patience, you can hopefully attain what you want.



Fitzgerald: Are you still involved with the DMRF?

McLaughlin: Very involved. One of the great things in connecting with them is knowing that a community of people exist who understand this disorder on a first-hand basis. I literally went to my first DMRF meeting and was surrounded by people with various forms of dystonia, and I immediately felt at home. I felt like, "My God, I've found my people!"

Fitzgerald: Exactly! It's like finding your tribe.

McLaughlin: It's really powerful to go from feeling completely isolated and alone to finding people who understand. I became more interested in talking with Janet Hieshetter, DMRF's executive director. We realized that the nature of my work is ideal for helping educate people and raise awareness, so I continue on the board of directors ex-officio, which means I'm not a voting member on resolutions, but I'm at the board meetings as often as I can be.

When I speak to audiences, I say: "Raise your hand if you've ever heard of dystonia." Rarely does a hand go up. It's a movement disorder that affects more people than you'd imagine given how unaware the general public is about it.

Fitzgerald: Do you know if the disorder is genetic?

McLaughlin: At the last science meeting of the board, I believe we're up to 19 different genetic markers for different forms of dystonia. The knowledge that there's a genetic component doesn't necessarily provide any meaningful therapeutic change in protocol. But I'm sure, eventually, when more genetic-level medicine emerges as therapeutic, that that information will be very important.

Fitzgerald: So what's on the horizon for you? I read that you have a book coming out.

McLaughlin: Yeah. I've had a lot of other things that have kept me from wrapping it up, but I'm committed to getting it done sometime this year. My current focus is on guitar and orchestra collaborations, as well as live performances but less on cranking out a record. I do continue to compose, and I arrange an annual Christmas program called "SimpleGifts" that has taken on a life of its own. I started the project when it was one of the only things I could do to keep playing, and it now has its own website, and we have an annual tour. Part of me takes great pleasure being an ambassador, but I just love to play music, too. That's what brings me my greatest joy. ■

by Paula Fitzgerald

Billymclaughlin.com
Dystonia-foundation.org
Focaldystonia.co.uk
simplegiftsmusic.net

THE STATE OF DYSTONIA

"You can't buy a ticket to dystonia," Billy McLaughlin jokingly tells audiences, but he certainly knows what it's like to live there. The movement disorder that sounds like a tiny country in Eastern Europe is in fact a dreaded diagnosis for musicians. Approximately one in 200 of them are afflicted with focal dystonia (FD), a movement disorder that causes muscles to contract and spasm involuntarily. Roughly 300,000 people in the US suffer from some form of it. Sometimes for a musician, the condition arrives gradually, often in the form of muscle stiffness, spasms and/or twitching. A note is missed or a finger slips—and it can prove devastating to a professional musician's career.

Dystonia is one of many movement disorders that include diseases such as Parkinson's, and it's categorized as either primary or secondary. "Primary dystonia is inherited, meaning at least one gene has been discovered," explains E. Thomas Chappel, MD. "Secondary dystonia is due to damage to a part of the brain called the basal ganglia, where most movement disorders arise. This damage can result from trauma, stroke, tumor, infection or toxicities."

FD occurs when the basal ganglia fails to transmit information properly to a given body part, resulting in uncontrolled movements or spasms. While there are different forms of dystonia, from generalized dystonia, which affects many body parts simultaneously, to cervical, the most common form—FD is task-specific, meaning it occurs only when doing often repetitive tasks, such as writing or playing music. Dystonia's underlying causes remain something of a mystery, despite the fact that it's the third most common movement disorder in the US. A progressive disease, it affects men, women and children of all ages.

While treatments exist similar to those used for other movement disorders, such as botulinum injections, oral medications, surgery, physical and occupational therapies, full recovery is rare. Medications used to enhance or replace the brain chemical dopamine, which is deficient in the basal ganglia of patients with movement disorders, are sometimes effective. Surgical treatment of movement disorders involves actually destroying areas of the brain that increase the symptoms, or placing a stimulator in an area that will diminish the symptoms.

Unlike Parkinson's, dystonia can be hard to pinpoint, and it can take years before patients are correctly diagnosed. In fact, up until the mid-20th century, patients with dystonia were often diagnosed as having hysteria, meaning the condition was considered a psychogenic disorder. Today, it takes on average three to five years for a patient to receive a diagnosis, which is down from five to eight years, according to Janet Hieshetter, executive director of the Dystonia Medical Research Foundation (DMRF). The key to an accurate diagnosis, however, is finding a movement disorder specialist. Although more treatment options are available now than in the past, research on dystonia remains painstakingly slow as Hieshetter acknowledges. "There are some new treatments on the horizon, getting the pharmaceutical industry to commit to and follow through on clinical trials is tough, but we're very optimistic."

McLaughlin, whose career was derailed with the onset of FD, now crusades to raise awareness of dystonia. He's been the subject of the award-winning documentary by director Suzanne Jurva, *Changing Keys—Billy McLaughlin and the Mysteries of Dystonia*, which chronicles his emotional and physical odyssey. In 2010, the DMRF named him their first Ambassador for Public Awareness. He's also a recipient of the American Academy of Neurology's 2010 Leadership in Public Neurology Award, an accomplishment he shares with Julie Andrews, Michael J. Fox and Paul Allen. ■ **ABILITY**