



# A Friend Indeed

## *Dystonia, Social Isolation, & Friendship*

In a DMRF survey, 84% of people with dystonia stated they have felt isolated because of the disorder. Loneliness and feelings of isolation are also common among spouses, family members, and the parents of children with dystonia. There is a growing body of research to suggest feeling lonely can have a powerful effect on health. Physicians are increasingly recognizing friendships and social connections as important prescriptions for patients.

The Dystonia Medical Research Foundation (DMRF) offers opportunities to connect with others impacted by dystonia and build networks for coping support.

### **Impact of Dystonia on Social Connections**

There are numerous ways in which dystonia can make it more challenging to feel connected to other people. Tom Seaman knows this firsthand. Within less than a year, the active entrepreneur went from noticing a little stiffness in his neck to spending nearly 24 hours a day on the floor with relentless, chronic pain. Cervical dystonia turned his life upside down. Now a Professional Life/Health Coach, he uses his experiences to help others address the complexities of living with chronic illness, depression, anxiety, and coping.

“Dystonia creates challenges that can change the dynamics of a relationship,” explains Tom. “While dystonia can end friendships, it can also bring special people closer to us.”

Pain, fatigue, and other symptoms may make it difficult for individuals with dystonia to keep up with the activities and schedules of friends and family. Symptoms may be unpredictable and complicate making plans in advance or keeping social commitments. Friends and family may not fully grasp what it is like to live with dystonia. “Friends may want to ‘fix’ us,” says Tom. “They may back out of our lives, not knowing what to say or do. They may expect us to ‘get better’ or ‘get over it.’ This misunderstanding can cause friction and tension.”

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

It is common for individuals with dystonia to withdraw and isolate from other people. Tom relates: “My depression about a life I thought I lost resulted in isolation and loneliness, which further fueled my depression. This also created

anxiety. I didn’t care enough about myself to seek help and didn’t want people pushing me to get help, so I remained silent about my internal pain and as isolated as possible.”

### **Health & Wellness**

The health benefits of a strong social circle are many. When comparing individuals who feel socially connected to those who do not, there are documented differences in important biological systems. Social isolation may weaken overall physiological processes necessary to repair and maintain the body. Social isolation is correlated to delayed wound healing times, increased pain, and poorer sleep quality. Adult friendships have been linked to lower risks of depression and premature death. *Feeling* isolated may be more detrimental than *being* isolated.

Tom adds: “We may begin to take worse care of ourselves. Lonely people are less likely to be physically active or eat properly. It’s important to take good care of ourselves and to know that our value and worth has not diminished due to dystonia.”

## “LONELINESS IS PAINFUL and can confuse you into thinking you are an outcast.”

### Inner Feelings & the Outer World

The interaction of loneliness and stress is complex. Loneliness is a stressor that can lead to anxiety, depression, irritability, distrust, hostility, and lowered self-worth. Individuals who feel lonely can find it more difficult to tolerate the ups and downs of daily living—minor negative experiences like traffic congestion, disagreements with other people, or issues at work seem more intense. Individuals who feel stressed may be more likely to engage in risky behaviors and not seek medical care when needed.

“We need to be careful how we treat people and not let the feelings and anxiety we have about our illness be taken out on others,” says Tom. “Be open with family and friends about how you feel. Ask them how they feel. Relationships are a two-way street.”

### Support Systems

Friends often encourage healthier habits and advise each other to seek medical attention when sick or in distress. Individuals with strong social relationships tend to navigate stressful situations easier. They tend to know where to look and whom to ask for assistance when having difficulty. They are more likely to have multiple streams of information to inform decision making.

Loneliness can make it more difficult for individuals to feel positive and at ease in social situations. “Being different can feel embarrassing,

making us self-conscious,” explains Tom. “We can feel as though everyone can see what we are feeling on the inside, causing great anxiety.” It can take time and practice to change the self-perpetuating cycles of loneliness, stress, and isolation.

### Support Groups

“When re-engaging the world, do what is comfortable,” Tom suggests. “Join a group where you can connect with people who have the same interests—clubs, meet-up groups, and dystonia support groups. Make friends with similar challenges, but also be around people who are different so you can gradually expand your comfort zone.”

DMRF support groups plug you into a group of people who truly understand life with dystonia, and provide access to the latest information on research and treatment.

Most importantly, support groups provide an opportunity to receive and give support. Tom explains: “Sharing our feelings is a way to break isolation. When we focus on the needs of others, there is less attention on our lonely thoughts and feelings.”

If there isn't a support group in your area, consider partnering with the DMRF to start one. For more info: [www.dystonia-foundation.org/supportgroups](http://www.dystonia-foundation.org/supportgroups).

### Community Events

Jennifer Kassis of New York is amazed by the new connections she has made since forming the Southern Tier Dystonia Support Group and hosting the first-ever Binghamton Dystonia Zoo Walk in September: “A couple came to the Zoo Walk because their daughter has dystonia. They saw me promoting the event on TV and wanted to meet me and get information on my support group. We cried and hugged. Truly a beautiful moment.” Jennifer has had symptoms of generalized dystonia since childhood.

Katie Carlson traveled to attend the Zoo Walk from Connecticut to support Jennifer after the two women connected online. “When I was diagnosed with cervical dystonia I felt depressed and alone,” Katie explains. “One of the most uplifting connections I made was with Jennifer Kassis, who listened to me and brought me hope, even in her own time of struggle. I was able to meet Jennifer in person at the Zoo Walk and thank her for all she has done.”

Katie attended the Zoo Walk with her husband and two small children. “I was honored to be able to support Jennifer's efforts to raise awareness and, for the first time in my life, meet others with dystonia. I can't thank the DMRF enough for making connections like these possible.”

*Continued on page 14*

*Continued from page 13*

For a listing of scheduled DMRF events as dates are confirmed, go to: [www.dystonia-foundation.org/events](http://www.dystonia-foundation.org/events).

### Online Forums

Online dystonia forums are support services that are available 24 hours a day, seven days a week, to people all over the world. Brandy Martin is a member of the Support4Parents of Children with Dystonia group on Facebook: "I've made many friends and received lots of information for my daughter as she started school this year. I don't know what I would do without the support and encouragement I receive from this group."

For information about the DMRF's online groups, go to: [www.dystonia-foundation.org/online](http://www.dystonia-foundation.org/online).

### Reaching Out

"We are social beings and require contact with others to be healthier," concludes Tom. "Surround yourself with people who lift you up, believe in you and your dreams, and give you a spark. Reach out because loneliness is painful and can confuse you into thinking you are an outcast."

Contact the Dystonia Medical Research Foundation (DMRF) to learn more about the resources available to help you feel more connected at 800-377-DYST (3978) or [dystonia@dystonia-foundation.org](mailto:dystonia@dystonia-foundation.org). Or visit [www.dystonia-foundation.org](http://www.dystonia-foundation.org).



*Tom Seaman earned a Bachelor's degree in Education and Psychology, after which he pursued private business ventures in health education. While pursuing his Master's degree in Counseling he developed cervical dystonia. After numerous ineffective treatments and years of physical and mental pain, Tom learned and applied a combination of techniques that greatly improved his quality of life. Tom is now dedicated to helping others with dystonia and chronic illness benefit from his experiences. He is a Certified Professional Life/Health Coach and author of the book, *Diagnosis Dystonia: Navigating the Journey*. He also co-leads the DMRF Cervical Dystonia Support Forum on Facebook.*



### Stay in Touch!

**Sign up for the DMRF's monthly e-newsletter for the latest updates and announcements:**  
[www.dystonia-foundation.org/email](http://www.dystonia-foundation.org/email)

## Tom's Tips for Nurturing Friendships & Making New Connections:

- When dystonia puts strain on a friendship, both parties need to accept that things have changed. Be open with your feelings. This can make relationships stronger and more meaningful than before.
- Take ownership of the qualities you have that will enhance other people's lives. Don't deprive others of your gifts and let others share their gifts with you.
- Show interest in others. Ask questions.
- Be careful about perceiving suggestions as judgments. People may be trying to help.
- Make an effort to joke about things, especially dystonia.
- Accept that some friendships simply fizzle out.
- When re-engaging the world, do what is comfortable. Maybe start online if you are hesitant to get out with people just yet.
- Go where there are people. Get used to being around others in a social setting.
- Stay in touch with people and make it easy for people to contact you.
- Open up to people. Acquaintances become friends when we are comfortable sharing intimate things with one another.
- Track down old friends you knew before your diagnosis.
- Create a social calendar and stick to it.
- With everyone: be authentic, friendly, understanding, flexible, a good listener, positive, supportive, dependable, and respectful.