

Hypermobility Basics: A Cultural Approach to Long Term Health

By Rachel Lee Davis, July 2021.



Hello dear reader! Before we start, a quick note about my background and the creation of this article: I was a dance educator and performer for over ten years. Combined teaching experience and specialty physio training provides much of my source material for understanding fascia trains in hypermobile bodies. The actual materials I will share about fascial trains, however, are not my creation. These are techniques and protocols were developed by a world-class physiotherapist for dancers, who shares her vast knowledge online for students, teachers and parents of dancers to

study and take to our local physios to help guide treatment. I met Lisa Howell¹ in 2015 at one of her workshops in North Carolina and it changed MY life for the next six years of dealing with then-unidentified hypermobile Ehlers-Danlos Syndrome. As my condition progressed to the point of not being able to dance or teach, my anchor to movement was her fascia mobility protocols, which I continued to manage symptoms and still use today in concert with Muldowny EDS Physio protocols, and OMT (Osteopathic Manipulation Therapy) provided by members of my medical care team. Lisa Howell is a personal friend of Dr. Linda Bluestein of Mayo Clinic², and has extensive experience with hEDS because so many hypermobile children become dancers. I hope they will eventually consider publishing a program specifically for hypermobile children and adults who may or may not be dancers and help support our efforts to make these techniques mor available to the average patient in the US.

I also plan to touch on the needs of children, so let me briefly give my qualifications for that. I am an educator with a specialty in literacy and child development, and I'm a woman with hEDS and high functioning autism, and mother of two hypermobile spectrum, high functioning autistic kids. Between the three of us we have worked with a few excellent physios and occupational therapists in the course of our journey to stability and ongoing preventative care. I'm incredibly grateful to these women, and other medical professionals who have taken the time to get to know my background and be willing to try some alternate techniques, as well as teach us even more about our bendy bodies and long term health.

A final thank you to the physicians and therapists who have taken time to read this, make suggestions and changes, and sign off, so to speak, on sharing it with others.

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¹ Lisa Howell, TheBalletBlog.com

² Dr. B is an expert anesthesiologist and internist who has treated hEDS and hypermobility spectrum disorders for over ten years and is going strong. She is also the author and speaker of the Bendy Bodies podcast <https://www.hypermobilitymd.com/podcast>.

Hypermobility Basics: Why are our bodies doing this to us?

I want to present a model to you for how we might approach long term health in a more peaceful and manageable way, but first lets take a look at some of the basics about WHAT we are living with, and WHY we cannot give up. Please share this section in particular with a spouse and other family members or caregivers so they can also understand what you are thinking, feeling, constantly juggling, and often worrying about on the inside.

No one knows better than I do how overwhelming the physical needs of a body can be when it is living with a hypermobility spectrum disorder. The lines between the physical, emotional and even spiritual worlds blur if not entirely disappear. We have to build a team with six or seven specialty physicians and usually have to coordinate our own care if we want anything done. We balance drug protocols with appointments, trying new approaches, and all that on top of the work of feeding yourself and maybe a family too. And just when you have a grip on life you find out one more thing that has to be dealt with. “Hope deferred makes the heart sick.” Middle Eastern Proverb.

1. Hypermobility spectrum conditions are most likely³ based in a dual dysfunction of collagen structures AND neurobiology. Treating only ONE side of it leads to ineffective solutions for most patients. *(Research is quickly advancing thanks to the Ehlers-Danlos Society and their network of physicians. A few significant voices which have informed this article are Dr. Hamonet at the Paris University, Dr. Alan Spanos and Dr. Charles Matthews who research and treat EDS in North Carolina, Dr. Sunil Patel MUSC, Dr. Henderson a well known for neurosurgical interventions in EDS, Lisa Howell physiotherapist specializing in dancers and hypermobility, and Dr. Linda Bleustein of Mayo Clinic).*
2. hEDS and joint hypermobility syndromes, arguably on the same spectrum⁴, are multi system, hereditary conditions that PROGRESS with exposure to triggers, illness and trauma (accidents, injuries, abuse, etc). We do our best to avoid acute illness or trauma, but these categories are often beyond our control. Trigger Exposure is not out of our control, and if we refuse to make lifestyle changes to manage the triggers we CAN control, many otherwise helpful alternative AND clinical medical treatments will be ineffectual and inconsistent.
3. Hypermobility spectrum disorders are a MULTIsystem condition; many branches from a central problem. Since the central issue is hereditary and occurs at the molecular level,

³ There is a great deal that medicine and researchers still do not know about the malignant nature of hypermobility disorders. The most severe cases typically fall into the hypermobile Ehlers-Danlos category while milder cases may only ever have a few minor digestive issues, seasonal allergies, bendy joints, bright mind, and trouble with injury recovery. What is known for certain is that these conditions are not benign, and while dysfunctional collagen is a primary motivation for many of our symptoms, it cannot explain the neurological disorders we develop such as dystonia, small fiber neuropathy and complex autoimmune conditions, now being recognized as far more frequent than previously supposed.

⁴ Dr. Alan Spanos, www.alanspanosmd.com

there is no cure. No way of rewriting the faulty coding. But that does not mean we cannot have a life, and even a good one! There are enough similarities in our core biology that it is entirely feasible that reliable protocols can be established for global, consistent care. Early intervention is key, late intervention is manageable, and it is never TOO late.

For a loved one or caregiver reading this, please realize that if your loved one is at any point of this process, but especially late intervention, they have been in pain for a very long time. They likely do not remember NOT being in pain. This can quite understandably lead to depression, fear of different activities and environments, foods, diets, doctors, and other anxieties. Since there is no established treatment protocol for Ehlers-Danlos, physicians try to treat our symptoms and often misdiagnose the cause leading to a progression of the illness or mental trauma in the patient. Ehlers-Danlos Syndrome is also very closely connected to Autism Spectrum disorders in both males and females.⁵ Autism is not the focus of this article, but if your loved one is also autistic (This may be high functioning autism hidden behind social camouflaging), they many have been misdiagnosed with bipolar II or other personality disorders that have degraded them and made them feel to blame for their emotional and relational struggles. Attached are a few helpful links from women with autism who are advocating for better treatment of women, and women on the autism spectrum.⁶

A Cultural Approach

We get a LOT of lifestyle advice as chronic illness patients. Too much advice really, considering what our physicians suggest alongside the social barrage of fad diets and exercise breakthroughs for weight loss, beauty and braun. Can you stand to consider more? I hope you can because what our physicians and our society DON'T have is your perspective. They don't know how you FEEL. That is why I decided to write this. I have incredible respect for my medical team and for the tools they are trying to use to help patients with their pain and anxiety. But they might not use words you can relate to, and you might feel more badgered than helped. "Oh if you just understood you would know WHY that is so hard for me." Dear reader, I know. And I've written this for your physician or therapist or friend to give to you so you can feel that they not only truly empathize with you, but that they believe what I do: You CAN get stable. You CAN feel better than you do now. You CAN do this. You know you have to do something, so why not try something that has worked for other EDS patients, written by an EDS patient? Here goes!

⁵ Academic article, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7711487/>. <https://www.autism.org/researchers-have-identified-a-relationship-between-ehlers-danlos-syndrome-and-autism/>

⁶ AspienWoman, <https://taniaannmarshall.wordpress.com/2013/03/26/moving-towards-a-female-profile-the-unique-characteristics-abilities-and-talents-of-asperwomen-adult-women-with-asperger-syndrome>, The Art of Autism, <https://the-art-of-autism.com/females-and-aspergers-a-checklist/>.

Culture is the word humans use for the unique mixture of beliefs and behaviors that define a small or large community of people. I say humans because when you're discussing culture you can't break it down into any more specific language without losing an essential aspect of being human. Cultural elements are often broken down and categorized as language, food, rituals, clothing, art, and many others. The reason I LOVE the idea of "culture" as word for what it means to deal well with EDS because it puts a profoundly positive spin on the otherwise insanely complex balancing act we perform daily. A protocol is something you "Obey." A culture is something you "Create." By building your own mini-culture for living with a hypermobility spectrum disorder, we are building a fabulous web of support with enough strands and stick to handle whatever flies our way. Below, I have described 5 Basic Strands, or categories, for a Cultural Approach to Managing Chronic Illness with a few tips in each to help the concept take shape. Your personal mini-culture may need to add a few more strands! Our family has a strong Art strand where we use drawing, movement, music and theater to keep our lives full of imagination and hope, essential mental health nutrients.

Tip: You don't need to take notes or try to memorize this the first time through! I've created a second handout of each element with expanded suggestions and baby steps for how to get started building yours.

5 Basic Elements for a Cultural Approach to Managing Chronic Illness

1. Language is Power

- a. As your own best advocate, it will empower and encourage you to spend time studying the vocabulary of your condition, and dialects of the various medical disciplines you will have to encounter.

2. Food is Community

- a. Diet has become a trigger word in and of itself. Too many people touting a one-thing cures all or overcomplicated theories that cause us even more anxiety. Still, it is a huge issue in the EDS community and we cannot ignore it. What we CAN do is build our diet needs into a household culture for everyone based on logical hypermobility spectrum disorder needs and established protocols based on mast cell interactions. What we need is something we can live with long term that is clear enough to teach to our kids and guide us when we want to eat out, travel or enjoy a satisfying snack.

3. Rituals for Life

- a. All great cultures have rituals that sustain them. Archeologically speaking, all of the ancient and modern systems for rituals have one thing in common (and I don't mean religion!). They all engage the BODY. In ancient times the rituals of body

were not separate from religious practice, but that has changed significantly as science has shown just how beneficial some of these religious ritual body movements are to human health. Yoga, meditation and mindfulness, dancing, just to name a few. Perhaps you already enjoy a Body Ritual in your family culture, but often our condition reaches a point where we can't dance or do yoga anymore because of pain and inflammation. So lets focus on another set of Body Rituals that can a starting place: Physio therapies.

4. Dress to Impress Change the World

- a. Culture and clothing are nearly synonymous terms. Why should it be any different for us? It is worth both the time and the money to research and invest in clothing that support the needs of our bodies for stability and protection. In the same vein, it is worth the time and effort to STOP wearing clothes that can cause us harm.

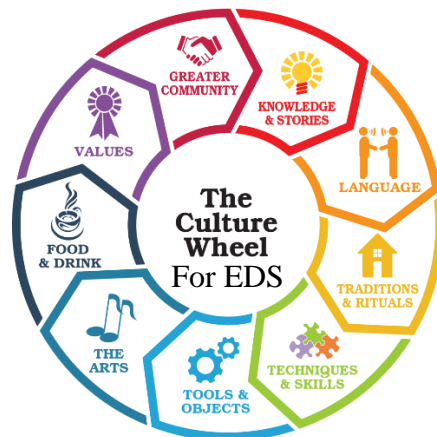
5. 7 Wonders of the World

- a. Culture always shows itself in architecture and structures. For us this element is about our home and work environments, and USING structures to keep from exposing our bodies to triggers. Each family may have different needs, or perhaps not need some of these things yet. See the accompanying handout for suggestions!

And there it is. Now we have to start threading them together. Building the web depends on you. It depends on you deciding that you CAN handle this, and surround yourself with support, encouragement and routines to help you. Spouses/Partners, you have the potential to help us become really and truly stable, or pull down our entire web. I hope you choose the former, like my incredible super hero husband did. Cooking, childcare, appointments, listening for hours as I processed through the material of an informal two year degree in medicine. We NEED you. Now, grab the accompanying handout and let's get you and your new team started.

What are your essential values for Life?

How can art and music other beautiful things be a part of your journey?



What do you want YOUR EDS story to be?

Are you building your toolbox for both health AND fun?