

The Flare, Heat & Weather Survival Toolkit

For EDS, Syringomyelia & Complex Neurological Conditions

Practical strategies for managing symptom fluctuations in EDS, syringomyelia, and related conditions

WHY YOUR SYMPTOMS CHANGE

If your symptoms change day to day—or even hour to hour—you're not imagining it.

Conditions like EDS and syringomyelia involve systems that are sensitive to:

- ✓ Temperature
- ✓ Body position
- ✓ Nervous system regulation
- ✓ Cerebrospinal fluid (CSF) dynamics
- ✓ Activity and energy use

Key takeaway: Your body is responding to real physiological changes—not being inconsistent.

MANAGING TRIGGERS

Heat Survival

Heat Can Be a Major Trigger

Many patients experience worsening symptoms in heat due to autonomic dysfunction and circulation changes.

Common Symptoms:

- Dizziness or lightheadedness
- Fatigue or weakness
- Increased pain
- Brain fog

What Helps

- ✓ Stay in cool or shaded environments
- ✓ Use cooling tools (fans, cooling towels, vests)
- ✓ Plan activities early or late in the day
- ✓ Take breaks before symptoms escalate

Weather & Barometric Pressure

Your Body May React to Weather Changes

Changes in barometric pressure can affect joints, nerves, and fluid dynamics.

You Might Notice:

- Pain increases before storms
- Head pressure or headaches
- Increased fatigue

What Helps

- ✓ Track weather alongside symptoms (Weather X app free)
- ✓ Adjust expectations on “high-risk” days
- ✓ Use supportive tools (rest, compression, hydration)
- ✓ Prepare ahead of known weather shifts

FLARE MANAGEMENT

What Is a Flare?

A flare is a temporary increase in symptoms—often triggered by activity, stress, illness, or environmental factors. Learn how to pace yourself, rest and recover.

Common Signs:

- Increased pain
- Fatigue or shutdown
- Cognitive difficulty
- Reduced tolerance for activity

Your Flare Plan

- ✓ Reduce activity (this is strategic, not failure)
- ✓ Prioritize rest and nervous system calm
- ✓ Simplify your day (“minimum viable day”)
- ✓ Stay hydrated and nourished
- ✓ Reduce sensory input (light, noise, stimulation)

ENERGY & HYDRATION

Energy Management

Avoid the Boom–Bust Cycle

Many patients experience: Do too much → crash later or PEM

Instead, Try:

- ✓ Break tasks into smaller steps
- ✓ Stop before exhaustion
- ✓ Alternate activity and rest
- ✓ Think of energy like a battery—not unlimited

Helpful Reframe

"You're not lazy—you're managing a limited resource."

Rest is productive.

Hydration & Electrolytes

Water Isn't Always Enough

Some patients benefit from balanced hydration that includes electrolytes.

Why It Matters:

- Supports blood volume
- Helps regulate heart rate and circulation
- May reduce dizziness and fatigue

Simple Tips

- ✓ Sip consistently throughout the day
- ✓ Consider electrolyte support (as appropriate)
- ✓ Monitor how your body responds

TRACK YOUR PATTERNS & PREPARE FOR YOUR DOCTOR

Your Body Has Patterns—Find Them

Tracking helps you understand triggers and prevent flares.

Track:

- ✓ Weather
- ✓ Activity level

Bring This Insight With You

Tracking and understanding your patterns helps you communicate more clearly.

Helpful to Bring:

- ✓ Symptom summary
- ✓ Timeline of changes

- ✓ Sleep
- ✓ Symptoms

Ask Yourself:

- What made today better or worse?
- What patterns am I starting to see?

- ✓ Top 3 concerns
- ✓ Questions

You're Not Imagining This

If your symptoms fluctuate:

It doesn't mean they're not real

It doesn't mean nothing is wrong

It means your body is responding to complex systems

Understanding those patterns is the first step toward managing them.

When to Learn More

Explore additional resources if you experience:

- ✓ Neurological symptoms
- ✓ Persistent pain or weakness
- ✓ Symptoms that don't match imaging
- ✓ Multi-system involvement

Created in collaboration with:

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Mission: Advancing research, education, and care for patients with complex neurological and connective tissue conditions

For more resources: bobbyjonescsf.org/i-am-patient/