



The
**Ehlers
Danlos**
Society

LOOSE CONNECTIONS



BRINGING TOGETHER
THE VOICES OF OUR COMMUNITY

FEB 2021 ISSUE

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Lilac-breasted roller in the Masai Mara National Reserve in KenyaCover
Jason Hafso



David & Goliath

KATE WYLIE

Newborn kitten and middle-aged woman
in leg braces, two paralyzed and perplexed
animals teetering up the single flight of stairs,
learning how to walk for the first and second time
in their respective lives. When the woman collapses
on the carpeted landing, the kitten curls into
a delicate black comma beside her, insisting they
not end there, not in a sigh of self-pity, not
in a weeping heap of heartache. So
the woman reaches for her discarded crutches
and stands through unfathomable will, gazing
down the flight, hand steady on the banister.



Vivi-Mari Carpelan Copyright © 2018

Image no 1: "Failing support" (photography). Photo ID 1: Two feet with bunions and bunionettes can be discerned in a watery blue realm with white twigs and sandlike grain, and in the middle, white spots with orange edges that turn the thoughts to fire.

I'm a visual artist who currently works from the comfort of my couch, using a simple technique on my iPhone to layer photographs I have taken in the past. I have always been obsessed by collaging and layering imagery to create an impression of the complex and ambiguous realm between the inner and outer self. At the base of these two images are photos of my awkward and deformed body that does not occupy physical reality in a smooth and natural way. The distortions aren't invisible, but they can be hidden. I feel shame and don't want to show them to anyone. But

I also find that no one wants to see them and acknowledge that they cause me unbearable self-consciousness and bottomless grievance. For instance, clothes and shoes rarely fit. I have been told things such as “You have a luxury problem” and “Feet not fitting into shoes is not a reason for operating on them.” The diagnosis at 52 years helped me gain a little bit of sympathy. A major boost to my self esteem has been the fact that my slippery toes are now undergoing fusion surgery and it seems worth it even if the procedures are aggravating other symptoms.



Vivi-Mari Carpelan Copyright © 2018

The shape of a female body from the knees to the nose with arms crossed and wearing hipster briefs is immersed in a shadowy, textured space with lines, streaks and blotches. The figure is brown, orange and teal against a beige space with greyish shadows.

Inclusion

LISA HUNTINGTON

INCLUSION MEANS A WELCOME AND safe community for all people.

Inclusion, accommodation, equal participation, welcoming communities are precious refuges to all marginalized people. Those of us with chronic illness and disability know what ableist non-inclusion and rejection looks like. We often know how ableism can make us feel like a burden. Too many people don't want to have to even think about someone's needs that are different from their normal. Yet being disabled also does not excuse someone from other forms of prejudice that lead to non-inclusion. Those of us who have intersectional marginalized traits experience multiple forms of prejudice and lack of inclusion.

I have never fit in. I am in my mid-50s. I received a hypermobile EDS diagnosis last year after a lifetime of symptoms, starting with a premature birth, a colic diagnosis, dysautonomia (undiagnosed until my hEDS diagnosis), stuttering since

I began to speak (which also appears to be hEDS-related for multiple reasons), and my first knee subluxation at age four. Unbeknownst to the young me or the adults in my life at the time, I am also non-binary transgender and bisexual/queer. In addition, I am neurodivergent, but I did not match the narrow and often inaccurate stereotypes of autism of the time, and I was female-bodied, so my neurodivergence went unrecognized. My parents and teachers did not recognize that I required a different type of learning environment. My neurodivergent traits were simply punished. I quickly became a target for school bullying and ostracization.

Teachers labeled me "socially anxious" and refused to intervene or make me feel included and welcomed. My biological needs, from food and water (I didn't eat or drink at school to avoid the restrooms, causing dehydration, electrolyte imbalance, low blood sugar, and low blood pressure) to my neurodivergence, were never accommodated, and health problems

stemming from that abuse were labeled as behavioral problems. In hindsight, I experienced my first POTS flare at age nine. I was overwhelmed with stress from trying to exist in a hostile environment, crashed physiologically, and became suicidal at 12. I made two suicide attempts at 18. The years-long response from my parents, doctor, and therapists was gaslighting and symptom psychiatrization.

The transgender community is small and vulnerable. My support system is barely existent. My wife is also transgender. We met at a transgender support group. She is a trans woman who does not pass for cisgender. She is also disabled. I know the sense of deep discomfort, and sometimes rage, that some people in the wider culture have with trans/non-binary people and even visibly queer people. I have to be aware for my own physical safety. Like most trans people, I am hyperaware of how I violate most people's expectations for me.

Being visibly transgender means that you are a continual public target for harassment, for casual cruelty designed to try to force people into conforming to our culture's sex/gender/sexual orientation binary, even if that means resorting to violence and/or social condemnation. It means people believe they have a right to debate the validity of your existence, and whether and when you deserve human and civil rights. My wife and I have experienced multiple instances of discrimination

and microaggressions, including from healthcare providers. It takes significant energy to shrug off anti-trans ignorance, knowing that you will experience further microaggressions and discrimination.

Using up "spoons" as a disabled person to handle the lack of inclusivity and some peoples' outright unwelcome is even more difficult. It also means I have to inquire if my LGBTQIA+ status will negatively affect how I am treated by healthcare providers. Can I bring my wife to an appointment, or will a provider's prejudice further compromise my care, like the ophthalmology tech who changed a single digit on our right lens prescriptions, costing us several hundred dollars we didn't have and bruising our dignity?

I participate in online EDS support groups and related diagnosis support groups for dysautonomia, MCAS, chronic illness, and chronic pain. I would like to participate without having to experience casual transphobia from random group members. Discussions regarding the appropriateness of mentioning one's trans status, even if it directly relates to a group's subject matter, have happened in some of these groups, sometimes productively, sometimes rather unpleasantly. I have sometimes felt forced to leave if I do not wish to receive verbal abuse from people who have no problem with cisgender women mentioning female body parts, but who jump on trans people merely mentioning gender identity, or

explaining how their transgender traits relate to EDS and chronic illness.

I notice that most of those groups are filled with posts from white people who are mostly straight and cisgender. I rarely see posts from Black people, other people of color, or posts from people who are clearly queer and trans. I see posts by Christians in these groups looking for other Christian, but I've never seen a post by a non-Christian seeking other people with EDS who have similar religious beliefs, likely because we don't feel comfortable exposing ourselves as non-Christian in what appear to be majority Christian groups.

True inclusion means removing double standards. It means making online and in-person spaces, from support groups to doctor's offices to the family dinner table, welcoming to anyone who the majority sees as "other." Toleration is not good enough. It means not relying on marginalized people to educate others about our communities. That also means creating communities that actively work to make their most marginalized members feel included and equal. ■■■

Lisa Huntington is a writer and weaver at Lisa Rayner Handwovens. They live in Santa Fe, New Mexico with their wife and three cats.

For those unfamiliar with the concept of "spoons" in relation to chronic illness, please visit *The Spoon Theory* by Christine Miserandino, <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>



Acrylic on canvas

Twitter/Instagram @littlefelrose

Faulty genes...

CEM. T

The impact one rare condition has on its patient,
faulty collagen in our genome,
Ehlers-Danlos syndrome,
You hide in our bodies,
Like it's your home,
We cry and groan,
But it's in these genes,
the pain never ending it seems,
Out of our hands,
Out of sight.

Strength within...

CEM. T

And in the end,
you realize you carried the strength all along,
it just took a storm to release it.





After ten years, I started painting again. It was both a way to alleviate boredom while newly disabled, and to find joy again in something I quit due to the pain associated with creating art. By limiting my painting sizes and focusing less on perfect outcomes, I have found joy. I try to create images that bring me joy, hope, or raise awareness for the causes close to my heart. I then turn the art pieces into greeting cards for various occasions.

Reflections

JULIANNA WENINGER

The cycle of grief
Spinning and spinning
And when you think it's over
It's only just beginning

I am not the same person I used to be
And that's okay
But I've had to reinvent myself so many times
The old me has faded away

I don't even recognize myself
What are my dreams and goals?
Every ambition has been shattered
By a condition that thrives on control

Control of my body
Control of my mind
Control of my actions
Control of my time

When I look in the mirror
I don't recognize this person
Bits of me slip away
As my health continues to worsen

I have no idea where I'm going
No idea what the future has in store
But I'll keep pushing the limits
Until I find what I'm looking for



30x10 inches

Acrylic on canvas



24x24 inches

Acrylic on wood

<https://www.maymlo.com/>

<https://www.instagram.com/maymloart/>

THE BOOK NOOK

Unbroken: 13 Stories Starring Disabled Teens

J.M. BAKER

INCLUSION IS INTEGRAL WHEN TRYING to adapt to life with the Ehlers-Danlos syndromes and its charcuterie board of friends (dysautonomia, POTS, mast cell, etc.). It does not matter whether you are newly diagnosed or you are an experienced zebra, it remains important.

As a self-described nerd, whenever I hear an able-bodied person talking about inclusion, especially in media, Inigo Montoya's voice pops into my head and responds with, "You keep using that word. I do not think it means what you think it means." Pick any type of media – TV, movie, print – and all too often we see those representations of inclusion to be more along the line of inspiration porn, using non-disabled actors to portray individuals with disability, and occasionally, even deletion of a disability all together! It is a rare breath of fresh air when you find a character that truly depicts what life is like to live with a disability, and that is exactly what I found

in *Unbroken: 13 Stories Starring Disabled Teens*, edited by Marieke Nijkamp.

Unbroken is a collection of 13 fiction stories featuring disabled teens dealing with disabilities that range across all spectrums, written by authors who self-identify as disabled and deal every day with the realities of physical/mental disabilities and neurodiversity. In these stories, disability is not necessarily the focus of the story, or used as a crutch (pun intended). There are many books that I have put down and never picked back up because the depiction of disability was just too unrealistic; not these stories. The intersectionality of these stories is almost guaranteed to hit home in one way or another, but for me, there were two stories in particular that I really identified with.

In the very first story "The Long Road," there was a quote that hit me as hard as accidental gluten hits my GI track. I was immediately reminded of my own EDS

journey and finding community support. In that first story, a family is making a journey to try to help their child find a cure for their malady. The discovery the main character has on that long road was one I had on my road to and accepting my diagnoses: “Do you want to know what helps me most? More than amulets, more than clean living?...Talking. Meeting others like me.” As soon as I read those words, I knew this book, these stories, would be different.

Not all of the stories will have the same impact for everyone. Some hit aspects of what it's like to live with a disability that made me step back and re-examine my own thoughts and experiences. Others affected me on a less personal level, but were still very well-written stories. One of the things I appreciated the most was the intersectionality present across all of the stories. No matter who you are, where you come from, what age you are, or what challenges your disability throws your way, there will be at least one moment in reading these stories that you just understand on a different level. It also does a great job exploring the different facets of what it means to identify as disabled and how that affects individuals differently, and in 13 short stories, it paints a decent picture of what different realities are like when it comes to dealing with disabilities.

I would be remiss not to include a warning. Like in our realities, the characters of these stories face some serious issues and challenges, not just the everyday

struggles of life with a disability, and everything that can come with that. Some of the subject matter includes, but is not limited to: self-harm, anxiety, dealing with disabilities being looked at in a negative light, misgendering, and mental illness. Please take that into consideration when picking up this book to read.

Even with the warning, I can't recommend this book enough, especially for those teens or young adults in your life who might be struggling with a disability, trying to accept a new diagnosis, or just wish they had more visibility in the media they enjoy. Before I end, I will leave you with a quote from another story that really hit home for me, and reiterates the importance of a support system.

“I’m just so tired of trying so hard all the time and failing every time, even at things I know I can do.”

I know those words have left my own lips more than a few times, and just reiterates how grounded in real-life experiences these stories are. ■■■





Do I Call an Ambulance Now?

ALY LANCHESTER

“IF YOU FEEL A SHARP, STRONG STOMACH pain, don't drive yourself to hospital, you won't make it. Call an ambulance.”

My cardiologist's advice is what passes through my brain at 4 a.m. when my chest suddenly tightens and I get a quick little burst of pain just under my ribs. Is this what an aneurysm feels like? Do I call an ambulance now?

The worst part of having Ehlers-Danlos syndrome isn't in the known, it's in the unknown.

Zebras have become adept at adapting. While our stripes don't completely blend into our surroundings, we've found ways to support ourselves through the hardships. Canes can be purchased, splints can be worn, and we start to define our own version of “normal.”

But not knowing what normal is – that makes things a lot harder. I never knew that my elbows weren't supposed to bend backwards, or that my unusually dry eyes weren't entirely down to my screen time. I didn't know that having kidney stones 17 times in the space of three years was akin to having as many children, yet more painful.

Living with vascular EDS you're faced with your own mortality – you know your life might be shorter – but you don't know by how much or how it'll happen. You don't know what an aneurysm feels like. But you need to plan for it. You need to live your life on the precipice of “what if” and grab the unknown by the horns and live life as if it could all come crashing down in an instant – at 4 a.m. when you feel your chest suddenly tightening.

See, the thing is, without having something to compare it to, you can start to drive yourself crazy. What is this new sensation? Is this an aneurysm or a panic attack? Do I call an ambulance now?

But then mentally you fall deeper down the rabbit hole: Will I fall in love? Will I have children? Will I see the world? It takes all your strength on a daily basis to claw your way out with your hypermobile fingers and cling to certainty.

There are so many unknowns, so many different ways a zebra can earn their stripes. So do I call an ambulance now? ■■■

WOMAN WITH EDS IN A GARDEN ■ RENCI DENHAM



Inclusion: Proud To Be a Zebra

BARBARA ALLEN

THREE YEARS AGO MAKING THE declaration, “I’m proud to be a Zebra!” would have been preposterous. Why would I be calling myself an animal I have very little knowledge of? What would make me so relatable to a zoo animal that I would be so proud to call myself one?

My story goes back, well, as you guessed it, long before I was born. In fact, my story starts before my great grandparents were born! As we all know though, human Zebras were not really understood or seen in the 1800’s.

Growing up, both sides of my family have always been normal – or rather, normal for our families. I never thought I was any different to any other kid or family. Little did I actually know!

What was my “Aha!” moment that made me think, “Are we really normal?” It was lying awake one night thinking about my father. He went from only needing a

mild lens to drive to legally blind in three months with no explanation. He would say he hurt down to the pure bone. His joints always flexed more than normal. He was dizzy and his heart would race just walking to the bathroom. He would get rashes/welts for no explainable reason. I could see him going down hill faster and faster and the doctors were running tests but nothing. There had to be something. I set out to find it!

I started listing the family members and what medical conditions they had. I made phone calls to family members asking what they remembered. I went through the family bibles looking at the family notes and the death certificates. I googled and googled and googled!

After two months I went to my doctor with 67 pages of research and family history on both sides going back to the 1800’s. I was determined to show enough evidence with my research as to why I think I have:

1. Chronic Migraine (full disclosure, I was diagnosed at age two with this);

2. Dysautonomia ;

3. Mast cell activation;

4. Hashimoto's; and

5. Ehlers-Danlos (joint hypermobility with vascular traits).

My doctor seemed impressed I had gone so far as try to prove my theories but Ehlers-Danlos is rare, and dysautonomia and mast cell activation are not that common either. Because I felt so strongly and I made a good case, she started ordering tests and sending me to specialists. The results were positive for all the above.

Unfortunately, by the time I had results my father's quality of life had left. He had suffered a brain bleed. It was devastating! He lost all short-term memory. This, with his previous dementia, put him in a state of constant confusion. I wish to this day I had put the puzzle together sooner so maybe I could have helped him. We lost him two years ago to a massive stroke. He was a wonderful, kind, and loving Zebra dad!

When my sister and I set down to explain Ehlers-Danlos to my 8-year-old nephew and 10-year-old niece, they were scared at first. I told them it makes them special because human Zebras are rare. They were happy to get tested and now tell anyone who will listen they are a human Zebra.

My doctor and some of the specialists were amazed I was the first person out of my family to be diagnosed. They didn't realize, they had their doubts at first. They would never have tested me without my being my own advocate. No doctor ever thought to test any of my family members even though there were some very clear signs. Zebras can be right in front of you but never actually seen.

I am proud to be a Zebra because it means my family is finally diagnosed and we have answers. We have a better understanding of our health and a better plan to protect it. Most of all I am proud to be a Zebra because it means we have finally been seen, heard, and recognized for our rare and unique stripes – I mean, traits. ■■■



Publisher Information



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The Ehlers-Danlos Society is a global community of patients, caregivers, medical professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes, hypermobility spectrum disorders, and related conditions.

We are proudly working to provide global learning conferences, collaborative research and education initiatives, awareness campaigns, advocacy, community-building, and care for the EDS and HSD population.

Our goals are worldwide awareness – and a better quality of life for all who suffer from these conditions. Research is at the center of what we do, so that one day we will have a cure.

OUR STRENGTH BEGINS WITH HOPE.

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