

10 gold nuggets for living well with dystonia

A guide to self-management and recent insights from research

1. Dystonia Affects More Than Just Movement

Many people experience non-motor symptoms such as pain, fatigue, sleep problems, low mood, anxiety, and loss of confidence. These symptoms often impact daily life as much as movement difficulties.

2. You Are Not Alone in This

Visible symptoms like tremors, head pulling, or voice changes can lead to stigma, social withdrawal, and reduced confidence. You are not imagining it—this is a common experience, and support is available.

3. Fatigue Is Real and Debilitating

Fatigue is one of the most commonly reported symptoms and can significantly affect activity levels and quality of life. It is not just tiredness—it's a neurological fatigue and should be paced and respected.

4. Sleep Disruption Is Common

Over 70% of people with cervical dystonia or blepharospasm report poor sleep quality, including difficulty falling asleep, staying asleep, or feeling rested. Sleep issues are often linked with pain, anxiety, and depression.

5. Mental Health Matters

Anxiety and depression are not just a reaction to dystonia—they are part of the condition itself. Around 40–60% of people experience these symptoms. Treatment and emotional support can help.

6. Balance, Walking, and Falls

Many people with dystonia report imbalance, shorter steps, and increased risk of falls, especially when multitasking or moving quickly. Targeted rehab can help improve postural control and safety.

7. Pain Is Often Under-Recognised

Pain affects over half of people with cervical dystonia and up to 90% in some studies. It may be muscular, nerve-related, or linked with poor posture and muscle overactivity. Pain should always be addressed.

8. Exercise Is Tricky—but Important

Exercise can worsen symptoms if too intense, but gentle movement like walking, yoga, stretching, or Pilates often helps. Aim for low to moderate intensity. It's okay to adapt or stop when needed.

9. Build a Plan That Works for You

The right kind of movement, at the right time, makes a difference. Consider:

- Stretching or walking early in the day
- Avoiding high-impact or high-fatigue activities
- Working with someone who understands dystonia

10. You Deserve Informed Support

Many people say they struggle to find allied health clinicians who understand dystonia. You deserve support from clinicians who listen, adapt, and help you work with your body. **cann** is [here to support you](#).

- [Find out more and check your eligibility here](#)

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