Internet Resources

Dystonia Medical Research Foundation website with resources on dystonia and mental health:

- **dystonia-foundation.org/living-dystonia/mental-health/**

Mental Health America:
- **mhanational.org**

Anxiety and Depression Association of America
- **adaa.org**

The American Psychological Association
- **apa.org**

The American Psychiatric Association
- **psychiatry.org**

National Suicide Prevention Lifeline
- **988lifeline.org**
- **Call 988**

Church and Mental Health Resources
- **churchandmentalhealth.com**

Psychology Today "Find a therapist"
- **psychologytoday.com/us/therapists**

Non-Motor Symptoms of Dystonia

Dystonia is a life-altering neurological disorder that affects the physical body, but the impact goes far deeper. The hallmark signs of dystonia are excessive, involuntary muscle contractions that cause abnormal postures and/or repetitive movements. Individuals diagnosed with dystonia also commonly experience symptoms that affect more than how the body moves. These are referred to as the "Non-Motor Symptoms of Dystonia"

Non-Motor Symptoms include:

Psychiatric
- Anxiety
- Depression
- Social phobia/anxiety
- Obsessive-compulsive disorder

Cognitive
- Fatigue
- Impaired executive function

Sleep
- Decreased sleep efficiency
- Disruption to quality of sleep
- Decreased sleep duration

Pain
- Quality of life
- Disabling

What is the DMRF?

The Dystonia Medical Research Foundation (DMRF) is a 501(c)3 non-profit organization that has served the dystonia community since 1976. The DMRF funds medical research towards a cure, promotes awareness and education, and supports the well-being of affected individuals and families.

The DMRF can put you in touch with others with dystonia for networking and support.

To learn more about dystonia and the DMRF, contact:

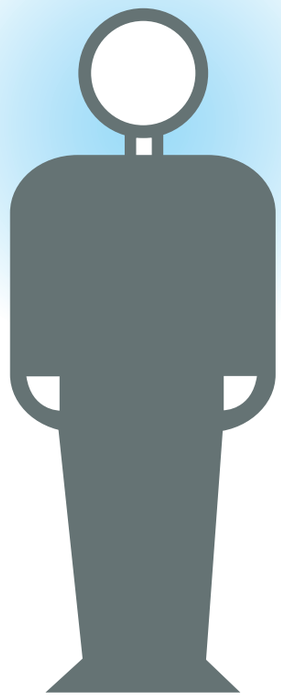
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Connect with the DMRF on Facebook, Instagram, LinkedIn, and YouTube.

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Non-Motor Symptoms of Dystonia



DYSTONIA MEDICAL RESEARCH FOUNDATION

When it's Time to Ask for Help

When discussing dystonia, it's important to remember that not everyone will have the same symptoms. Some people might experience things like depression, anxiety, pain, or trouble sleeping, while others may only have one or two of these issues. This shows that dystonia affects people in different ways, and each person's experience is unique. Recognizing this can help doctors and caregivers create treatment plans that are more tailored to each individual.

It may be time to talk to a mental health professional if you:

- Don't feel like yourself
- Have no appetite
- Lack energy or are unable to get out of bed
- Feel overwhelmed by sadness
- Feel out of control of your emotions
- Can't do the things you like to do
- Have friends and family who have expressed concern about you
- Feel like you need help
- Are having thoughts of self-harm

If you need assistance, reach out and be specific about what you are experiencing.

Resources for Patients

Mental Health Providers and Doctors Visits

During doctor's office visits for treatment, there often isn't enough time to discuss non-motor symptoms, which are important for overall care. To ensure your concerns are addressed, consider scheduling a separate appointment with your treating physician specifically for this discussion. Alternatively, when you book your treatment appointment, ask the scheduler for extra time to go over your questions without feeling rushed. This way, you can get the comprehensive care you need.

Chronic pain is a common problem for most people with dystonia and may contribute to mental health concerns. Ask your physician to refer you to a mental health professional in the pain management department, or someone who specializes in dealing with chronic pain. A team of specialists may be needed to implement a complete treatment plan.

Support Groups

Sharing your experiences and learning from others in similar situations can be extremely beneficial. In addition, speaking about these issues can help reduce the stigma around both mental health and dystonia. The DMRF hosts many online or in-person support groups, specifically for people with dystonia, that can provide a sympathetic and understanding ear. In addition, the DMRF has online Facebook forums to provide community support.

Therapy

In-person and online mental health treatment both offer distinct advantages, depending on an individual's needs and circumstances. Online therapy is ideal for those with mobility challenges or in remote areas, enabling therapy at home. On the other hand, in-person therapy can provide a more direct, face-to-face connection, which some people may prefer for a more personal experience. Regardless of the format, it's important to assess your specific needs and set clear goals for what you want to address in therapy. If possible, choose a therapist specializing in movement disorders. Be sure that the therapist is licensed and that the platform—whether in-person or virtual—is secure and respects privacy. Finding the right therapist may take time, but many offer free consultations to help determine compatibility, which is essential for effective treatment.

Self-Care Tips

Listen to Your Body: Contact your doctor if your dystonia symptoms change to discuss possible adjustments to your medications.

Make a Stress Reduction Routine: Regularly practicing stress-reduction techniques, like breathing exercises and guided meditation on apps like "Calm" and "Insight Timer", as they can significantly improve your quality of life.

Embrace Exercise: Engage in regular exercise for its numerous benefits and consider working with a physical therapist to create a personalized exercise plan.

Don't Snooze on Sleep: Prioritize quality sleep as a crucial self-care activity and consult your doctor if you're struggling to sleep well most of the time.

Acknowledge Grief: Recognize and accept complex emotions, including feelings of loss, especially during times of change or hardship.

Carefully Explore Integrative Therapies: Discuss any interest in non-traditional therapies with your doctor while being cautious of health scams and unproven treatments for dystonia.

Caregiver Support

Taking care of someone with dystonia means not just helping with their physical symptoms, but also keeping an eye on their mental health. Dystonia can make people feel anxious or depressed, especially since their condition can change suddenly. As a caregiver, it's important to notice if your loved one seems upset or is pulling away from things they used to enjoy. Encouraging them to talk about their feelings can create a supportive space. You can also help by finding mental health resources or support groups that focus on supporting loved ones with dystonia. Doing fun activities together and sticking to a routine can boost their mood and overall well-being. By paying attention to their mental health, you can make a big difference in their happiness and quality of life.