From Me and My Friends, to You and Yours
Hypermobile Ehlers Danlos Syndrome (hEDS)/ Hypermobility Spectrum Disorder (HSD)

What is hEDS/HSD?
There are 13 types of Ehlers-Danlos syndromes, with hypermobile Ehlers-Danlos Syndrome/Hypermobility Spectrum Disorder being the most common. It's a connective tissue disorder, caused by a genetic defect affecting the gene that produces collagen (a type of connective tissue). Collagen is everywhere - from ligaments to blood vessels to digestive organs and even eyes - so EDS has a big impact on someone's body! A good analogy is that where your connective tissue is like superglue, mine is like a poundland glue stick. hEDS is considered the most benign of the Ehlers-Danlos Syndromes as it mainly affects the joints. The main symptoms are: joint hypermobility, widespread joint pain, dislocations and subluxations (partial dislocations), fatigue, skin that bruises easily or is more stretchy than usual, and frequent injuries.

It often comes with other common comorbidities including:

- Postural Orthostatic Tachycardia Syndrome, in which someone's heart rate increases a lot when they stand up, and this causes symptoms like dizziness, palpitations, and fainting
- Gastroparesis, which is when someone's stomach empties slower than usual, causing nausea, stomach pain, and vomiting
- Mast Cell Activation Syndrome, which causes allergic reactions of varying severity, sometimes seemingly at random

There are many other comorbid conditions, but these are the most common. Not everyone gets all of them, or any at all, but lots of people have at least one.

A diagnosis of hEDS is made based on excluding other causes of the symptoms, often with blood tests, and using the diagnostic checklist. Those who have hypermobility with symptoms like pain, but do not meet all the criteria on the checklist are diagnosed with Hypermobility Spectrum Disorder (HSD)

How does hEDS/HSD impact my body?
Because connective tissue is everywhere, my HSD causes a wide range of symptoms. The most significant ones are chronic pain, chronic fatigue and subluxations. My chronic pain is constant in my neck, shoulders and hips. Other joints are affected more sporadically. I would say that I've had pain in pretty much every joint over the past few years, including fingers, elbows, ribs, etc. I injure myself frequently, which is another cause of pain. This is because my HSD causes me to have poor proprioception - I don't really know where my body is in space - so I walk into and trip over things quite often! One of the most difficult symptoms to deal with is fatigue. It's believed fatigue in hEDS/HSD is caused, at least in part, by muscles having to overcompensate for weak ligaments. Fatigue is different to being tired, as it is not alleviated by sleeping. When my fatigue is bad, it can make it difficult to study, talk, sit up or even think, as it can feel like a heavy cloud of fog on my body and mind.

How does hEDS/HSD impact me mentally?
Being in pain and fatigued all the time is very draining at times. I can't always do everything I want to do, and while this is something I've become accustomed to over the past few years,

that doesn't make it any less difficult. There is often a feeling of loss and grief that comes with being chronically ill, whether that's because of no longer being able to play sports, missing out on events like concerts, or even little things like holding my arms up long enough to plait my hair. I can also get quite stressed when I feel like I'm letting friends down if I don't come to something, or teachers down for not doing work, etc - they inevitably don't mind, but that doesn't stop me feeling guilty.

Having HSD also adds a lot of unpredictability to my life, due to the nature of flare ups. Sometimes I know that I've done too much and it will cause a flare, but more often than not it seems random, that I've done everything right and still feel awful. This has caused plans to be changed at the very last minute more times than I can count, when I wake up feeling awful or crash halfway through the day.

On the other hand, my HSD has also made me a lot more resilient, particularly to little things that used to throw me off. A day derailed or something not going exactly to plan doesn't bother me as much as it used to, as I've had to get used to my body being the culprit of this many times. It's also made me more empathetic and understanding of what other people are going through. I wouldn't say these positives are worth the pain, but I am still grateful for how my HSD has impacted me positively.

How does hEDS/HSD impact my life?
HSD affects every aspect of my life. I plan my days in quite a lot of detail in order to maximise energy and minimise fatigue, which often leaves little room for spontaneity. I can't do as much as my peers because I need to rest more, and this usually means sacrificing fun and the things I really want to do in favour of survival. Long days are difficult because I have to rest often, and being upright gets increasingly painful as time passes. I take medication around 3-5 times a day, and sometimes walk with a stick to minimise pain and fatigue. I expend a lot of time and energy on managing my symptoms, and this includes (but is not limited to): doctors appointments and the admin that comes with them, managing injuries, doing strengthening exercises and stretching, resting when needed, and managing medication

Despite my best efforts, I still cannot fully control my HSD. Bad symptom days and flares are unfortunately inevitable. When this happens, I have to cancel all plans I can't manage, and shift my focus towards resting. This includes education - I try my best to prioritise my health over my work, although sometimes I struggle to draw the line. My life has been hugely changed by my HSD, but I have learnt that this does not mean it will only ever be awful, and I continue to find joy in unexpected places.

A friends' perspective
I first became friends with Sophie in the early days of January 2018, I knew her first as a friend of a friend and we slowly started interacting more and more through Twitter. When she first opened up to me about her condition I'll be truthful and tell you that I knew next to nothing about Hypermobile Ehlers-Danlos syndrome (commonly referred to as EDS). My basic level of knowledge consisted of seeing my friend express that they were in pain all the time and how they had to miss certain events because she hadn't paced herself in the run up to it. All in all I was quite oblivious.

In taking the time to learn about her condition I came to realise that a little bit of knowledge can help when supporting my friend, Hypermobile EDS. The main thing I've learned is that you can be empathetic to the ends of the earth but you can never truly understand what she's going through and that is a vital distinction to learn. Many a time Sophie has told me about yet another doctor who didn't listen to her or a flare up that has ruined some plans and all I can do is listen, support and love her through it all. It doesn't have a finish line, this is a lifelong thing and therefore your love and understanding also have to be lifelong.

The smallest acts i've found can be supportive to your friend for example if you're going to queue somewhere for an event make sure ahead of time there are adequate places for your friend to sit, or if necessary have the courage to ask the people running the event to provide a chair for your friend, they may be hesitant on 'inconveniencing' people but it's important to note that some people would rather suffer in silence than speak up, so be able to be that voice for them if required!

Also be flexible and adaptable if a flare up occurs it may ruin certain plans and your friend will undoubtedly feel awful for 'ruining plans' understand that it's completely out of there control, change the plans to a move low level physical activity and ensure that as long as they're not too fatigued you still hang out, pacing is effective but not foolproof and when plans fall through learn to understand and adapt than harbour resentment and anger.

I would say that Sophie & I's friendship blooms a little more each time we talk, our empathise are in full force and are currently full time jobs and i think that can help her feel less alone in a situation where the outcome is unknown, i will forever listen to her babble on about poems, pieces and people that she admires that also suffer from chronic illnesses and am forever reading informational posts she sends me to keep my knowledge and understanding up to date.

What can friends do to support you?

- If we're out, stopping to rest or finding chairs/places to sit - sometimes I feel annoying and don't ask, even when I really need it!
- Learn a little bit about hEDS/HSD and the comorbidities so that you understand what I'm going through. It can be tiring to explain things over and over
- Listen when I talk about my illness and don't feel that you have to find solutions - sometimes a listening ear is so valuable, and some things just don't have easy solutions
- Get to know my pain behaviours. These vary from person to person but some of mine are: zoning out, fidgeting, rubbing/massaging the affected area, talking/engaging in what we're doing less. Understanding these will help you spot when my pain is bad, even if I haven't told you

Resources to find out more

https://www.ehlers-danlos.org/
https://www.hypermobility.org/
https://www.nhs.uk/conditions/ehlers-danlos-syndromes/
https://www.ehlers-danlos.com/heds-diagnostic-checklist/

About the Author(s)

I'm Sophie (she/her) and I'm 18 years old. I was diagnosed with HSD in September 2020, but I've had symptoms since I was 13 or 14. I'm about to start a history degree. Outside of this, I love reading, writing, playing video games, and I'm a member of the LUNA Online Activities team. You can follow me on instagram (@sophiemattholie_) to see what I'm doing!