CPCF UNITED · FREE PATIENT RESOURCE · theEDSCaregiverPharmacist

FREE GUIDE

6 Things to Know
After an EDS Diagnosis

A starting point from someone who gets it.

- What EDS actually means for your body
- The medical team you need to build
- Why medications work differently in EDS
- The words that change your appointments
- What to track from day one
- Finding your community

Written by a Pharmacist & EDS Caregiver

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WELCOME

You Found the Right Place.

If you're reading this, you or someone you love just received an EDS diagnosis — or you've been living with symptoms for years and finally have a name for them. Either way, welcome. And I'm so glad this found you.

I'm a licensed pharmacist. My husband has EDS. I know this world from both sides of the prescription pad — the clinical and the deeply personal. What follows isn't a medical textbook. It's the honest starting point I wish someone had handed us.

Before you read on, a note:

- This guide is for educational purposes only and does not replace personalized medical advice.
- EDS is highly variable — what is true for one person may not be true for another.
- Use this as a starting point for conversations with your healthcare team, not as a substitute for them.
- If you are in a medical emergency, please call 911 or go to your nearest emergency room.

WHAT'S IN THIS GUIDE

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01

EDS Is a Spectrum — Your Experience Is Valid

Ehlers-Danlos Syndrome is not one condition — it's a group of 13 recognized subtypes, all involving problems with collagen structure. Collagen is the scaffolding of your body, found in skin, joints, blood vessels, organs, and the gut. When collagen doesn't form correctly, the effects can show up almost anywhere — which is why EDS looks so different from person to person.

You may be hypermobile but not have dislocations. You may have severe chronic pain but look completely fine on the outside. You may have been dismissed by dozens of doctors before getting here. All of that is real, and all of it is valid.

The 13 EDS subtypes include:

- Hypermobile EDS (hEDS) — the most common; diagnosed clinically, no genetic test yet
- Classical EDS (cEDS) — fragile, stretchy skin; genetic test available
- Vascular EDS (vEDS) — affects blood vessels and organs; requires careful monitoring
- Kyphoscoliotic, Dermatosparaxis, Arthrochalasia, and several others — all rarer
- IMPORTANT: Most people with EDS have hEDS. If you haven't been subtyped, ask your geneticist.

Common Co-Occurring Conditions

EDS rarely travels alone. Most patients are eventually diagnosed with one or more of the following — knowing this helps you ask the right questions early:

Condition	What It Is	Why It Matters
POTS	Dysregulation of heart rate and blood pressure when upright	Causes dizziness, fainting, rapid heart rate — very common in hEDS
MCAS	Mast cells overreact, releasing histamine and other mediators	Can cause reactions to foods, medications, smells, heat, and stress
Dysautonomia	Broader autonomic nervous system dysfunction	Affects digestion, temperature regulation, sleep, and more
Small Fiber Neuropathy	Damage to small nerve fibers causing burning pain	Often undiagnosed; requires a skin punch biopsy to confirm

Chiari Malformation	Brain tissue extends into spinal canal	More common in EDS; can cause headaches, neck pain, neurological symptoms

02

The Medical Team You Need to Build

EDS is a multisystem condition, which means no single doctor can manage all of it. Building the right team takes time — and many of these specialists have long wait lists. Start making referral requests early, even before you think you need them.

Specialist	Role in Your EDS Care	Priority
Geneticist / EDS specialist	Confirm diagnosis, identify subtype, coordinate care	Start here
Rheumatologist	Joint health, pain, inflammation management	High
Cardiologist / electrophysiologist	POTS and dysautonomia evaluation and treatment	High if dizzy/fainting
Gastroenterologist	GI motility, gastroparesis, SIBO	High if GI symptoms
Allergist / Immunologist	MCAS diagnosis and treatment	High if reactions present
Physical therapist (EDS-trained)	Stabilization, not stretching — critical distinction	High — ongoing
Neurologist	Neuropathy, headache, Chiari evaluation	As needed
Pain management specialist	Complex pain, nerve blocks, ketamine	When pain is uncontrolled
EDS-aware pharmacist	Medication interactions, sensitivities, MCAS-safe formulations	Ongoing — find one you trust

Finding EDS-knowledgeable providers:

- The Ehlers-Danlos Society (ehlers-danlos.com) maintains a provider directory — start there.
- EDS Facebook groups are invaluable for local recommendations from real patients.
- Telehealth has opened access to EDS specialists across state lines — worth exploring.
- When interviewing a new provider, ask: 'How many EDS patients do you currently treat?' — the answer tells you everything.

03

Why Medications Work Differently in EDS Bodies

This is the one I wish every newly diagnosed EDS patient knew on day one — because it explains so much that may have felt confusing or even humiliating before your diagnosis.

EDS bodies process medications differently. This isn't in your head. It's biology.

Local anesthetics often don't work

Published research on 980 EDS patients found that 88% had inadequate pain control during dental procedures with standard lidocaine. If the dentist's numbing shot never works for you — this is why. There is a specific combination protocol that works much better. Ask your provider about mepivacaine + articaine.

Medications may need different doses

GI motility issues in EDS mean oral medications are absorbed inconsistently. Some patients do better with liquid formulations, sublingual medications, or topical preparations. Standard doses can be too much or too little depending on your gut function that day.

MCAS can cause reactions to inactive ingredients

If you have MCAS overlap, you may react not to the medication itself but to the dye, coating, or filler in the pill. Red dyes, polyethylene glycol (PEG), and titanium dioxide are common culprits. Ask your pharmacist for dye-free formulations or consider a compounding pharmacy.

Some medications carry extra risk in EDS

Fluoroquinolone antibiotics (like Ciprofloxacin and Levofloxacin) carry an FDA black box warning for tendon rupture — a risk that is significantly higher in EDS. Oral steroids can worsen tissue laxity with repeated use. Always tell every provider you have EDS before starting a new medication.

> *"Start low, go slow" is the EDS medication mantra. Document every reaction. Your symptom diary is your most powerful clinical tool.*

04

The Words That Will Change Your Appointments

EDS patients are frequently dismissed, disbelieved, or given generic advice that doesn't account for their unique physiology. How you frame things matters enormously. Here are phrases that open doors instead of closing them.

Instead of: 'The numbing doesn't work'

> *"Say: 'I have EDS, which causes documented resistance to standard local anesthetics. Published research shows only 8% of EDS patients get adequate pain control from lidocaine. I'd like to discuss an alternative protocol before we begin.'"*

Instead of: 'I react to everything'

> *"Say: 'I have Mast Cell Activation Syndrome alongside my EDS. I can react to inactive ingredients in medications — dyes, coatings, and fillers. Can we check the full ingredient list before prescribing and look for a dye-free formulation?'"*

Instead of: 'I'm in a lot of pain'

> *"Say: 'My pain level today is [X]/10. My baseline is [Y]/10. The pain is [describe type and location]. It is affecting my ability to [specific function]. I have tried [treatments] with [results].'"*

At any new appointment:

> *"'I have Ehlers-Danlos Syndrome — hypermobile type. It affects my joints, autonomic nervous system, GI tract, and medication responses. I also have [POTS/MCAS/other]. Before we discuss treatment, I'd like to make sure you're familiar with EDS — do you have other EDS patients?'"*

05

What to Track From Day One

Your symptom history is your most powerful clinical tool — especially in a condition that is invisible on most standard tests. Providers who see patterns over time are far more equipped to help you. Start tracking now, even if imperfectly.

Daily symptoms to log:

- Pain level (0–10) and location — be specific (right hip, lower back, jaw)
- Fatigue level (0–10) — separate from pain
- Brain fog / cognitive symptoms
- GI symptoms — nausea, bloating, bowel changes
- Heart rate episodes, dizziness, fainting or near-fainting
- Skin flushing, hives, or itching
- Sleep quality
- Subluxations or dislocations — which joint, what you were doing

Track for every medication and supplement:

- Name, dose, time taken
- Any reaction within 48 hours — even mild ones
- Whether it helped, and how much
- Date started, date stopped, and reason for stopping

Track for every flare:

- Date, time, duration
- Possible triggers (activity, food, stress, weather, illness, new medication)
- Symptoms and severity
- What you tried and whether it helped
- Whether you needed medical care

Tracking tools that work for EDS patients:

- A simple notebook or printed tracker works — consistency matters more than the tool.
- The free printable trackers in CPCF United resources cover daily symptoms, flares, medications, and appointment prep.
- For digital tracking: Bearable app, Symple, or even a Google Sheet work well.
- Before every appointment, write your top 3 concerns in order of priority — EDS appointments run long and time runs short.

06

You Are Not Alone

The EDS community is one of the most generous, knowledgeable, and fiercely supportive patient communities that exists. These are people who have spent years navigating a system that wasn't built for them — and they share what they've learned freely.

Finding your people is not a luxury. It is part of your care.

Where to find your community:

The Ehlers-Danlos Society (ehlers-danlos.com)

The leading global organization for EDS. Provider directory, research updates, support groups, and a helpline.

EDS Support Group (Facebook)

Over 40,000 members. One of the most active and moderated EDS groups online. Real patient experiences.

POTS Support groups (Facebook + Reddit r/POTS)

Specific to dysautonomia. Invaluable for medication and lifestyle management tips.

MCAS Awareness groups

Critical if you suspect mast cell involvement. Patients share what works and what doesn't.

CPCF United (cpcfunited.org)

Where you found this guide. Resources written by a pharmacist & EDS caregiver, grounded in both clinical knowledge and lived experience.

> *"Getting an EDS diagnosis can feel like both a relief and a weight. You finally have a name for what has been happening to your body — and now you have to figure out what to do with it. Take it one step at a time. Build your team slowly. Track everything. And know that there is a whole community of people who have walked this road and want to help you walk it too."*

WHAT'S NEXT

You've taken the first step.

This guide is just the beginning. If you're ready to go deeper on medications, drug interactions, the dental numbing protocol, MCAS overlap, supplements for POTS, and printable trackers for every appointment — the full EDS & Medications Guide covers all of it.

40+ pages • 6 printable trackers • Doctor scripts • $37

— The EDS Caregiver Pharmacist —

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