

LIVING WELL WITH EHLERS-DANLOS SYNDROME

*An Empowering Guide to Splints,
Self-Care & Support*



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EVABELLE JEWELRY



Living Well with Ehlers-Danlos Syndrome

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Support

By Evabelle Jewelry



Hi there —

If you've just been diagnosed with Ehlers-Danlos Syndrome (EDS), you may feel overwhelmed, confused, or even invisible. I want you to know you're not alone.

I created this guide from my heart. This ebook is here to help you feel understood, supported, and empowered as you begin your journey.

With care,
Shar – Evabelle Jewelry



What is EDS?

Ehlers-Danlos Syndrome (EDS) refers to a group of inherited connective tissue disorders caused by genetic mutations that disrupt collagen and elastin production—the key structural proteins in skin, joints, blood vessels, and organs .

Symptoms often include:

- Joint hypermobility (joints move beyond their usual range)
- Skin hyperextensibility, fragility, or bruising easily
- Tissue weakness, loose ligaments, and frequent dislocations or sprains

Types of EDS & Primary Features

There are 13 recognized types of EDS. While each has unique features, several share key characteristics:

- Hypermobility (hEDS): Extremely flexible joints, prone to sprains/dislocations, pain. Skin soft but not always stretchy
- Classical EDS (cEDS): Hypermobile joints + soft, fragile skin that tears or bruises easily; may show delayed wound healing or scoliosis
- Vascular EDS (vEDS): Affects blood vessel strength; thin skin, easy bruising, risk of arterial rupture; more serious prognosis

EDS is often misunderstood or misdiagnosed, especially because it's an “invisible” illness. But your pain is valid. Your voice matters. And there are tools that can help.



Managing Ehlers-Danlos Syndrome

A practical approach to everyday support



Daily Support

- Wear splints or braces for joint stability
- Pace activities to manage fatigue
- Use ergonomic tools & joint protection techniques

Physical & Occupational Therapy

- Gentle strengthening (physiotherapy)
- Activity adaptations (occupational therapy)
- Hydrotherapy or low-impact movement



Symptom Relief

- Pain: paracetamol, ibuprofen (as advised)
- Neuropathic pain: gabapentin or amitriptyline
- GI issues or POTS: tailored medical care

Whole-Body Wellness

- Therapy for emotional resilience
- Symptom tracking and journaling
- Join support groups or online communities



There's no cure — but there is support.



Why Splints Are Recommended for EDS

People with EDS often have joint hypermobility, meaning their joints move beyond the normal range. While this may sound like a talent, it actually places stress on ligaments and soft tissues, leading to pain, instability, frequent subluxations (partial dislocations), and early joint wear.

Splints provide external support and help stabilize joints that are prone to:

- Overextension
- Subluxation or dislocation
- Fatigue from repetitive movements

They can:

- 🩹 Limit excessive joint movement
- 🎯 Improve joint alignment and function
- 🛡️ Reduce pain and inflammation
- 🙌 Protect delicate joints during daily activities
- 🧘 Encourage healing and reduce injury risk
- 💍 (Bonus) In jewelry-style forms, blend support with personal style

Splint use is often part of a multidisciplinary approach that includes physical therapy, pain management, and lifestyle adjustments. Some splints are designed for both function and comfort, allowing people with EDS to move with more confidence and less pain.



Types of Splints & How to Use Them

1. Finger Splints

Purpose: Limit hyperextension and support misaligned joints

Uses: Swan neck deformity, trigger finger, PIP/DIP hypermobility

How to use: Wear on affected fingers during daily tasks or typing

2. Wrist Splints / Braces

Purpose: Maintain neutral wrist position, reduce overuse

Uses: Carpal instability, typing strain, wrist subluxation

How to use: Especially useful during sleep or repetitive hand tasks

3. Elbow Splints

Purpose: Prevent hyperextension and protect weak joints

Uses: Chronic elbow instability, strain from repetitive reaching

How to use: Use during activities that stress elbow joint or overnight

4. Knee Splints / Hinged Knee Braces

Purpose: Stabilize knee movement and prevent hyperextension

Uses: Knee instability, pain, patellar misalignment

How to use: Recommended during walking, standing, or flare-ups

5. Ankle Splints / Braces

Purpose: Prevent sprains and provide support during movement

Uses: Ankle instability, rolling, flat feet

How to use: Wear during walking, flare-ups, or whenever unstable

6. Toe Splints

Purpose: Align toes and prevent deformities

Uses: Hammer toes, toe drift, joint subluxations

How to use: Worn in shoes or at bed/rest times for gentle correction



Types of Finger Splints & What they do

Hyperextension

Hyperextension is a condition where a joint is forced to move beyond its normal range of motion, typically in the direction opposite to flexion. In other words, the joint bends too far backward, creating strain or instability.

Splints that treat hyperextension:

Swan Splint



DIP, PIP or joint
Treats mild hyperextension

Thumb Splints



IP/MCP splint ring
Treats hyperextension

MCP Splints



Trigger Finger

A condition in which a finger bends, gets stuck and then snaps straight.

Splints that treat triggering:

Trigger finger splint



DIP, PIP or IP joints
Stabilizes the joint

Trigger MCP splint



MCP joints
Stabilizes the joint

Lateral Deviation

Bending or curvature of a finger toward the ulnar side.

Splints that treat lateral deviation:



Buddy Ring

Designed to keep your fingers securely aligned, this ring ensures your digits stay together without straying apart.



How to size for splint rings?

Most Accurate Sizing Method



Use a standard ring sizer for the most reliable fit

When to Use Measurements (mm)



Only use soft tape or string to measure if you're ordering an adjustable splint or you don't know your ring size

How to Measure for Adjustable Splints

- 1 Wrap tape/paper around the center of the joint
- 2 Mark where it overlaps in mm
- 3 Optional: Measure base or knuckle too
- 4 Make sure it's snug but not tight



Fit Tips

- Shouldn't be too tight or leave deep marks
- Adjustable splints work better for swelling
- Thumb sizes vary - measure both joints if needed

For Custom Orders, Include:

- Finger & joint type (e.g, middle finger, PIP)
- Ring size or mm circumference
- Any swelling or lateral deviation



Tips for Living with Ehlers-Danlos Syndrome (EDS)

Support your body, protect your joints, and nurture your well-being.



Joint Protection & Mobility

- Use splints, braces, or kinesiology tape to support hypermobile joints
- Avoid locking or overextending joints during daily movements
- Try low-impact exercises like swimming, Pilates, or gentle yoga
- Change positions often to avoid joint strain or stiffness



Daily Living Aids

- Use ergonomic tools and jar openers to reduce hand stress
- Install grab bars, reachers, or adaptive gadgets for mobility
- Wear supportive shoes and avoid high heels when possible
- Use compression garments to help with POTS or blood pooling



Pain Management

- Alternate heat and cold therapy for pain and inflammation
- Try TENS units, massage tools, or gentle bodywork (like myofascial release)
- Track pain triggers with a journal to spot patterns
- Practice pacing — avoid overexerting on “good” days



Mental & Emotional Wellness

- Seek out therapists familiar with chronic illness if possible
- Use grounding practices like deep breathing, meditation, or journaling
- Find online or in-person support communities
- Be gentle with yourself — healing is not linear



Medical Advocacy

- Bring a symptom journal and photos to appointments
- Prepare a list of questions ahead of time
- Educate your doctors about your subtype if needed

Trust your body — you deserve to be heard





How to Talk to Doctors (and OT/PTs) When You Have EDS

You deserve to be heard, respected, and supported.

✓ 1. Prepare Ahead of Time

Bring a short written list of symptoms, concerns, or flare-ups

Note which joints dislocate, hyperextend, or cause pain

Include photos or videos if symptoms come and go

Be ready to explain your EDS subtype (if diagnosed)

✓ 2. Speak Clearly & Confidently

Say: "I have a connective tissue disorder that affects my joints."

Describe how it impacts your daily life, work, or mobility

Use plain examples: "My thumb dislocates when I pick up a mug."

Don't downplay your symptoms — this helps professionals understand your reality

✓ 3. Ask Specific Questions

What treatment options are safe for people with hypermobility?

Are there splints or braces you recommend?

Can I be referred to an EDS-aware specialist or OT?

Is there a physical therapy plan that avoids overstretching?

✓ 4. Know Your Boundaries

You can say no to treatments that worsen your symptoms

Mention the EDS Society or bring EDS resources if needed

Consider bringing someone with you for support

If you don't feel listened to — you have the right to find another provider



Jewelry-Style Splints

At Evabelle, we believe medical tools should feel beautiful, not clinical. That's why our splints are designed to be both elegant and functional.

Wearing a beautiful splint can:

- Boost confidence
- Start conversations
- Help you feel seen, not hidden

You deserve tools that support your body and your spirit.

Closing Words

EDS is a long journey, but you don't have to walk it alone. Whether you're managing flare-ups or just learning how to support your joints, I hope this guide gives you both clarity and comfort.

I see you. I believe you. You're doing amazing.

With love,

Shar

Evabelle Jewelry – Handmade with Heart



Sources for Splint Use in EDS:

The Ehlers–Danlos Society. Orthotic & Supportive Devices for EDS. www.ehlers-danlos.com

Castori M. (2012). Pain in Ehlers–Danlos Syndromes: Manifestations, Therapeutic Strategies and Future Perspectives. Pain Research and Treatment. <https://doi.org/10.1155/2012/878673>

Hakim A. & Grahame R. (2003). Joint Hypermobility. Best Practice & Research Clinical Rheumatology, 17(6), 989–1004.

Tofts LJ, Elliott EJ, Munns CF. (2010). The Differential Diagnosis of Children with Joint Hypermobility: A Clinical Review. Arch Dis Child, 95(6), 484–489.



SPLINT FIT CHECKLIST

Use this guide to check if your splint fits properly and comfortably.

General Fit

- ☐ The splint sits snugly on the intended joint without sliding
- ☐ The splint does not feel too tight or restrict circulation
- ☐ You can move the surrounding joints freely
- ☐ No pinching or sharp edges touching the skin

Comfort

- ☐ No red marks or pressure points after wearing for 30+ minutes
- ☐ You can wear it during daily tasks without discomfort
- ☐ You don't feel tempted to constantly adjust or remove it
- ☐ It feels stable and supportive, not loose or floppy

Function

- ☐ It prevents the motion it's meant to block (e.g. hyperextension, lateral deviation)
- ☐ It allows healing or joint protection without forcing awkward angles
- ☐ It doesn't interfere with normal blood flow or finger alignment
- ☐ You can wear it under light gloves (if needed)

For Adjustable Splints

- ☐ You can slightly loosen or tighten for swelling
- ☐ The adjustment doesn't cause sharp edges or instability

SYMPTOM JOURNAL

Track your daily experience to help identify patterns, communicate with doctors, and support your care journey.

Date: _____ Overall Symptom Rating (1-10): ____

SYMPTOMS NOTICED TODAY

- | | |
|--|---|
| <input type="checkbox"/> Joint pain or instability | <input type="checkbox"/> Dislocation or subluxation |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Fatigue |
| <input type="checkbox"/> GI issues | <input type="checkbox"/> Headaches or migraines |
| <input type="checkbox"/> Dizziness / POTS symptoms | <input type="checkbox"/> Bizziness / POTS symptoms |
| <input type="checkbox"/> Brain fog | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Skin issues | _____ |

WHEN SYMPTOMS OCCURRED

- ☐ Morning ☐ Midday ☐ Evening ☐ All Day

WHAT I ATE/DRANK TODAY

- ☐ Low ☐ Moderate ☐ High Notes: _____

TREATMENTS OR TOOLS USED

(e.g. splints, heat, meds, pacing, rest) _____

NOTES OR PATTERNS I'M NOTICING
