Looking Inward, Reaching Out: Dystonia & Isolation

In a recent survey among individuals reporting a wide spectrum of dystonia diagnoses, 84% stated they have felt isolated because of the disorder. Loneliness and feelings of isolation are common among individuals with chronic illness, so it is not surprising that individuals in the dystonia community reflect this tendency. A recurring sentiment among survey participants is that the symptoms and diagnosis of dystonia make them feel “different” and therefore separate from other people—even loved ones. The onset of dystonia often sparks an intense period of reflection about one’s life, relationships, career, future, and sense of self.

The onset of dystonia marks an induction into a new community. The Dystonia Medical Research Foundation (DMRF) offers opportunities to connect with others who know firsthand what it is like to live with the disorder. There are resources in place to help individuals with dystonia communicate with one another and build networks of support. No one has to face dystonia alone, even though at times it may feel that way.

Social Movements
Carol Smith was diagnosed with childhood onset dystonia as an adult, shortly after a sibling was diagnosed. “I’ve had problems moving my whole life, but it was normal for me. I couldn’t understand all the staring,” she explains. “The symptoms I displayed as a child were considered my fault—I wasn’t ‘picking up my feet.’ I fell up the stairs, I fell down the stairs. I walked with a peculiar gait, always in a hurry. I found it easier to run than to walk.”

As a nationally certified Licensed Professional Counselor with special expertise in grief and loss, Carol has been exposed both professionally and within her own family to the various forms dystonia can take as well as the ways in which different people respond to symptoms and diagnosis. She suggests a play on words to highlight how dystonia has both a physical and emotional impact: “This is a movement disorder. We need to pay attention to how it moves us, not only physically but psychologically.”

There are a number of ways in which dystonia can make it challenging to socialize or feel connected to other people. Symptoms may make it difficult to walk, sit, speak, or see. Dystonia may be painful. The uncontrollable and constant muscle contractions are often exhausting. It is not uncommon for people who are not informed about dystonia to mistake symptoms for signs of substance abuse, mental impairment, or bad manners—and this can lead to any number of unpleasant social situations.

Carol acknowledges, “there is a fine line between being noticed and being affirmed. We want to be noticed, but not for something that’s wrong with us. And yet, if my meds are working and the symptoms aren’t on display all the time, people are suspicious.”

Dystonia can also cause complications in terms of transportation, finances, and (in)accessibility of public spaces. Living with dystonia requires frequent problem-solving, and brainstorming creative new ways to accomplish tasks.

Carol cautions to be mindful of avoidance. Depression, anxiety, and anticipating judgment from other people may cause individuals with dystonia to withdraw. “When a person feels exposed or misunderstood, minimized or discarded, there aren’t too many ways to address that or even redirect it,” she explains. “It’s essential for us not to
take that personally. It is easier to avoid social situations and very normal to ask ourselves Why participate? Why go to all that trouble? The answer is simple: Because we can, and we will. We are not ‘less than.’ Coping requires a healthy reality check of what we can do, and when—in contrast to others’ perceptions of what’s wrong with us.”

The DMRF offers several options to start connecting within and beyond the dystonia community.

Support Groups
A DMRF support group connects you to other people who understand life with dystonia, and provides access to the latest information on research and treatment. Chandler Shumate has lived with cervical dystonia since the early 1970s and discovered the Dystonia Support and Advocacy Group of San Diego County in 1987, 14 years after his diagnosis. “At a support group meeting,” he explains, “you learn the little things people do to cope with their symptoms and think, Hmm, I didn’t know that. Maybe that will help me.”

If there isn’t a support group in your area, consider starting one. The DMRF is happy to walk through the process of establishing and leading a support group with interested parties. For more information on support groups, call 312-755-0198 or email dystonia@dystonia-foundation.org

Online Forums
The Internet is a valuable resource for communicating with others in the community. Online dystonia forums are support services that are available

Tips for Avoiding Isolation
• Seek expert medical care. Better controlled symptoms may mean greater social freedom. Consulting a properly trained doctor with experience treating dystonia can make a significant difference in managing symptoms, pain, and fatigue.

• When you feel isolated, communicate what you are feeling to family and friends. Talk to your doctor about feelings of depression and anxiety.

• Keep a journal of symptoms and feelings to help identify patterns about what make a “good” or “bad” day, allowing you to be better prepared for either occurrence.

• Enlist a family member or friend to help you explore new opportunities or try new activities.

• Identify specific obstacles. Step back and examine what is preventing you from feeling connected or participating in an activity and explore ways around those impediments.

• Beware of talking yourself out of opportunities. When you choose to opt out of an activity, take a moment to step back and imagine the outcome you are trying to avoid. Are you anticipating a catastrophe, a frustration, or an inconvenience? A catastrophe may very well be a situation to avoid, while a frustration may be something you can handle with a little planning. An inconvenience may be something you can deal with relatively easily.

• Reach out online. If you don’t have internet access at home, perhaps there are opportunities at a local library, community college, or other public space.

• Is there assistive technology that might be helpful for you? If typing is difficult, is voice-response software an option? If speaking is difficult, could a typing device or voice amplifier help? What about a mobility aid for walking or balance?

• If getting from place to place is a challenge, is public transit an option? Is there a local organization that can help you access transportation? Can you enlist the help of family or friends?

• Be your own best friend and advocate. Encourage yourself to learn or invent new ways of doing things.

• Reach out to the DMRF. Join the mail and email lists so you are aware of meetings, support groups, campaigns, and resources that may appeal to you. There are ways to be actively engaged with the DMRF without necessarily traveling or a large time commitment.
Battery Powered Person: Pat Brogan Refuses to Let Dystonia Win

Ten years ago, basketball coach Pat Brogan was training for a triathlon. On a September morning in 2001, he was struck by a hit-and-run driver while riding his bicycle to the local YMCA. He sustained a concussion, brain and spinal contusions, and severe injuries to his face. Months into his recovery, Pat began developing inexplicable pain and postures in his neck. After consulting multiple doctors, he was ultimately diagnosed with dystonia. For a decade, Pat has white-knuckled his way through escalating dystonia and complications from deep brain stimulation surgery. He literally had to relearn how to use his body and invent new ways to coach and compete. In September of this year, Pat completed The Dewey Beach Spring Triathlon: half-mile swim, 15 mile bike race, 3.5 mile run. He is also back to coaching basketball.

When Alison Guzzio met Pat through a mutual friend, she was so taken by his story and dystonia advocacy efforts that she developed a team that vowed to help. With the help of Nadiene Friedrich, Brad Verrico, and Megan Burns, they created a short film entitled Battery Powered that chronicles Pat’s experience at the Dewey Beach triathlon. They hope the film will impact dystonia fundraising efforts and bring awareness to Pat’s upcoming event, the 9th Annual Help Find A Cure 4 Dystonia Benefit, December 21, 2012 in Hazleton, Pennsylvania.

Learn more about Pat’s story and view Battery Powered at http://www.dystonia-foundation.org/patbrogan. For information about the Help Find A Cure 4 Dystonia Benefit and other DMRF events, go to: http://www.dystonia-foundation.org/events

Symposia & Community Meetings
The DMRF offers a schedule of symposia and meetings for individuals with all forms of dystonia as well as family members and friends. Each year, the DMRF hosts a regional dystonia symposium in a different part of the country, and half-day community educational forums in numerous communities. The DMRF also hosts a national symposium for children and families. For the latest listing of scheduled events, go to: http://www.dystonia-foundation.org/events

Sharing Your Story
Sharing your story is a way to connect with other people. Your story is also a powerful instrument for improving dystonia awareness. Imagine if you began, one person at a time, helping people better understand dystonia? It can start with a neighbor or the server at a favorite restaurant. When Scottie Roberts of California explained that dystonia was the reason he coached his son’s T-ball team from a wheelchair to the team’s parents, he discovered that one of the mothers had an affected family member. You never know who you might touch by sharing a bit of your story. For more info: http://www.dystonia-foundation.org/face2face

For More Information
Contact the DMRF to learn more about the resources available to help you feel connected. You can reach us at:
• 800-377-DYST (3978)
• dystonia@dystonia-foundation.org
• http://www.dystonia-foundation.org/

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24 hours a day, seven days a week, to people all over the world. “I used to feel much more isolated and lonely with my generalized dystonia,” explains Ian Thomson of Wisconsin. “The DMRF Facebook pages opened a world up for me. Now I participate daily in the discussions with other patients. We give each other emotional support, hope, ideas to discuss with our health care professionals—and we know that we’re not alone.” For more info on joining the DMRF’s online groups, go to: http://www.dystonia-foundation.org/online

Sign Up for Updates to Your Mobile Phone
The DMRF is now able to send updates on activities and events directly to your phone. To sign up for DMRF text alerts, scan this code with your smartphone or text DYSTONIA to 90999.