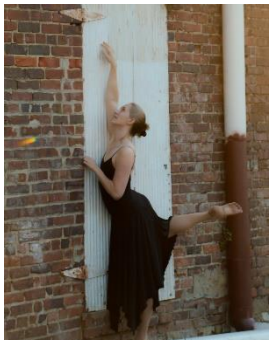
Dancing for Joy! Finding movement again in hypermobile spectrum disorders.

By Rachel Lee Davis, July 2021.



In 2015 I had the opportunity to take a dance educators workshop with the amazing Lisa Howell. She is from New Zealand and trained in Australia, which are the two leading nations in the world for physiotherapy techniques. It didn't take long to realize that the fascial mobility approach, discussed in detail in Anatomy Trains by Thomas Myers, could help anyone. I practice the techniques on family and friends as well as myself and incorporated it into my teaching at every opportunity as long as I could. Life happened, and after several hospitalizations and many confused doctors, I was diagnosed with Hypermobile Ehlers-Danlos Syndrome as a stated part of the spectrum of hypermobility disorders. As my husband and I began to understand hEDS, we quickly realized why the fascial mobility approach had always worked for me! We also realized why it was not "sticking" (small inside joke. Fascia sticks to itself when it is injured and dehydrated). As we continued my fascia routines throughout the next year of tests, diagnosis, new medications and finally a life changing surgery, it became evident that the technique could be a real game changer for the hEDS/JHS community. My recovery was methodical, and carefully observed by numerous physicians and physical therapists who have asked about what I did differently. Of course, with EDS there is never only ONE thing that helps recovery! We are juggling a never ending balancing act where too much or too little in any one direction can cause it to fall. But one thing that most definitely NEVER helps is bad physiotherapy or zero physiotherapy. The purpose of this article is to share some of my story, and to teach about fascial mobility in hEDS from a patient's perspective. I've also included some tips and advice for finding and vetting a good physiotherapist for you and your loved ones.

Disclosure: This article is not comprehensive, and should NOT replace a customized therapy plan of care from a qualified and Ehlers-Danlos Syndrome knowledgable and experienced, professional physical therapist. Please take this article to your physiotherapist to help him or her support your care. Please take this article to your neurosurgeon, headache specialist and personal physician so they can see what you are doing at home, and hopefully help advocate for better physiotherapy for their patients! More information can be found at HypermobilityMD.com, TheBalletBlog.com, and AnatomyTrains.com, as well as general searches about fascial health.[1]

Rachel Lee Davis, July 2021

[1] https://www.anatomytrains.com/fascia/. You can also search for a provider in their worldwide network.

Part 1 – What is Fascia and why is it so important for hypermobility syndromes?

Fascia is the largest organ in your body, far larger than your skin. It not only runs under all of your skin, it also wraps around all of the major structures of the body and connects the organs to each other in a very unique way. Fascia is made up of different proteins than muscle and as such, has quite a different structure. Less like muscle fibers and more like tubes of water, fascia communicates faster than the nervous system and can even anticipate movement and shift before you are consciously aware of moving. Fascia creates cross connections from the interior systems to the periphery systems of the body on what are called fascial planes. When you wake up stiff in the morning you are feeling fascia on planes that have not moved during the hours of sleep and compression by the body. When a site of injury is stiff, or a surgery has adhesions between your skin and the organs beneath, that is fascia.

Healthy fascia slides smoothly across itself. Unhealthy, damaged or dehydrated fascia (it is primarily water) does not. It also stops sliding and sticks together with lack of movement, a considerable issue for patients with hypermobile EDS. When fascia doesn't move for a long time and is dehydrated, it forms adhesions that are a kind of fuzzy thick scar tissue that restrict muscle function, organ function and nerve function wherever it sets in.

In the Ehlers-Danlos population, our bodies become filled with these adhesions because of the frequent soft tissue injuries, dehydration from POTS, inevitable fear of movement. While anyone is affected by lack of movement, back problems and plantar **fasciitis** in desk jobs for example, Hypermobile Spectrum Disorders have both greater risk and greater need. As research and data grow from the neurologists, rheumatologists and neurosurgeons beginning to get involved in our care, the more they realize how difficult it is to manage pain in our bodies. Some of the typical treatments, botox for example, work initially, but we keep on needing them at a much higher frequency than others. In the meantime, our bodies are becoming toxic from medications and pain killers we can't live without. What the Anatomy Trains approach offers is a set of protocols that an EDS patient can do at ANY point in their care. They are safe, gentle, and progressive in a manner that allows careful observation of physiological dysfuctions without aggravating the problems. A physiotherapist can catch issues before the patient has a flare, and the patient has a straightforward and safe set of movements that they can do at home every day, knowing it is helping their entire body.

I began using fascial mobilizers after a workshop with Lisa Howell in 2015. I subsequently purchased half a dozen of her books with different protocols for core strength, deep stabilizers and rotators, feet, and other elements of our bodies that dancers must focus on. Far from being compartmentalized, her approach begins from the same place every good EDS physio protocol begins: Lying down, breathing, and learning to listen to the body. Her mantra (simplified) is Isolate, Mobilize, Strengthen, Integrate. After my EDS diagnosis and the subsequent diagnosis of CCI and occult tethered cord, we realized that I could FEEL the cord teathering in isolation because the fascia adhesions that had filled my body and restricted my spine in years past were all dealt with. In addition to fluids and traditional Chinese acupuncture,

fascial adhesions around the spinal column and pelvis had been resolved, and when the cord was detethered, my entire spine decompressed ½ inch (observed, measured and tissues around the spine and neck manually tested by my primary physician and another incredible EDS physical therapist in my region). I NEVER thought I'd have a body like this again this side of heaven. Perhaps there were miracles along the way, like meeting Lisa Howell and having Dr. Sunil Patel in my insurance network. But I also believe in the kind of miracles we create for others, and I hope fascial health can be one of those for you.

Fascia in EDS

Fascia is NOT like muscle. Fascia is a complex tubal system of collogen,and elastin filled with water. Check out this video for a close up https://www.youtube.com/watch?v=uzy8-wQzQMY. Regardless of diagnosis, hypermobility means some sort of collogen dysfunction, which means fascia is even more vulnerable in our bodies than it is in others. As we began play on our bellies and crawl and walk, our fascia didn't teach our joints where to go in space, inhibiting the development of strong proprioception. If part of that fascia adhered to the inside of your spinal column, it could slowly compress the spine over time as you grow causing pain, damage to discs, pulling on the brain and more. This is beginning to be identified as occult tethered cord, a very real syndrome that currently has no reliable imaging technique for diagnosis even late in life, let alone early intervention.

Did you know that one of the largest fascial planes of the body consists of two lines of fascia that run from the top of your head, down both sides of your spine and crisscross right at lower lumbar region where we most frequently tether, and continues on down the back of the hips and the back of the legs into your feet. When this plane is restricted it creates rope like bands in the hamstrings, chronic leg pain, pelvic instability, often plantar fasciitis, and spine instability that create chronic muscle spasms through the lower back and hips. The spinal column is wrapped in a tissue called dura matter that is known to dysfunctionally "tether" to the surrounding structures or be tethered to by the underlying spinal cord and meninges.[2] Want to guess what dura matter is!?? FASCIA. It's the body's deepest layer of fascia in fact. And in our progression of illness and ever-increasing pain, so much fascial scar tissue builds up around the structures and muscles the pelvis, the entire length of the spine, and other joints in the body.

You're probably even more aware of your body now than when you started this article. That's good! But not if it leaves you feeling hopeless about what's next. Perhaps you're experience of PT has been even MORE pain, not less. If it is, you're not the only one. Most physicians know VERY little about good physiotherapy, let alone the particular needs of

[2] There are several different types of cord tethering. However, inelastic filum terminale, the classic finding for Occult Tethered Cord, is currently known to be the most common in Ehlers-Danlos. It can only be seen in imaging very rarely, usually after it has created havoc in the surrounding spinal structures. A cord may also be tethered by fatty tissues, tumor or other causes. https://www.aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Tethered-Spinal-Cord-Syndrome

hypermobility patients. What if every EDS patient had access to physiotherapy that could properly address this essential organ in our bodies from the very first day of diagnosis? It will take work, but it's not impossible. That dream is why I wrote this article for you, and it's accompanying handout for Fascial Health. I want to see other patients with stories like mine. I want to see the children in hypermobile families know that they can have help with the random pain in their legs or backs or arms without a scary trip to the doctor. I hope you might end up like me, dancing for joy again IN SPITE of my disorder.

A special note here for Ehlers-Danlos lifers who are now wheel chair bound or feeling limited by other accoutrements. There are many ways to move, and to dance. Perhaps you'd like to sing, or act, or do ballroom! Maybe you want to travel and feel like that is also gone. The possibilities of technology for those in wheelchairs now is astounding. There are many parts of your body that DO still work and that you can enjoy. It may be a bit harder to find help, you may have to be extra brave and get creative in ways others won't have to consider. I want to assure you that there are many fascial mobilizers and dural mobilizers that you CAN do, that can help you feel better.

Neurological and Spinal Manifestations of the Ehlers–Danlos Syndromes, Henderson et al.

https://www.ehlers-danlos.com/wp-content/uploads/2017-American_Journal_of_Medical_Genetics_Part_C__Seminars_in_Medical_Genetics-17.pdf

Part 2 – Interviewing your new physio therapist

What is a GOOD physiotherapist for Ehlers-Danlos and Hypermobility?

First of all, a good physio will VERY gently evaluate you without demanding too much movement. They should not challenge you with "Lets see if you can do ___!" They should begin by testing various muscles, posture, and gentle movements in lying, sitting and standing.

Second, manual examination of the neck and other joints. A good EDS physio knows how to gently test your cervical vertebra while you are lying down, in order to feel muscle guarding and end-ranges of motion in the bones. End-range means the natural point at which the ligaments HALT the movement of the vertebra. A good EDS physio will NOT treat you without dynamic MRI imaging and a neurosurgical evaluation, depending on what they feel in your neck and spine. Go back to him/her when you do!

Beighton Score – This has long been held as the gold standard for measuring hypermobility. So much so that physicians will rely on it for DIAGNOSIS, when it was never meant to be a diagnostic tool. For one thing, the Beighton does not consider hypermobility in the ENTIRE body, rather only a limited observation of limbs, lower trunk and fingers. A good physio will do a Beighton score AND observe hypermobility in other areas of your body.

Third, soft tissue interactions. Make sure your physio can describe to you what "dystonia" is in Ehlers-Danlos versus Parkinson's. Also mention periodic paralysis, myotonias,

allodynia, and, of course, fascia. Do they know what fascia is? What is their approach to your body considering the likelihood of significant restrictions, adhesions and difficulty with hydration? Compare their examples to videos in the accompanying handout before making a final decision about working with ANY physio who claims to "understand fascia."

Fourth, a good physio is teachable. They should always work with you personally, NOT hand you over to a tech assistant. They should be open to articles you share about your diet and desire to approach your body with an Anatomy Train/Fascial Health approach. One significant sign of an unteachable physio (or doctor) is one who doesn't ask you personalized questions. That is different from "personal" questions! They should pick up enough unique information about your body within the first 20 minutes to be able to craft some truly unique questions about the story of your body. Go with your gut, but if you give them a second try and they STILL don't see you as a unique individual, go find someone else.

Fifth, a good physio for EDS should demonstrate knowledge about Ehlers-Danlos and it's comorbidities in a NON Arrogant manner. Constantly reassuring you, even interrupting to do so, is a sign that they are not really listening and possibly not as experienced as you need.

- Ask them how they handle POTS and the breathing issues, syncope, pre syncope, dizziness, drops in blood pressure and proprioceptive issues that come with that (even if you don't have an official test for type, if you have EDS you have autonomic dysfunction and need a physio who is familiar with that).
- Ask about Mast cells – mast cell inflammation is NOT just in the skin and gut. Some people, like myself, have our primary reactions in our spinal fluid! Twitchy Mast cells are a global body response to triggers, and exercise is one of those. Your physio's plan should be gentle and slow on your body, carefully monitoring headaches, nerve pain, brain fog, breathing issues, tingling or numbness, and any of your own known mast cell flares. (Mast cell flares can be delayed reactions. A good physio will ask you to follow up within a few hours or the next day after a treatment to make sure you're ok and monitor their program's effectiveness for you! Especially if they tried dry needling).

Sixth, once you are able to begin treatment, a good physio will start by giving you exercises to do LYING DOWN and without resistance (no weights no bands!). They will focus on your breathing and your core stability. They will evaluate you for leg length discrepancy and determine if it is Functional (can be fixed with isometric adjustment) or Structural (requiring a shoe lift). Once your pelvis is level, you can begin core strengthening. A good physio will emphasize your core stability with greater priority than any other area of the body, and constantly re-check your core before progressing your plan of care.

Seventh, a good physio will go slow. He/she will closely monitor your progression. If you do your homework, you can spend an entire month working on only 3-4 basic exercises! That is GOOD. Your body has to retrain a lot of movement, stillness and, well, existence, and it will be healthier and happier if you give it time.

Finally, A good physio will as you what your goals are. Not just what you think you need, but something you really, really WANT to be able to do again. A good physio will be creative and help you dream.