

# DYSTONIA

## A PARENT'S GUIDE



**CHILDHOOD DYSTONIA**  
**AWARENESS UK AND EUROPE**



# DYSTONIA – A PARENTS GUIDE

## From our families to another.

When our children were diagnosed with dystonia, We felt lost, holding papers full of medical jargon.

No one could explain what life would look like for our children or for our families. If you're reading this, you're probably at the beginning of your journey, and we want to tell you something important:



## You are not alone.

This isn't just another medical leaflet. It's written by parents like you – who've faced the same questions, and worries, and who've learned to navigate this path step by step.

We're not experts, just experienced.

**We're here for you.**

Note: This is a guide that is written by parent's and not all terms are used by medical professionals. We are using terms that are widely used and accepted within the dystonia communities.



# WHAT MIGHT DYSTONIA LOOK LIKE DAY TO DAY ?

Dystonia varies greatly among children, even with the same diagnosis. You might see:

Clumsiness.

Unusual walking.

Speech changes.

Trouble with hand function or use.



Symptoms can worsen with stress, leading to tiredness or frustration. In some genetic or degenerative diseases, dystonia can be progressive. In conditions like cerebral palsy, it may change as child grows.

Children have good days and hard days. Some need mobility aids, feeding support, or assistance with dressing.

**All of this is normal.**





# WHAT IS DYSTONIA ?

Dystonia is a neurological condition that affects muscle movement. It causes involuntary muscle contractions, which can result in :

Twisting or repetitive movements.

Abnormal postures (like hands curling inward or feet turning outward).

Jerky, shaky, or very slow movements.

Occasional pain or fatigue due to muscle tension.



## Types of Dystonia in children:

Focal dystonia – affects a single area (hand or neck).

Segmental dystonia – affects two or more adjacent areas.

Generalised dystonia – affects the entire body.

Dystonia-plus syndromes – includes dystonia with additional symptoms (tremors, epilepsy).

Dystonia may occur independently or as part of other conditions including cerebral palsy, genetic disorders, or metabolic conditions.

Some children are affected from birth, whilst others develop it later due to an injury, illness, or neurological changes.





# UNDERSTANDING TRIGGERS

One of the surprising aspects of dystonia is how certain factors can cause noticeable flare-ups. Identifying these triggers helps you manage them better.

## Common Triggers Include:

### **Tiredness**

Lack of sleep or overexertion.

### **Stress & strong emotions**

Excitement, anxiety and excessive noise.

### **Illness**

Even minor illnesses can temporarily increase symptoms.

### **Sensory Overload**

Crowds, bright lights and loud sounds.

### **Physical Activity**

Long walks, sudden posture changes and repetitive movements.

### **Gut Health**

Constipation, food intolerances, gut inflammation (the gut and the brain are closely connected).





# UNDERSTANDING TRIGGERS

## Managing Triggers.

### Track patterns

Keep notes of what seems to set things off.

### Build in downtime

Regular rest, quiet play and calm spaces.

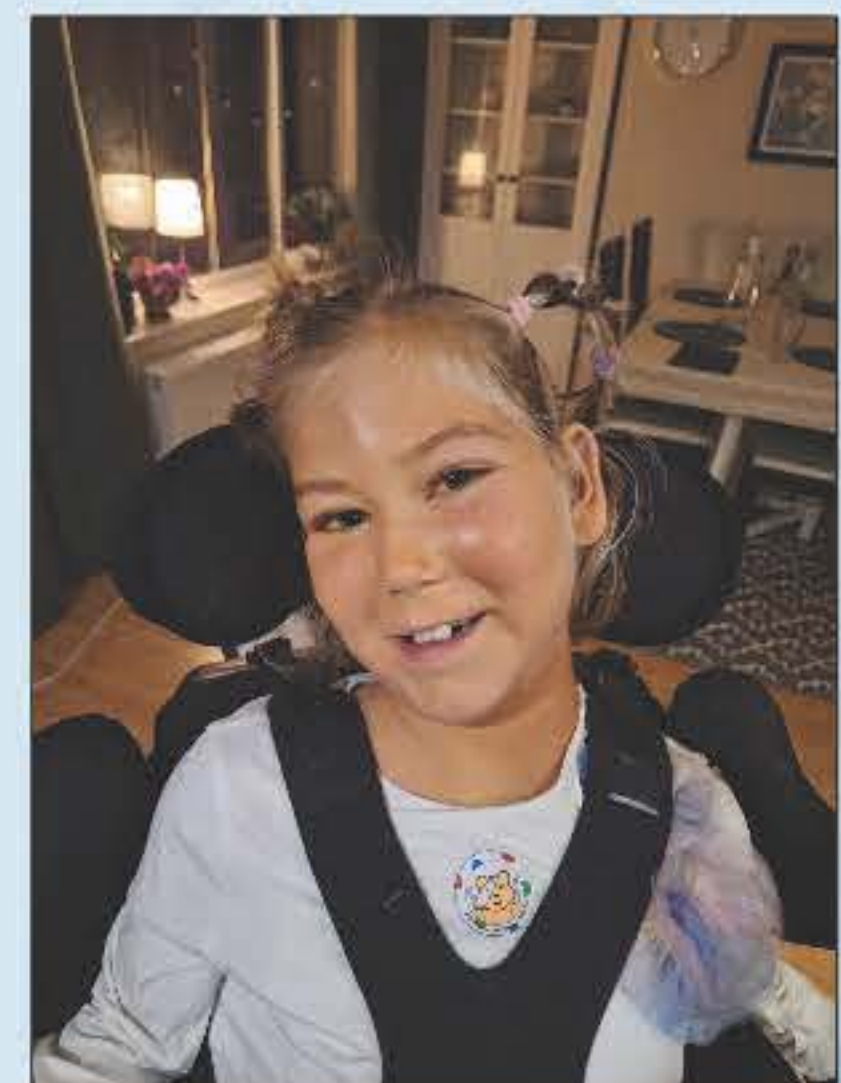
### Watch the gut

Monitor bowel habits and offer gut-friendly foods.

### Ask for help

Teacher, therapists, family... it takes a team.

You're doing an amazing job. We know it's not always easy, and there are days you'll feel like you're guessing but every observation you make helps your child.





# UNDERSTANDING DYSTONIA EPISODES

When Dystonia is triggered, symptoms can worsen to different degrees:

## Dystonic Flare-up

A temporary worsening of symptoms that includes:

More intense muscle spasms or twisting movements.

Increased difficulty with movement, sitting, or speaking.

Pain or fatigue.

Emotional distress or frustration.

What helps: Keeping your child calm, giving prescribed medication, allowing rest, and avoiding triggers.

## Dystonic Storm (Status Dystonicus)

A rare and serious medical emergency where:

Muscle spasms become extremely powerful and unrelenting.

Basic functions like breathing, eating or sleeping become severely compromised.

Complications can include elevated heart rate, fever, and metabolic disturbances.

**Requires immediate emergency medical care.**

## Dystonic Crisis

A sudden and severe worsening characterized by:

Muscles tighten or twist very strongly.

Significant pain, movement difficulties or breathing challenges.

Triggered by illness, stress or abrupt medication changes.

**This is considered a medical emergency requiring prompt treatment.**





# WHAT HELP IS OUT THERE ?

## NHS Pathway (UK)

Your GP can refer your child to a paediatric neurologist, preferably with a movement disorder specialty. Ask about clinics like:

Evelina London Children's Hospital (Complex Motor Disorders Service).

Great Ormond Street Hospital.

Birmingham Children's Hospital.

Queens Medical centre, Nottingham

Alder Hey (Children's Hospital), Liverpool



## Treatment Options

Your child may benefit from:

Botulinum toxin injections to reduce muscle contractions.

Medication (e.g., Baclofen, Trihexyphenidyl, Clonazepam, and Gabapentin).

Physiotherapy and occupational therapy.

Deep Brain Stimulation (DBS) and Intrathecal Baclofen (ITB) pump- surgical options considered in more severe cases.

Speech & language therapy.



## Dystonia severity action plan (DSAP)

### Purpose:

To help families, carers, and healthcare providers manage symptoms at home, recognise when extra help is needed, and know when to seek emergency care.

**Green Zone:** Daily care (stable condition).

**Amber Zone:** Worsening symptoms (caution).

**Red Zone:** Emergency (Act immediately).



# BASIC TERMINOLOGY

## Movement and muscle terms

### **Muscle Contractions**

When muscles tighten or squeeze on their own, Even when not intended.

### **Spasms**

Quick or Slow, involuntary muscle movements—like little “jerks” or twitches.

### **Tone**

How tight or relaxed a muscle is:

High tone: Muscles are too tight.

Low tone: Muscles that are floppy or relaxed.

### **Posture**

The way someone holds their body.  
Dystonia might make someone’s head tilt or arm twist unintentionally.

### **Spasticity**

A different type of muscle stiffness; often seen in cerebral palsy and frequently in combination with dystonia.

### **Dyskinetic movements**

Uncontrolled movements that can look like writhing, twisting or jerking. Some may be called chorea.



# BASIC TERMINOLOGY

## Treatment Terms

<b>Tone Management</b>	Strategies and treatments to help control abnormal muscle tone (medications botulinum toxin, braces, therapy).
<b>Botulinum toxin</b>	Medicine injected into problematic muscles to help them relax.
<b>Intrathecal Baclofen (ITB)</b>	An implanted pump that delivers Baclofen through a tube to the spinal cord area.
<b>Deep brain stimulation (DBS)</b>	A treatment where tiny electrodes are placed in the brain to help control abnormal signals.
<b>Therapy Services</b>	Physiotherapy, Occupational Therapy, and speech and language therapy.

## Medical Terms

<b>Dopa-Responsive dystonia</b>	A type that improves with dopamine-containing medication.
<b>Basal Ganglia</b>	Brain structures that help control movement. Dystonia is often linked to problems here.
<b>Neurotransmitters</b>	Chemical messengers in the brain (like dopamine) that help nerve cells communicate.
<b>MRI Scan</b>	Detailed imaging of the brain and body to help diagnose and understand conditions.



# OTHER HELP AVAILABLE

## SUPPORT AT SCHOOL (UK SPECIFIC):

Ask your SENCO about an EHCP (Education, Health and Care Plan).

Schools are legally required to make reasonable adjustments under the Equality Act 2010.

Your child may qualify for 1:1 support, access arrangements, or specialist equipment.



## FINANCIAL AND PRACTICAL SUPPORT

Disability Living Allowance (DLA).

Carer's Allowance.

Motability Scheme (if your child qualifies for higher-rate mobility).

Blue Badge parking permit.

Family Fund grants for equipment, holidays, or respite.

Consider applying for a Disabled Student Allowance later in education





# GET SUPPORT

CHILDHOOD DYSTONIA AWARENESS UK AND EUROPE – THATS US !!.

DYSTONIA EUROPE – ADULT AND YOUTH SUPPORT.

DYSTONIA UK – ADULT AND YOUTH SUPPORT.

CPOTENTIAL, NEWLIFE, SCOPE.

GENETICS ALLIANCE UK – If your child's Dystonia has a genetic link.



SOCIAL MEDIA AND FACEBOOK SUPPORT GROUPS.

## You've got this– and We've got you !

You're doing better than you think. You are your child's biggest cheerleader, advocate, and safe space. While you don't need to know everything all at once, you do need support.

**Search for us on facebook:**

Childhood dystonia awareness UK and Europe

Childhood dystonia awareness UK and Europe support group

Join our parent forum, share your story, or just send a message when you need a chat.

**Together, let's raise awareness and help each other.**

We would like to share our gratitude to all involved in the making of this booklet Thank you.

