

Understanding Ehlers-Danlos Syndrome

Support. Manage. Thrive. ♥

Ehlers-Danlos Syndrome (EDS) is a group of hereditary connective tissue disorders that affect the body's collagen. It can impact skin, joints, blood vessels, and internal organs.

You are not alone.

With the right knowledge, support, and self-care, it's possible to improve quality of life.



COMMON SYMPTOMS

Symptoms vary widely, even within the same family.



★ Because EDS affects the whole body, treatment often requires a team approach.

TIPS FOR MANAGING EDS

1. EDUCATE YOURSELF



- Learn about your type of EDS.
- Follow reputable sources and patient organizations.
- Keep a list of questions for your healthcare team.

2. BUILD YOUR CARE TEAM



- Find practitioners who understand EDS.
- Common providers: rheumatologist, geneticist, physiotherapist, pain specialist, cardiologist, and occupational therapist.
- Regular check-ins help prevent complications.

3. MOVE SMART



- Low-impact exercise builds strength and stability.
- Focus on physical therapy, Pilates, swimming, or yoga.
- Avoid overstretching and high-impact activities.

4. PACE AND PRIORITIZE REST



- Balance activity with rest to manage energy.
- Use pacing techniques and break tasks into smaller steps.
- Good sleep hygiene can improve pain and fatigue.

5. MANAGE PAIN HOLISTICALLY



- Work with your care team on a pain plan.
- Options may include medication, heat/cold therapy, relaxation techniques, and mindfulness.
- What works today may change—be gentle with yourself.

6. SUPPORT YOUR BODY



- Stay hydrated.
- Eat a balanced diet rich in nutrients.
- Consider supplements (e.g., vitamin C, D, magnesium) after consulting your provider.

TIPS FOR FAMILIES & CAREGIVERS



- ♥ Listen and validate. Pain may be invisible, but it's real.
- ♥ Learn about EDS together.
- ♥ Offer practical help without taking over.
- ♥ Encourage, don't push.
- ♥ Celebrate small victories.
- ♥ Take care of yourself, too.
- ♥ Support and patience make a big difference.

YOU ARE MORE THAN YOUR DIAGNOSIS

EDS is a part of your life, but it does not define you. Focus on what you can do, not what you can't.



Be kind to yourself



Set realistic goals



Find joy in everyday moments



Connect with your EDS community

*You are strong. You are not alone.
You are enough. ♥*



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Remember

Living with EDS can be challenging, but you can build a full, meaningful life with the right tools, support, and self-compassion.



Keep advocating.
Keep hoping.
Keep going.