Out of Control
Finding Peace of Mind When Your Body is Running Your Life

“I feel I maintain a sense of balance, but in some fashion dystonia is always in control. I have to take meds every six hours and breakthrough meds sooner if I start to feel an attack coming on. My dystonia is well controlled, but I always feel like it’s calling the shots to some degree because I cannot predict whether or not an attack will happen.”

~ Jenelle Dorner, PhD, Neuroscientist & diagnosed with secondary dystonia due to mitochondrial disease

Dystonia takes away a person’s ability to be in complete control of his/her body. The brain—the body’s command center—is overridden by chaotic signals that cause the muscles to contract and move involuntarily. The chronic, unpredictable nature of symptoms can make individuals with dystonia feel as though the disorder is the prominent force governing their lives. The dystonia experience may include mobility problems, communication difficulties, pain, medication side effects, and inconsistent response to treatment. These complications intensify the universal challenges of family, relationships, work, school, and everyday living.

Research has shown there are three particularly challenging psychological stressors that commonly face people with a chronic disorder: a sense of powerlessness, loss of control, and a loss of hope. A spiral into depression and helplessness can be both physically and mentally debilitating. Protecting against these negative effects can help promote a greater sense of peace and balance.

Life Turned Upside Down

“There are no easy adjustments when your life is turned upside down,” shares DMRF Vice President of Support and psychologist, Karen K. Ross, PhD. “Our family was overwhelmed with my son’s diagnosis of early onset dystonia more than 35 years ago. We didn't have the DMRF or support groups—or even doctors who knew about dystonia. I think everyone in the family suffered from shock and feelings of helplessness.”

Adjusting to life with a chronic illness is a grief process, much like mourning a death. Dr. Ross recommends embracing a “patient active” concept (adapted from the cancer support community) as a guide for how individuals and families impacted by dystonia can navigate the experience. “The patient active concept is about feeling and acting empowered to do whatever is required to improve the quality of your life,” she explains. “A patient active approach is made up of the feelings, actions, and attitudes that move a person from being a ‘patient’ to an ‘active’ participant in their health and in their life.”

Stress management is critical. Dr. Ross explains, “It’s essential to find ways, on a daily basis, to calm the chemical reactions going on in your body when stress is triggered. We need to do this for our body and for our brains.” Physical exercise, for example, as a beneficial physiological effect. There are more tools for overall wellness available now than ever before: numerous styles of stress reduction and meditation, adapted exercise programs, web-based videos and podcasts, and even counseling and coaching via phone or online.

“My belief is that anyone going through a major change in their life, such as dealing with a physical disorder, can benefit from some kind of professional help,” says Dr. Ross. “A therapist, online coach, or spiritual leader can provide empathy, support, and feedback to help you achieve a sense of well-being and help you nurture compassion for yourself.”
Finding the New Normal

For 20 years, Reverend Mike Beck has been “living in a body with a mind of its own.” He is diagnosed with several focal dystonias, each with distinct symptoms and challenges. He developed spasmodic dysphonia (dystonia of the vocal cord muscles) in 1992, and hand dystonia about a year later. In 2003, blepharospasm appeared (causing excessive blinking and forced closure of the eyes) and oromandibular dystonia followed (causing involuntary movements in the jaw and face). Just as he would adapt to one diagnosis, the dystonia surfaced in another set of muscles. His relationship with the disorder began to resemble a chess match: two opponents trying to out maneuver the other, his body the playing board.

For information on support resources available through the DMRF, visit www.dystonia-foundation.org/support

Continued on page 22
Continued from page 21

“You have to learn to live one day at a time,” he says. “And that is not easy.” As a church leader, Rev. Mike had devoted his life to a busy vocation that required him to speak before crowds of parishioners, drive to the hospital in urgent situations, and attend to families in distress. Dystonia eroded his ability to do all of these by making his voice unreliable, impairing his vision, and even diminishing his range of facial expressions. Despite years of managing dystonia through proactive medical care and creative problem-solving, he stepped down from leading his congregation in 2006. “The decision to leave my ministry wasn’t an easy decision to make, but the dystonia really made the decision for me. I didn’t want to do it, but I didn’t have a choice.”

“From a knowledge and perspective standpoint, my professional training has helped me cope,” he explains, “but no matter how much you know, when it’s you that is walking the hard road, you are a fellow struggler. In many ways I had to learn to deal with loss as a beginner.”

And so, as he had done for years prior, Rev. Mike was once again faced with the challenge to re-invent himself to accommodate dystonia. He says, “In terms of dealing with the ups and downs, the first thing to realize is that life will never be the same after the diagnosis. It’s going to be hard. You have to try to keep a positive state of mind. Ask yourself, will this experience make me bitter or better? Is my life half-empty or half-full?”

Later in 2006, several months after deep brain stimulation (DBS), Rev. Mike was facing one of the darkest periods in his life. After an exhilarating—but brief—reprieve from his symptoms immediately following surgery, the process for finding his optimal DBS settings was proving long and daunting. He recalls an appointment with his programming nurse: “She realized how discouraged I was. She taught me something critically important. She said, ‘You’ll probably never be able to do what you did before, but you still have value. You are not your illness.’” Rev. Mike recalls this as an extremely influential moment that provided a sense of peace and helped reset his outlook for the future.

After a year of adjustments to the DBS settings, the blepharospasm and oromandibular symptoms improved somewhat. Rev. Mike continues to receive botulinum neurotoxin injections in his vocal cord muscles, eyes, and hand. He remains involved in ministry by guest speaking, leading workshops, and teaching short-term classes. He channeled the creativity he once put into writing sermons into authoring books. He credits dystonia with fortifying his capacity for gratitude, humility, and sense of humor.

“Finding your new normal, it takes time to get there. There will be numerous times you’ll get discouraged. When it comes to feelings, we tend to think of ‘good’ feelings and ‘bad’ feelings. Feelings are just feelings—what you do with them is what’s important.”

Karen K. Ross, PhD serves as the Vice President of Support on the volunteer Board of Directors for the DMRF. She is a clinical psychologist and marriage and family therapist formerly in private practice in California. Karen began working with the DMRF since the very early stages of the organization, soon after her son was diagnosed. She authored the book Holding the Hope: A Parent’s Guide to Living with Dystonia. She created two relaxation/meditation audio programs for dystonia-affected individuals and caregivers, available through the DMRF. She is a frequent contributor to the Dystonia Dialogue and presenter at DMRF events. Her son is grown and benefitted greatly from deep brain stimulation surgery.

Rev. Mike Beck’s journey with multiple focal dystonias has required him to constantly adjust to new challenges.

Rev. Mike Beck earned degrees from Taylor University, Butler University, and Asbury Theological Seminary. For 25 years, Rev. Mike served churches in Greensburg, Corydon, and Franklin, Indiana. He is the author of No Longer Silent: Doing Pastoral Ministry with Excellence and Grace. His second book, Living in a Body With a Mind of its Own: The Emotional Journey of Dystonia, is scheduled to be published in the summer of 2013. Rev. Mike and his wife Mickey have been married for over 40 years. They have two sons and four grandchildren.