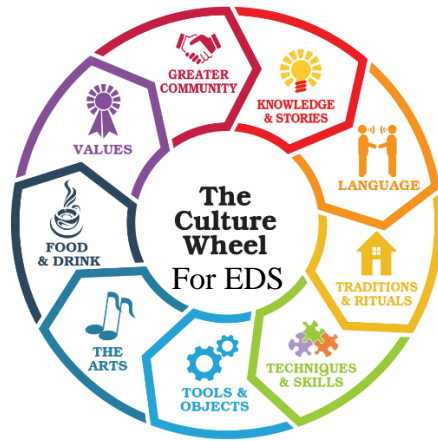


5 Elements for a Cultural Approach to Managing Chronic Illness

What are your essential values for Life?



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

Are you building your toolbox for both health AND fun?

What do you want YOUR EDS story to be?

Hi fellow Zebras! And all other wonderful human beings who have downloaded this for help. This is a longer document designed to give Reasons, Resources and Encouragement for using this mode. The Reasons are not just for you, they are for caregivers who don't know what you are feeling or needing and need someone to explain it. The Resources are for your whole family or whatever your cultural unit looks like. Add more! Email me great suggestions too. And the encouragement is because I can't give advice to people without reminding you that you are WORTH it, that you CAN do this, and that you are NOT alone. I suggest approaching this with a highlighter and using the space provided in the left margin and the bottom of each page for your own notes. Ciao!

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1. Language is Power

By learning the language and vocabulary of our conditions we empower ourselves to be the best advocates with medical professionals who are not typically used to a patient being able to understand and clearly articulate their own needs.

- a. Keep a diary of terms; learn which specialties use which terms for which issues, and even create some of your OWN linguistic metaphors for describing what you feel and observe! For example: What most neurologists ask is “Do you feel a shock? Like an electrical shock?” I know what they are talking about but my body’s feeling FOR THE SAME CONDITION tends to feel more like the burning, tearing of a pulled muscle rather than an electric shock. Knowing this means I can tell them “Yes” even though I’d prefer different adjectives.
- b. Take time to study diagnostic criteria. Doctors don’t usually FEEL any of our symptoms themselves, so when they ask you what you are experiencing they are looking for very specific words that they have been trained to recognize. If you know what words they are looking for, you can honestly evaluate your symptoms and MATCH THEM to the vocabulary. Voila – same day diagnosis. (Ok, maybe a little over exaggeration of timing but really, it does work).
- c. Physicians tend to NOT know the language of other specialty conditions with the accuracy and skill of that other specialty’s dialect. When you go to a specialist, have prepared IN WRITING the symptoms you have FOR THAT SPECIALTY. Focus in their comfort zone and wait for them to get interested before opening up your other related conditions.

2. Food is Community

Diet has become a trigger word in and of itself. Too many people touting a one-thing-cures-all or overcomplicated theories of nutrition that cause us even more anxiety. Still, food 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. Using established protocols for nutrition in individuals with unstable mast cells (regardless of diagnosis), we can help our bodies stabilize, and help our children avoid inflammation from the start. What we need as EDS patients is something we can live with long term that is clear, teachable, and can guide us when we want to eat out, travel or enjoy a satisfying snack with friends.

- a. If a child is on the hypermobility spectrum, they have been born with “twitchy mast cells” (Dr. Iweala, UNC, 2019) likely because of the neuro-collagen dysfunction. They don’t develop later! What develops later is the progression of the malignant nature of this mast cell instability, which is often not deemed pathological until adulthood or until it’s so severe that a child or teen is starving due to severe reactions to food. Our biology has the potential to progress from a basic mast cell activation disorder to a full blown syndrome and mastocytosis.
- b. Why not build an eating plan centered on mast cell specific anti-inflammatories? Also called an **anti-histamine diet**. This is a protocol developed for acute mastocytosis patients who are too far gone to do anything EXCEPT eat this way. Logic says that if we have a genetic condition that is based on the same molecular reactivity, why not aim to soothe it BEFORE it makes us so sick?
- c. There are many helpful blogs, medical and patient created articles and lists for this idea. It is not new, but too many doctors are not aware of it when treating patients, and too many patients refuse to make lifestyle changes even if they could radically alter our disease progression. No more of that. *For more on understanding anti-histamine diet options and building an environment for mast cell control naturally, see “Going Cold Turkey: Anti histamine diet basics.”*

3. Rituals for Life

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 due to pain and inflammation. So, lets focus on another set of Body Rituals that can be a starting place: Physio therapies.

- a. Physio Therapies – called physical and occupational therapy in modern medicine. *Some also believe that mental health therapy should also be included as a fundamental aid to the body's recovery, a connection long denied by modern science but reflects our ancestral practices!*
- b. Joint and soft tissue injuries in the hypermobility spectrum disorders do not just appear out of the blue. The body is born with the potential for these injuries from the very start. How, when and what occurs through the course of development, puberty and adulthood depend upon the environment the body is in. Perhaps the twitchy mast cells, unmitigated by diet and management of environmental triggers, cause the first signs of acute inflammation. Perhaps exposure to trampolines, roller coasters or more aggressive traumas accelerate the progression of injuries or cause them to seem to appear quite suddenly after a single event.
- c. **Good physiotherapy**, which includes occupational therapy during developmental stages, should target the body holistically.
- d. **Good physiotherapy** should target the neurobiology that allows us to develop balance and coordination. This is primarily the vestibular and proprioceptive systems of the body. Hypermobility spectrumites are BORN with bodies that do not naturally develop these systems with efficiency. Much like Autism body-brains need support for developing the sensual receptors that govern social interactions and communication, hypermobility spectrum kids need support for proprioception and vestibular senses that would otherwise stabilize the joints and soft tissue through playtime and natural exercise.
- e. The next article in this informative *series is called Dancing for Joy: Finding movement again in hypermobility spectrum disorders. I have included a special page to help you find and interview a good physio. Please take it to your physicians so they can also learn about good physiotherapy for hypermobility.*

4. Dress to ~~Impress~~ Change the World

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.

- a. UV protected clothing – if we don't SEE the reactions in childhood, we definitely do later. UVA and UVB protection help decrease mast cell reactivity. Get an umbrella! Get a throw on UV shield treated scarf! Protective clothing is safer than sunscreen too.
- b. Compression clothes – we usually don't get these until our POTS tests come back thumbs up. Did you know that one of the fastest ways to improve proprioception with benefits in mood, behavior, sleep and injury prevention, is compressive clothing? It's standard for autistic kids, and while there is ample evidence showing that Autism and EDS are VERY closely connected, parents shouldn't wait for diagnosis to help their kids. Compressive under shirts and leggings are easy to buy in packs online, and with a little training, your kids might just LOVE how they feel.
 - i. It has been demonstrated that mental health improves with compression because the sensory input relieves the constant neural messaging of instability that directly affect mood and self-image.
 - ii. Consider 100% cotton since MCAS/MCAD can lead to allergic reactions to fibers like polyester and rayon, or at least make these VERY uncomfortable.
 - iii. If you cannot wear compression clothes due to nerve pain (allodynia) consider regular time in the water. The water acts as a natural compressive to boost proprioceptive development.
- c. Anti reflective AND Polarized sun glasses, blue light filters
 - i. Don't underestimate the power of sight. Visual photo sensitivity called photo-oculodysnia is quite common in hypermobility disorders. It can trigger migraines and other global reactions through the body.
 - ii. Maybe you don't feel this now, but perhaps your body has never really felt the difference? Try using less LED lighting, stay away from fluorescence, turn on blue light filters on every screen, and wear anti-reflective and polarized sunglasses for a week and see how you feel.
- d. Ditch the heels – high heeled shoes were proven LONG ago to cause pelvic instability and put the wearer at risk for chronic ankle injuries and plantar fasciitis.

5. 7 Wonders of the World –

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, but here are a few things you can do in your home or family cultural unit to help with the long term needs.

- a. Thermal curtains – also called black out curtains
 - i. Not only is light a challenge for many of us, but so are heat and sleep. We don't need every window to be literally blacked out, but thermal curtains with some UVA/UVB blocking fabrics can help your home feel less triggering. We use full blackout curtains in the bedrooms so that we can control light for the kids' sleep routine.
- b. Air purifiers – When I get to buy or build my own house there is going to be NO installed carpet. Dust, dust mites, and other common particles of houses can be a bear to deal with when you have twitchy mast cells. They are one of the first signs that your children might be struggling too.
 - i. In addition to anti-histamine diet in our household culture, air purifiers have made it possible to adopt a hypoallergenic dog, literally cured my sons diagnosed asthma and my daughters chronic sinus infections and upper respiratory issues (also medically documented for her entire life up till we implemented the diet culture).
- c. Investing in a UV protected tent for the pool or beach – this was necessary for me and gives me peace of mind for the kids' long term health.
- d. Weighted blankets for sleep and soothing – We can't live without them now. Weighted blankets, like compression clothes, are like 10-12 hours of proprioceptive therapy a day, all during sleep. It helps the body that struggles to find itself in space maintain and support a healthy sleep pattern. Sleep issues are one of the diagnostic observations for hEDS, and cause constant issues in adulthood. Start early!

And there it is! 5 Elements for beginning to build a culture of health for you and yours.

Baby Steps Towards Building a Cultural Approach

Now we have to start threading these elements together. Building a culture depends on you. It depends on you deciding that you CAN handle this, and surround yourself with support, encouragement and routines to help you even when it is exhausting to communicate.

We all need extra help in life. If you need help organizing your new culture, finding physicians, walking through a new diet plan, learning language and symptoms through conversations, help approaching new appointments or simply to let of steam, please visit my website at www.RachelLeePAC.com. I offer both one time and regular patient advocacy consulting for patients with EDS, Autism and other chronic illnesses, and I would love to be with you on your journey.



Spouses/Partners/Caregivers/Parents - Listen UP! You have the potential to help us become really and truly stable, or to drown us in anxiety and pain. I hope you choose the former, like my incredible super-hero husband did. After 10 years of watching me try to do everything we're expected to do as moms and partners, on top of trying to pursue some of my own passions do that I didn't die inside, we realized that in order for me to put in the work that stability would take, I needed a break. He took over ALL of the cooking, childcare, driving to appointments, grocery shopping, and listening for hours as I processed through the material of an informal two year degree in medicine. He let me educate him on the new diet needs me and my children would have to have, and humbly supported me while I experimented, failed, adjusted, and fought back every step of the way. **We NEED you.** And because of his efforts we have been able to build stability and health with a team of incredible medical support for me and both children, in less than 2 years. So that you can understand, it takes the average female patient **over 7 years** to get proper treatment and diagnoses for chronic illnesses and that does NOT INCLUDE STABILITY or building a new normal for themselves or anyone else. If you love them, commit to this like you've never committed to anything before. Now, let's get you and your new team started!

1. BABY STEP 1: Language - We can't focus on one element too much or we lose our balance. However, I suggest beginning your focus on Language, especially if you are newly diagnosed. Here are some resources for helping you learn your new dialects!
 - a. Books:
 - i. Disjointed, ed. Diana Jovin (authored by over a dozen EDS experts in North America).
 - ii. Understanding Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder by Claire Smith
 - b. Articles:
 - i. Going Cold Turkey: Anti-Histamine Diet Basics by Rachel Lee
 - ii. Dancing for Joy! Finding movement again in hypermobility spectrum disorders by Rachel Lee
 - iii. Resources for Fascial Health – practical handout by Rachel Lee
 - c. Web Links
 - i. www.EhlersDanlos.com

2. BABY STEP 2 – Food and Ritual.
 - a. Food: You'll have to double up on this one, but hopefully my articles have given you a decent start. As you work on building up your food community you can choose to really go Cold-Turkey (just don't eat it), or take a more gradual approach to slowly replacing food items and relearning your core home menu. My BEST advice is to please not try to make food creative and interesting when you do this? Your family can handle eating the same things for a few weeks while you Build a Culture for everyone. Loved ones, it's not just a fad! It's long term health. Give your support for 3-5 months and watch the amazing changes.
 - b. Ritual: I hope *Dancing for Joy* is both an inspiring and practical read. As you work on finding your trusted physiotherapist and establishing treatment, this article can give you a grounding in safe, healthy at-home practices that you can begin right away. Any good therapy program for hEDS begins with breathing and exercises lying down, learning to listen to your body. Working on this every day will most definitely help you to build fascial health. However, if all you can do right now is just drink water, that's OK! Start your fascia work 3 days a week, and focus the other 4 days on drinking water like a shark.

3. BABY STEP 3 – Repeat

- a. Repeat Baby steps 1 and 2 until you have strengthened each element enough to really lean on your web. You'll notice strengthening by noticing when things become second nature, and require less thought to complete. You'll notice strengthening when your anxiety about a meal or exercises begins to fade and confidence grows. That's when it's time to REVIEW what you know, AUDIT the plan, and ADD something new. Repeat, repeat, repeat.

4. BABY STEP 4 – 7 Wonders and Dress

- a. Baby step 4 is a bit like a strobe light. Looking at 7 wonders of the world or Dress to Impress may happen intermittently. You have a bad reaction to sun one day, decide you can't take it anymore and go invest in a \$50 UV jacket or umbrella. A child is so sleep deprived that they are suffering and so you break the flow to get him a weighted blanket and dark curtains. That is OK. And more like what real life is like anyway. Now it's time to really build these last two elements. They require time and money, which means a plan is good.
- b. Make a list of what you need. EVERYTHING you need or think would make life easier to live without becoming a hermit. Don't worry about price. Enjoy the idea of maybe going camping without getting sick, or a day at the beach. What do you need to do that safely? Work that in with your medical needs as well.
- c. List top priority items that you can invest in one at a time, in order of importance and urgency. Begin setting money aside every week, or as it comes in, towards these purchases. If you are low-income like our family, you may find it helpful to buy a bunch of urgent and important things all at once with a tax return or gift money, even if you're not ready to use some of them. Be sure to invite family to love you by helping you get healthy for birthdays – pink compression sleeves and knee pads, a superhero weighted blanket, special water bottles, etc.

5. BABY STEP 5 – Live.

- a. The awesome thing about this approach is that you can just keep using it. It'll help you focus on what is urgent and important when needed, but also remind you that the GOAL of all of this is to HAVE A LIFE, not just survive!

You are worth fighting for, dear reader. You are amazing, and I know you can do this. I know because you and I are alike. I know what you are feeling, and I know that in spite of the pain and trauma of what your life has been like that somewhere in there your body there is a soul still alive, kicking and still capable of being amazing.

Sincerely, Rachel Lee, www.RachelLeePAC.com