

Living Well with Dystonia: Practical Tools for Everyday Life

Short Description: Simple, practical strategies for managing dystonia day to day – from exercise tips to stress reduction, energy balance, and support.

Living with dystonia brings daily challenges – but small, consistent strategies can make a real difference.

This brief guide shares practical tools to help manage symptoms, support wellbeing, and build confidence in everyday life.

Self-Management and Lifestyle

You may be encouraged to:

- **Engage in regular, appropriate exercise** – including alignment, position awareness, gentle lengthening exercises, walking, swimming, at a level that supports energy without over-fatiguing the body and addresses your individual presentation.
- **Use relaxation techniques** – such as mindfulness, deep breathing, or grounding strategies to help reduce stress, which can exacerbate symptoms
- **Identify your sensory tricks** – like light touch, humming, or using mirrors, which may temporarily reduce spasms
- **Monitor symptom patterns** – keeping a journal or record of how symptoms change across the day or in different environments
- **Balance activity and rest** – managing fatigue and ensuring recovery time

Our Approach

At CANN, our clinicians are experienced in working with people with focal dystonia. We tailor our approach based on what matters most to you. This might include:

- Working around your condition to help you maximise what you *can* do
- Gradually reintroducing tasks that are meaningful to you using adapted techniques
- Helping you build routines that support long-term function and wellbeing
- Collaborating with your neurologist and other healthcare providers
- Developing a tailored exercise programme that supports your energy levels, improves body awareness, and addresses your individual presentation

We take a person-centred, practical approach with the goal of helping you feel more in control of your body and confident in daily life.

Additional Resources and Contact Information

If you're living with dystonia, it can be reassuring to know you're not alone. Alongside support from your clinical team, there are a number of organisations and resources offering information, advocacy, and community connection.

Additional Resources

- **Dystonia New Zealand** – www.dystonia.org.nz
National advocacy, awareness, and community connection.
- **Dystonia UK** – www.dystonia.org.uk
Patient-friendly information, research updates, and personal stories.
- **Dystonia Medical Research Foundation (USA)** – www.dystonia-foundation.org
Education, treatment guides, and support resources.
- **National Spasmodic Dysphonia Association (NSDA)** – www.dysphonia.org
Specific resources and community support for voice-related dystonia.
- **Blepharospasm Foundation (BEBRF)** – www.blepharospasm.org
Focused on dystonia affecting the eyes and face.

Disclaimer

This resource is provided for general information only. It is not a substitute for professional medical advice, diagnosis, or treatment. Always seek the guidance of your GP, physiotherapist, or another qualified health professional before making changes. Cann Charitable Trust accepts no responsibility for any outcomes resulting from use of this material.