

Not Just Any Body: Living Well with Dystonia

Dystonia is a movement disorder that impacts the physical body, and it can also affect emotional and psychological health. Living well with dystonia includes treating the physical symptoms, protecting emotional and psychological well-being, and accommodating your unique treatment needs as an individual.

There is no single strategy for living well with dystonia that works for everyone. The following suggestions have been compiled from individuals with dystonia, support leaders, and healthcare professionals.



Seek Out Expert Healthcare Providers.

It often takes a team of experienced professionals to diagnose and treat dystonia. This may include a movement disorder neurologist, physical therapist, psychiatrist, psychotherapist/counselor, and others.

Actively Participate in Your Treatment. Learn about dystonia. Make informed choices about your care with the input of your medical team.



Develop a Multi-Layered Support System.

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.



Cautiously Explore Complementary Therapies.

Talk to your doctor about non-traditional therapies that interest you. Different complementary approaches may work for different people, but keep in mind that numerous practitioners and outfits falsely claim to have a unique ability to treat dystonia.



Exercise.

The benefits of exercise can be profound.

Consider working with a physical therapist to develop an exercise plan that works for you.

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.

Treat Depression & Anxiety.

Depression and anxiety can dramatically 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.



Be Mindful of Stress.

Regular stress reduction and relaxation practices can have a positive impact on symptoms and overall well-being.



Take Care of Your Relationships.

Resist the temptation to isolate from other people. If family or love relationships are strained, consider enlisting the help of a therapist to bring you closer to those you care about.



Remain as Active and Social as Possible.

It may be physically and/or mentally demanding to go certain places or complete specific tasks. Plan ahead, pace yourself, and rest when needed.

Embrace Awkward Social Situations.

Your symptoms may flare at extremely inopportune times. Strangers may occasionally misinterpret your body language. Be forgiving with yourself in these moments.



Do Things You Enjoy.

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.

Contact the DMRF for Assistance.

We can be reached at dystonia@dystonia-foundation.org or 800-377-3978. Look for the DMRF on Facebook and Twitter.

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