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UNDER
DIAGNOSED



Getting a Diagnosis for EDS

CHRISTIE COX

INTRODUCTION



Ways to Deal - and Heal - with Rare Chronic Illness

Tired of being told there's no name or treatment for your illness? That it's all in your head or that your pain can't be real because you're too young/old/healthy/normal to have a chronic disorder? What if instead there was someone who knew what you were going through and could teach you strategies for coping with rare chronic illness?

This is not a false hope – you can live your best life! Turn pain into possibility by learning more about the elusive connective tissue disorder hypermobile Ehlers Danlos Syndrome (hEDS). No matter whether if you're struggling to get a proper diagnosis or have suffered in silence for decades. Wherever you are on your journey navigating the complexities of chronic illness, you're not alone. Join the patient community of patients helping other patients.

Christie Cox

Cheat Sheet to Getting Diagnosed with Hypermobility or Hypermobile Ehlers Danlos Syndrome (hEDS)

By Christie Cox, author of Holding It All Together When You're Hypermobile

Getting a diagnosis turns out to be one of the hardest things to accomplish when you suspect you are hypermobile. The complex medical system in the US is not patient-centric. Add to that the fact that there are only a few specialists or clinics that do exist, making for long wait times that are arduous. Worst of all is just wanting to feel heard, listened to and validated but being told that what you are experiencing is "all in your head."

Doctors are trained to "look for hoofprints" - to find commonalities to determine a diagnosis. They are not trained to recognize a rare sighting in the wild. But there's very little that's common about EDS. That's why hypermobile people have adopted as their mascot the zebra - whose stripes camouflage it in the wild, making sightings rare.

The harsh reality is that many with EDS are simply dismissed by the medical profession and sometimes even their loved ones as not suffering at all. You'll need to pack a lot of patience as you experiment through trial and error to find what treatments address your individual symptoms. **But it's important to be diagnosed:** not only is it critical for your sanity, but also for your medical records. You will be taken more seriously at medical appointments and be able to begin to pinpoint treatment solutions.

To help my fellow zebras, I recommend taking the suggested steps on the following pages to arm yourself with data in order to begin the path to diagnosis of hypermobile Ehlers Danlos Syndrome (hEDS).

"Being diagnosed with EDS is not a life sentence."

Lara Bloom, EDS Society

"Zebras in the wild have unique black and white stripes as distinctive as human fingerprints. This helps explain why none of us present with the same symptoms to doctors but have come to recognize one another."

CHASING A ZEBRA

Step 1 – Track Your Symptoms

If you think that you might be affected, first pay close attention to your body. Notice and document all symptoms no matter how unrelated they might seem to connect the dots and show evidence of patterns with your care team. Write down and journal what ails you, track and log any symptoms, and record things you've tried that have either worked (or failed) at treating the issue(s). Documentation is vital to getting a proper diagnosis. I have several editable medical templates for varying types of tracking, logging, journaling, appointment preparation and more that you can download for free at <https://bit.ly/medicaltemplates>.

Step 2 – Use Available Information to do a Preliminary Self-Assessment

To begin the process of determining hypermobility, use the suggested resources below to initiate collecting evidence on your own. This information is also critical to bring to your medical appointments.

- Use [the checklist](#) from the EDS Society website to get you started.
 - Learn about the [Beighton scale](#), a physical evaluation method to quantify joint laxity and range of motion. It uses a simple 9-point system where the higher the score the higher the laxity, with the thresholds varying for younger versus older individuals. At present it is the only standard physical evaluation used commonly to test hypermobile joints.
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CHASING A ZEBRA

Step 3 – Learn All You Can

The more you learn about the disorder and its potential symptoms and comorbidities (like dysautonomia, Mastocytosis), the more you'll understand your treatments, emotions, and the best ways to create a healthy lifestyle based on your individual needs. You can learn lots about hEDS in my new book, **Holding It All Together When You're Hypermobile** available in August 2022 on Amazon that includes support on not only the physical challenges, but also the emotional aspects of coping with a chronic illness like EDS. You should also read other books out there on hypermobility ([see the list available on my website for your use](#)), research and watch lectures and webinars by EDS specialists on sites like [EDS Wellness](#), [EDS Awareness](#), and [Hypermobility Syndrome Association \(HMSA\)](#). Lastly, read up on the [internationally accepted criteria for EDS established in 2017](#). It's also vital to understand why it's so hard to get genetic testing. Read more on [Genetic Testing for EDS](#) where expert doctor Alan Spanos MD shares guidance on how to get your family provider to diagnose you faster.

Step 4 – Seek Medical Evaluations, Diagnosis and Potential Treatment from Medical Specialists

This step can take a long time but the key is preparation. Sometimes communicating is hard when you are emotionally invested and feel overwhelmed or have brain fog. You likely will have only a few precious minutes with your doctor to tell your story, share symptoms and ask questions. It is much more likely you won't be dismissed if you come prepared with a detailed and thorough accounting of your symptoms.

- **Create an agenda.** While it is frustrating not being heard by a doctor, it can be equally disorienting to have someone really listen to you! Creating a checklist of the topics you want to cover in the typical 15-20 minute time with the provider is essential for achieving clear and concise communication. Apps are useful and readily available (use my list of useful apps).
- **Begin by succinctly summarizing your issues.** Clearly state upfront the goals of your appointment and stay focused on them.

CHASING A ZEBRA

Step 4 – Seek Medical Evaluations, Diagnosis and Potential Treatment from Medical Specialists (Cont'd)

- **Be specific regarding your symptoms.** Precisely describe the nature of symptoms, frequency, location or type and any effects on your abilities to function are key data points. Have these and a copy of your existing medications (including any supplements you take) organized alphabetically.
 - **Ask for an evaluation.** Bring copies of your Beighton scale and diagnostic criterion documents and review them with your physician.
 - **Focus on relief for your worst symptom.** Try one thing at a time. Ask about treatment options, any potential side effects and interactions with existing medications, allergies or conditions.
 - **Take notes and ask questions.** There's usually a lot of information to absorb and it can be overwhelming. I encourage you to take written notes at all major doctor appointments. You may want to go over specifics or ask them to repeat things to be sure you understand everything clearly.
 - **Bring support.** Given the complex nature of how EDS symptoms present, documentation and preparation can help, but so does bringing a "member of your tribe" (especially if its a male) to the appointment to help by taking notes while you concentrate and focus on conversing with the doctor.
 - **Follow up.** Get a copy of your visit or care summary so you can ensure accuracy and recall. Most providers offer online patient portals as well – be sure to ask for secure access. If testing is ordered, call your insurance provider to ensure prior approval in advance to avoid financial surprises.
 - **Write it down.** Document all activity in your records including medication changes, diagnosis, testing, and referrals to specialists.
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GET THE EDS 411

Cheat Sheet to Getting Diagnosed with Hypermobility or Hypermobile Ehlers Danlos Syndrome (hEDS)

Remember, you are not at the doctor for validation but for a trained professional to help problem-solve with you. Be careful not to become an internet sleuth and attempt to diagnose yourself – allow trained medical professionals to do that for you. Instead, seek understanding from other community members and find support groups at [EDS Awareness](#), the [EDS Society](#), and their patient forum at [Inspire.com](#).

For more insights on becoming a rare medical zebra searching for wellness in the wild, watch for my upcoming patient introductory eBook *What I Wish I Knew Before Diagnosis* with more information on hEDS, common symptoms and how to approach the treatment path. You can also learn how to be your own best advocate by prioritizing your self-care with my free guide [Self-Care Is Not Selfish](#), or teach the caregivers in your life how to better communicate their support for you during this challenging time with [Dear Loved One](#).

If you want to go deeper, get a copy of my book, **Holding It All Together When You're Hypermobile** available this August on Amazon. It's the story of my first-hand patient experience of chasing an hEDS diagnosis and includes decades of research and interviews with EDS expert medical providers and advocates that culminates in a practical guide to living with hEDS – giving you the help and resources you need to get the life you want despite chronic illness.

For more, go to www.holdingitaltogether.com and subscribe to my EDS-related patient resources newsletter. A portion of all book proceeds goes to support medical research at the [Norris Lab at MUSC](#) where the scientists have identified the genetic markers for hEDS and are developing a blood test to reduce time to diagnosis. See the full list of participants in the book on my website.

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ABOUT THE AUTHOR

"Prior to my diagnosis, my life used to be unmanageable, and there have been times since that I've still felt alone, confused, frustrated, and even hopeless. I understand the chronic pain and fatigue and feelings of being dismissed by medical professionals and loved ones alike. It is like pushing a boulder uphill sometimes when your body gives out just as you think you are getting stronger again. But slowly I've worked my way back to health and happiness and discovered on the way that the process I took to find my way back could help others. There are techniques that can help you self-manage the flares and hope to live well with hEDS".

Christie Cox

Author, Advisor and Advocate

Christie Cox was always bendy and sometimes witty. It wasn't until she was properly diagnosed with Ehlers Danlos Syndrome at 48 years old that she understood her quirkiness. Following decades of unrecognizable and untreatable health issues, since learning of her condition she has gone from being disbelieved to determined. Mrs. Cox now devotes her focus, energy, and passion to supporting others facing a similar fate. Patients helping patients. Pay it forward!

