



## Living Well with Myoclonus-Dystonia

### **Myoclonus-dystonia (M-D)**

is a complex disorder that requires individualized care and attending to your needs as a whole person. Although M-D is a movement disorder that impacts the physical body, it can also have an impact on emotional and psychological health. Not only can the experience of symptoms be stressful, but individuals are vulnerable to obsessive compulsive disorder, alcohol abuse, depression, and anxiety. Disability and/or pain influence quality of life. Living well with M-D is possible and includes treating the medical symptoms, protecting emotional and psychological well-being, and accommodating your unique needs as an individual.

### **What is M-D?**

Myoclonus-Dystonia (M-D) is a movement disorder characterized by rapid, brief muscle contractions (myoclonus) and/or sustained twisting and repetitive movements that result in abnormal postures (dystonia). Non-motor features may include mood and anxiety disorders.



There is no single strategy or approach to living well with M-D, but the following considerations may be helpful.

**Seek out Expert Healthcare Providers.** It often takes a team of experienced professionals to treat M-D. This may include a movement disorder neurologist, physical therapist/occupational therapist, psychiatrist, psychotherapist/counselor, and/or other healthcare providers.

**Actively Participate in Your Treatment.** Learn about M-D. Investigate treatment options and make choices about your care with the input of your medical team.

**Understand Your Genetics.** Ask your doctor if you are a candidate for genetic testing and what you might learn about your diagnosis from a genetic counselor.

**Develop a Multi-Layered Support System.** Find multiple opportunities where you can talk about your experiences and feel understood. Seek out supportive family and friends, local dystonia support groups, online support groups, community events, and self-help resources. Enlist the help of a psychotherapist or counselor to help navigate concerns and vulnerabilities.

**Listen to Your Body.** Respect and honor your individual need for sleep, rest, nutrition, exercise, relaxation, and time/scheduling. Treat pain assertively with medication, topical agents, and other methods. Keep a journal to record responses to treatment, triggers, and the factors that make you feel better or worse.

**Exercise.** The benefits of exercise can be profound: strength, endurance, energy, stress reduction. Because M-D symptoms can be triggered by sudden or repetitive movements, consider working with a physical therapist to develop an exercise plan.

**Seek Help When You Need It.** If you need assistance, reach out and be specific about what you are having trouble with. Accept help when offered, and without guilt.

**Be Mindful of Stress.** Physical and emotional stress are notorious for exacerbating symptoms of M-D. Incorporating regular stress reduction and relaxation practices into your routine can have a positive impact on symptoms and overall well-being.

**Take Care of Your Relationships.** Avoid isolating from other people and social situations. If family or love relationships are strained, consider enlisting the help of a therapist to mediate discussion and bring you closer to those you care about.

**Remain as Active and Social as Possible.** Plan ahead, pace yourself, and rest when needed. You may find that it is physically and/or mentally demanding to go certain places or complete specific tasks. Before you conclude, *I can't do that* or *That will exhaust me*, ask yourself if that is true. Is there a creative way to continue to go there or do that?

**Do Things You Enjoy.** Coping with M-D can be time-consuming and exhausting, and it can be easy to let pleasurable activities and fun fall by the way side. Create space in your routine for activities and experiences that invigorate you and keep you going.

### **Treat Depression and Anxiety**

M-D often includes symptoms that can affect mood and behavior. Depression and anxiety can impact quality of life and the severity of motor symptoms. Consider being evaluated for depression and/or anxiety, and if symptoms are present seek treatment.

### **Embrace Awkward Social Situations**

Your symptoms may act up at really inconvenient times: a job interview, a date, the grocery store check out line. Strangers may occasionally misinterpret your body language. Be forgiving with yourself in these moments. You can decide whether or not it is appropriate to explain what is happening to the people around you—it is your choice.

### **Be Aware that M-D is a Risk Factor for Alcohol Abuse**

A study has suggested that over 40% of individuals with M-D meet criteria for alcohol dependence. If you are concerned about your drinking, or a loved one has expressed concerns, consider consulting a medical or mental health care provider.



**DYSTONIA  
MEDICAL  
RESEARCH  
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#### **About the DMRF**

The Dystonia Medical Research Foundation (DMRF) is a 501(c)(3) non-profit organization dedicated to advancing research for more dystonia treatments and ultimately a cure, promoting awareness, and supporting the well-being of affected individuals and families.

<http://www.dystonia-foundation.org>

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