



The
**Ehlers
Danlos**
Society

LOOSE CONNECTIONS



BRINGING TOGETHER
THE VOICES OF OUR COMMUNITY

JUN 2021 ISSUE

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Duplex for Spring

KATE WYLIE

after Jericho Brown

Nature's final affirmation is taking me back
despite the faults & failures of my body.

Despite the faults & failures of my body,
I'll still become air after death for you.

I'll still become air after death so you can
breathe me in, your lungs filling with green.

Breathe me in. Remember that familiar green.
I'm growing back as grass between your toes.

I'm returning as the world beneath your feet.
Nature's final affirmation: you're not alone.

The Body Is a Natural Disaster

KATE WYLIE

Believing levees could hold the flood at bay
was foolish, but we still built them anyway.

Coffins rose with the river and floated away.
Some dead never returned. And I could say

it was horrible: watching the city where I
was born devoured, how the gray-black sky

broke like it never had before that summer,
how bodies thrashed and twisted underwater,

how families gathered on their rooftops, waving
to the helicopters hovering overhead, saving

anyone they could, not hearing the screams
of masters finding beloved horses drowned,

or churchgoers when the high roof frowned
and gave way to gallons and gallons of rain.

I was a child when the world first ended.
I was a child when I learned about heaven,

how God has a plan and our understanding
has hardly anything to do with its ending.

Doctors pressed blue fingers into my skin,
tracing places where tendons should have been

and shook their heads. I was a child
learning early how to live without.

I was a child growing apart from her limbs
watching dead bodies sink instead of swim.

The river made me a master of loss,
a weathered fencepost reclaimed by moss.

The body is a natural disaster. The body is blind.
It takes what it wants, and leaves nothing behind.

On Becoming Despite Chronic Disability

NATASHA WEIN

THE FIRST TIME I HEAR ABOUT Ehlers-Danlos syndrome, a woman who grows to be my dear friend rocks knees-to-chest in a chair in front of me talking about things I cannot see or understand: daily physical therapy, body work, subluxing hips and shoulders, pain killers, uninformed doctors, having to take care walking, and a life full of excruciating pain that is hard to believe. Leigh talks about grief and loss and the pockets of trauma her body harbors from each unexpected injury and each devastating setback. She cries in frustration when she cannot find the proprioceptive awareness to complete an exercise that she could yesterday. She is fierce and honest and brave. She is fun and young and bright. She is bitter and aged and aware. I draw a portrait of Leigh and she hangs it in her home.

You are in pain and it matters.

Two years later, my physical therapist tells me she thinks I am hypermobile and to see an EDS specialist. I am diagnosed

with hEDS and cEDS and as I make sense of this with my current state of disability, history of subluxing joints, mysterious and normalized chronic pain, GI upset, POTS, and dysautonomia, my experience of my body and its breakdown all make sense. I am devastated.

I am in pain and it matters.

I text Leigh and we keep up about EDS management, what it's like to live with an invisible illness, to need regular assistance, and to live in an unreliable body, in addition to music, work, art, and life. I learn she curls up when she sits in chairs to relieve pressure on her hips and hip-flexors. Meanwhile, I do not sit because of my spinal nerve compression. I learn to understand the hypermobility aspect of EDS as a severe bodily vulnerability that unfolds differently in unique individuals based on their unique body map, movement patterns, and accumulation of injuries and that is why it "looks" so different on each person. I learn that it always has some psychological impact,

as it impacts our relationship to our bodies, confidence, abilities, access to opportunity, and the nature of how we relate to others and how others relate to us. I learn about pain – different kinds and their meanings – and how chronic pain impacts my experience of and relationship to pain. For someone with EDS these are often not events with a beginning and end, but ongoing troubles that form chronic patterns of painful experience that mirror the chronic nature of EDS. There is a way in which focusing on the pain and grind of symptom management works against itself, if you fall into it; I learn the importance of psychological care and upkeep in order to live a fulfilling and sustainable life that leaves explicit space for healing, peace, comfort, surprise, and new patterns to emerge that pain and the necessity of daily upkeep otherwise shroud out. I learn the importance of going at my own pace.

Today, I will take care of myself.

I remember being small, before I can take care of myself, and how nobody tells me, “It is going to be okay.” For months, my spine injury requires me to be upright or temporarily lying down, so I spend upwards of 10 hours a day standing, but with my cardiovascular resilience weakening. POTS symptoms of severe fatigue, brain fog, weakness, and lightheadedness slowly debilitate my life until I am spending more time lying on the floor and feeling hopeless about EDS-related conditions than I am on my feet doing the things I love. I text Leigh. We exchange various POTS treatment

suggestions and heart reconditioning techniques; she says to me, “It gets better!” I lie on the floor of my apartment with ice packs and bolsters and feel less insufferably alone with managing this relentless illness that is mostly not seen or understood by others; I have a teammate.

It is going to be okay.

I remember growing up a competitive athlete and the reliance I still have on my body to play, express myself, and be active. In order to manage pain and regain a more functional life, I prioritize my spine health and posture which means refraining from my natural instinct to climb trees, trampoline, somersault, cartwheel, swing on swings, or give my friends piggy-back rides. I abruptly give these things up in my early twenties and I am left to question: who am I without who I used to be?

I am losing a version of myself to my limitations.

I grieve. With love, I allow every past-self that both was and was not to be with me in my present and I honor it, so I can create a future-self that I want to be. I remember that I am both limited and gifted because I dare to dream. I choose my health – even when invisible to others – so that I can paint, cook, walk in the spring sun, lie under my favorite Ginkgo tree, and hug my friends in a body that I work to make a more safe place to live in.

I am still becoming. ■■■



Shown is a surreal portrait of a the profile of a young women drawn in ink pen, white colored pencil, and different shades of purple colored pencil on brown chipboard. Her eye is a clock dripping numbers down her cheek like a tear and her brain is represented anatomically where a smaller version of a woman sits in the back of her mind hugging her knees and looking forward. Her ear is detailed, her hair drawn back in a bun, and the spinal cord illustrated inside her neck.

Natasha Wein is an artist working out of Stockbridge, MA. For more on her work, find her on [Instagram @nweinart](#) or visit her website www.nweinart.com.

Can I Believe I Can Keep Positive Changes?

ELLEN LENOX SMITH

LIVING LIFE WITH CHRONIC PAIN HAS meant dealing with twenty-six surgeries and two presently incurable conditions, which can often leave you on edge and, unfortunately, sometimes waiting for the next shoe to drop. I try so hard not to feel scared, negative, and anticipating something about to go wrong again. For individuals with a history of serious chronic health conditions, the future can often feel threatening awaiting the next challenge, but the reality is there and can haunt me at times. Chronic pain patients often expend a great deal of emotional energy attempting to fend off fears of serious challenges such as further deterioration to vulnerable bodies and psyches. Daily, I have to keep pushing those thoughts away.

Every day of the life I have been living for the past sixteen years has entailed work towards a goal for a better quality of life. Endless hours a week are spent on strengthening exercises, manual

physical therapy appointments, surgeries and recuperation, testing, caution on how to move without hurting myself, along with an examination of all foods and medications put into the body. Each day requires a calculation to keep safe and attempt to minimize pain levels.

So where do those emotions go when it looks like I have hit a better moment? At first, I quickly slip into believing this is for keeps and fall right into the dream of that life I once had, returning to me. But shortly, after I experience that feeling of excitement, I often revert to the negative framework of waiting for the other shoe to drop and wonder when that moment will possibly slip away from my hard-earned success. I wish my mind wouldn't do this – slipping into the mode of self-doubt coupled with the possible fear and questioning like it is about to be withdrawn. Do you experience this too?

So, why did I question this?

We just attempted, for only the second time in years, going to the beach to read and enjoy being at the ocean. I was excited until the emotions crept in as to what the physical cost to me might be for walking on the sand again. Would it again sublux (partial dislocation) the legs and feet or even worse, dislocate my damaged hip? Well, with talking myself down, I walked about ten feet on soft sand and was able to sit and read on the beach for the first time in years. This once common and enjoyable trip to the beach required an expenditure of a great deal of emotional energy to calm the emotions down and to try to believe this would work, which it did. I avoided physical damage, but it was so annoying that this exciting adventure was being marred by the “what if” thoughts.

Why did I question this?

We just went to New York City to see three of our four sons, wives, and three of our four grandchildren and didn't pack my wheelchair for our one-night stay over. This was the first trip in thirteen years where we left the chair behind. I have been now walking the dog up the street, walking in stores, and have been having my legs hold, after years of surgery on my legs, living for four years in a wheelchair and until recently, still needing the use of a scooter or wheelchair in a store. The trip to NY turned out to be successful! I was

able to use my legs without damage of subluxations. Yet, I again had to remind myself this was possible but those emotions of doubt and questioning as to if this could really work kept trying rise to the surface of my consciousness.

I wish we could learn to totally shut down the mind. I have heard that what we think about we can bring about. If that has any merit, then why would I be so immature to think about the negative when I work daily to make life have a more positive outcome? I will continue to find those moments in my life that help to shut down this thinking – like when I kick in the pool and the mind shuts off for me or when I try meditating each morning and run through my mind what I am grateful for. It does not come for free to focus on the positive while working to attempt to eliminate the negative. Those of us who have had ongoing medical issues have to work even harder to shut our minds down and believe we can have better moments and even deserve them. May you have success with training that mind to shut off the negative so you can find the courage to try to find peace, purpose, and hope that has been denied at times with your medical issues.

May life be kind to you. ■■■

Ellen Lenox Smith is the author of *It Hurts Like Hell!: I Live With Pain; And Have a Good Life, Anyway;* and *My Life as a Service Dog!*



I took a photo a few years ago of myself on one of my bad days; I had multiple, subluxes and dislocations and felt as if my world was crumbling around me. I painted the image from that day and tried to make it beautiful while trying to keep the mood of the picture the same.

BOLD BETWEEN THE STRIPES ■ MORGAN TRIPP



I painted this during Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders Awareness Month. I hope to sell it and donate the money to The Ehlers-Danlos Society.

THE BOOK NOOK

Every Heart a Doorway

J.M. BAKER

ACCEPTANCE IS ONE OF THE hardest hurdles that an individual with one of the Ehlers-Danlos syndromes can face, simply because the immense number of facets that acceptance has. As individuals with chronic conditions, we deal with issues and struggles healthy people just wouldn't understand. It's not that they won't, but if they haven't walked or rolled a mile in our shoes, they truly don't know. But still, we seek acceptance from society, from friends and family, and the hardest of all: self-acceptance.

What if you could have that though? What if you could be with and talk to others who live the same struggles and have the same thoughts as you? Well, I found that, in book form. I found sense of belonging and acceptance in the *Wayward Children* series by Seaman McGuire. I picked up *Every Heart a Doorway* after discovering McGuire on a page that was spotlighting disabled authors. McGuire has spoken quite a bit about identifying as a disabled and neurodivergent author and how it can

really be a struggle to have an invisible disability. McGuire's *Wayward Children* speaks to that struggle for acceptance in a very unique and fanciful way, and also really does a good job showing how hard acceptance can be at times, but that finding it can be life-changing.

Children often seem to get completely lost in imagination and adventures, but some happen to live out their adventures — falling down a rabbit hole, crawling through a wardrobe, falling into a well, etc. You're probably familiar with some of those tales. Eleanor West was one of those children. Eleanor discovered her door at a young age and went to a world where she fit in perfectly. A place that felt like home. A place where she was accepted as who she was without question.

Unfortunately, Eleanor West found herself back in our reality, much against her will, and spent every second of her remaining adult years doing two things: trying to find her door to her perfect world again,

and creating a boarding school for children and teens who want to find their door and go back to a world that accepted them for who they were despite their flaws.

Now, if you could find a door that would take you to a place where you are accepted as you are – despite EDS and the myriad of comorbidities, accessibility aids, feeding tubes, and everything else – would you go through? And if you did but found yourself back here in our reality, would you spend all of your time looking for that doorway to go back again?

I know I would, but in a way, I already found my door. That door led me to the EDS community and (surprise!) acceptance. Finding support and friendship in the EDS community really

helped me find self-acceptance for not just EDS, but everything that comes with it. The community taught me how to advocate for myself so I could find more acceptance out in the “biotypical” world.

Like many of the kids at Eleanor West’s Home for Wayward Children, I may never be able to find an actual doorway to a different world. But also like those kids, in the process of searching for my door I found strength and acceptance from those that truly understand, the EDS community, because they live my truth. I find strength and understanding from our community, much like the kids at Eleanor West’s Home found strength and unquestionable acceptance in each other, as they faced life together and doorless. ■■■



Mixed Media on Paper, 18 x 24 inches
www.maymlo.com | [@maymloart](https://www.instagram.com/maymloart)

PRODUCT REVIEW

Hand Massager

R. BOLES VERACES

I'VE ACQUIRED A NUMBER OF MASSAGE machines over the years. Almost all I've used a couple of times, to wind up tossing them out a few years later after they've acquired enough dust. I nonetheless keep searching for one that helps. Thanks to Facebook advertising, I recently ran across a number of hand massagers. Along with my hEDS, I was diagnosed with osteoarthritis in 2000, and recently it's become a painful presence in my hands, so for once the ads were appropriate.

The concept seemed valid; air is used to inflate bladders around wrist and fingers, simulating an encompassing massage. Of less clear value, many include little nubs that purport to be similar to acupressure. There are a number of these hand massagers on the market, all somewhat similar. Some are only for hands, some include the wrist. After some superficial research, I chose one that included the wrist, as (no surprise) I have some difficulty there as well, due not only to EDS wrists but also decades of computer work. They

range in price from around \$75 to \$130 (US). Mine was a few cents shy of \$80.

For me there was a moment of psychological reluctance at first. If you've read Frank Herbert's *Dune* or seen any of the screen adaptations, the massagers might remind you of the nerve-induction box used in the Bene Gesserit test of humanity, and you can easily imagine



that's about to happen to your hand. Rest assured, it doesn't – and there's no chance of getting your hand stuck inside; if the power runs out and the bladders are filled with air, they release and let your hand free, I...tried it.

The massager I settled on provides sessions of five, ten, or 15 minutes. It has three strength settings as well as a heat option. It provides three different programs; "refresh" massages the top of the hand and the wrist, "recover" focuses on the top of the hand, and "relax" works on the bottom of the hand and on the wrist.

I've only ever used the low intensity setting; I suspect anything more might be painful for me rather than helpful, and low seems to be sufficient. I've found the heat barely warms your hand, which isn't what I hoped, and as weak as it is, drains the rechargeable battery more quickly. I suspect too that, like me, you'll find little use for the three programs; I settled on the "relax" as being the best for me.

The instructions say to place it on a stable surface. However, I have nearly no surface at a height which doesn't bend

my wrist, and I've found placing it my lap works well for me. The rechargeable battery is reasonably powerful, lasting through several treatments (fewer if using the heating option) but doesn't recharge particularly quickly.

I wondered at first if there were any results, still every few days I tried again. As time went on, I noticed that I had begun seeking it out it on the days one or both hands ached. I'm grateful for the difference it makes; while not profound, the improvement in my pain level is noticeable every time. I do wish it were a bit more customizable. I do wish I could control which area it focuses on, I'd appreciate better control than the three settings.

I recommend trying one out. This is the first massager I've owned that's still in use, more than three months later. There is a caveat: if your hands or wrist dislocate very easily, these might not work for you, so look for return policies, and be careful. I hope you find one that can help you. For the record, I purchased the massager (iVOLCONN Model IN-006H) myself, and have received no benefit for this review. ■■■

Wheelchairs, Crutches, and Heels

ALEXIS ROSE VELAZQUEZ

Quick take my heels!
He's calling the police.
My flats are in the backseat.
Please take my goddamn keys.

My sister drove a sports car
The most mobility she had
And with her sweet long curly waves
She looked like a movie queen.

My sister loved to dream
It was her joy to drive.
Handi stickers make her cry.

But on on Mother's Day
This old man
He said my sister stole some land

Mustard dress with honey curls
He saw Venus in a whirl
This old man said strip the heels.

Glowing green clover eyes with swirls of caramel clouds
Beauty was her disguise
Though much misfortune held her eyes

Beautiful broken girl unseen.
Tossed by the world without relief
Does anyone see you?
Does anyone care?
About the pain you always bear

Three times a month
These old men say
To strip the heels
And keep her sun at bay

For beautiful girls can't be in pain
And Spanish girls with speeding cars
Are liars don't ya see?
The old men jealous for her beauty
Try to damn her in her grief
Until she falls in front of them
Or unless she's in her splints
They pull up on at her windows
And spit at her glass and lips

Not all disabilities are always visible
Some come and go:
They don't relent
People think that beauty
Means a lack of pain
Or that those pained can not be beautiful
For *how* could they bear the rain?

Broken Girl

ALEXIS ROSE VELAZQUEZ

Broken girl
Young curvaceous girl
With mead and amber hair
Eyes aglow
She holds hell and heaven in her hands
Tiny ringlet curls
The porcelain doll with blushing cheeks
Green eyes that see things beyond your dreams
Sunshine, she dances.
She paints worlds –
Shakes with excitement

Suddenly the noises louder
She sees not the room grow darker
Moonshine blackness
Stabbing needles in her translucent velvet arms.

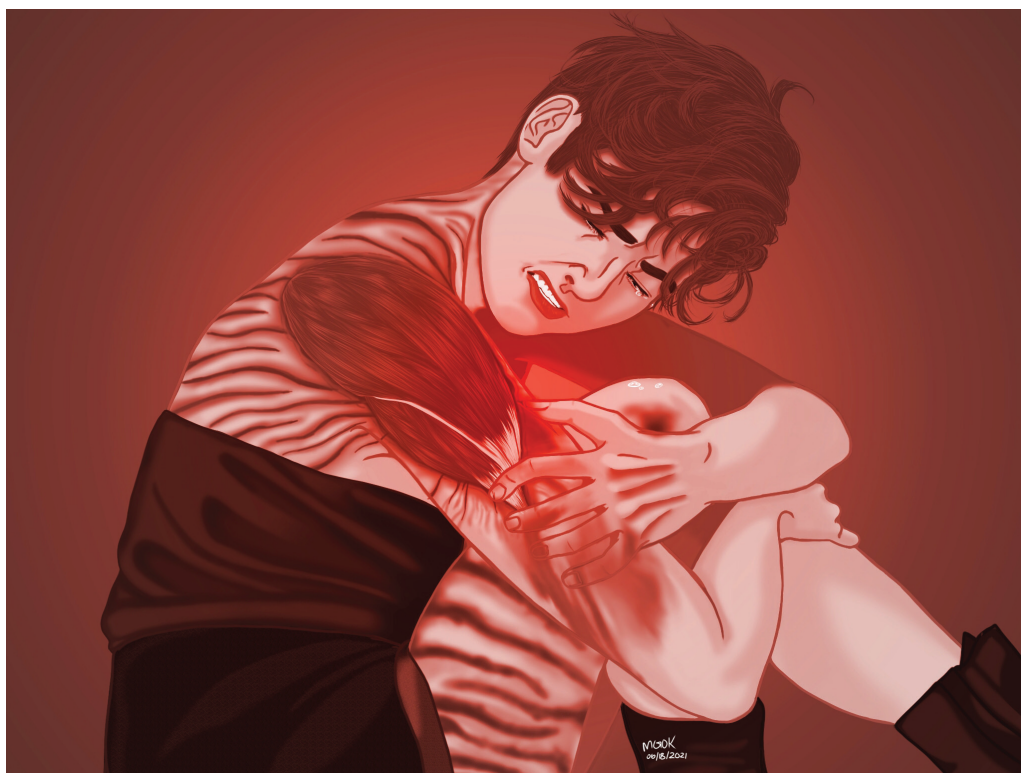
Her head's in stitches now

You're done
No more
The doctors say

You may not dance
It's not allowed
You may not walk
Nor feel too proud

Did you know, sweet sister, that was the last time you would dance so joyfully?
Did you know sunshine that people would try to dim you?
Did you know walking would be wearisome?
That energy would fade and the day seem more dreary-dum.

Would you have danced more?
Would you have run more?
If you had known it could not be so again?



IN THIS PIECE, I DREW A SELF-PORTRAIT showing how I feel having a few symptoms of EDS. I drew myself where you can see me pulling at my skin to the point you can see my shoulder and arm muscles and I made scratches that look like zebra stripes. I also added zebra stripe bruises to my legs because I bruise easily on my legs. (Well, I bruise anywhere real easily, but I always seem to find the most on my legs.)

My biggest reoccurring symptom, as of late, has been the chronic pain. Most days it feels like I want to pull and scratch my skin and muscles until I get to the point when I'm down to only the bones, but even then I'd probably still feel the pain — because the pain is bone deep on most occasions. Anytime I have a flare-up, even the

ones that don't deal with the chronic pain, I feel angry and sad and pitiful.

I feel angry because no matter how many new medications I consume, no matter how many new doctors I see, no matter how many epsom salt baths I take, it always seems like they never help and if they do, then it lasts for a month or so at best. Then it's back to the flare-up norm for me.

The pain and other physical symptoms aren't the only things caused by my EDS. There's also the mental aspect. I get angry when people tell me that it's all in my head, that I'm making it up, or that it isn't real. I get mad when someone looks at me funny or weird when I park in a handicap spot and I appear to be completely fine, that I don't look disabled.

I get mad when someone tells me I'll be fine whenever I go out, because more than half the time, that is not the case. More than half of the time, I'll have a flare-up occur that makes me unable to drive.

Despite all the negative emotions and the harsh strain that's put on my body and even though I'll be told things or get judgmental looks from people, I still keep pushing forward. I know that EDS is going to be a part of me all my life and I've accepted this is just how my life is gonna be. I can only keep going and do my

best with what I can do. What message I hope gets out to others is that no matter how bad EDS has made your life right now, you can keep going. You can do your best and accomplish your dreams. Don't let EDS, or anyone else keep you from doing what you want to do. Don't let EDS or what other people say to you keep you down. You get up out of bed, drink some water, eat a yummy breakfast, and take a nice shower. If you can't, that's okay. Be patient with yourself. You are amazing and you've got this! ■■■



Holding Through the Silence

CLAIRE BEHNING

Note: Italicized words are quotes said by medical professionals

A handful of almonds

Wait and watch

Hold off, No further action needed.

My bones scream at me, how can you not hear
The loudness ruptures through my skin as I sit here
Can't you see the shatter lines cracking through the glass
I am pain's reluctant companion, trailing behind while holding hands
Buzzing, Stabbing, Piercing, Aching
Hope for numbness to overwhelm
For then instead just like a friend I don't have to feel it all for myself

Nothing too serious

An active young lady

Pleasant demeanor

A lovely, if worried girl

Begging my body to not be so broken
But what if it actually isn't
Catastrophize, Overdramatize, Untethered from reality
It's all made up. You want attention. You're too young to be this sick.

But how is sick supposed to look, I feel so tired and defeated
Just because I carry it well, doesn't mean it isn't heavy

Hear me, hear my pain
See my broken wings
Even if you can't tell me how to fix them
I have not lost who I am, I am just different now, and that is okay
I need to give myself permission to grieve my past life
But I can't do that if you won't even acknowledge that it died

***No magic pill provides solution
Diagnosis will be pointless
Nothing will come from this regardless of recording***

The frail wicker unravels
Each joint hinges out of place
I lie, I wait, I shiver
Holding out for someone to hear the trumpeting
 silence echo against porcelain plates
When I think of pain and the invisible silence in which it forever lies
I consider all the ways in which I hold my light
Although at times it is lacking and a little hollow
I create my own path through the dark
Blooming in stripes that will never dim and hold on till tomorrow

a new song today

NATALIE CACOULLIS

Yesterday is gone,
today there is a new song,
one that says,
right here, right now,
what can I do now?
what's good about now?
Breath it in,
let it kiss your insides,
focusing on the good things,
with belief that there is a way,
gives rise to hope,
and a better feeling of today.

Let the sun shine,
let the sun shine,
let it rain, and then,
be sunny again,
all seasons are the Earth's friend,
life is in the movement and change,
while some golden things,
stay the same.

love and kindness

NATALIE CACOULLIS

Love and kindness
cannot be taken away,
they're ours to choose them,
every single day,
the beauty of the heart,
is in essence and art,
housed inside, & flowing
there are the grown trees,
and experience's knowing,
the stars that spark,
the green new seeds,
and Noah's ark,
the changing breeze,
so many ways,
it's personal, and
it's universal,
to be the unique
house of love,
filled with what we choose,
watered, and nurtured,
not dependent on others,
to do with our own values,
love and all it's colours,
it's here to stay,
when we keep it that way.

Acceptance. Affirmation. Acceptance.

MARK C. MARTINO

I FOUND MY FIRST COMMUNITY IN 1974 during freshman orientation week at Rice University. Walking through a welcoming event, I noticed the Rice Players, the primary theater group on campus. They immediately took me in, and later that first week, they took me to a gay bar. It wasn't that I had had bad role models as a queer kid in Virginia, I simply hadn't had any at all. I had no way to identify myself apart from different. But more than four decades later, I can call up a particular moment in the club – thank you, random stranger – when a previously unidentified part of me relaxed into happiness at finding something I didn't know had been missing, a feeling that, for the first time, I belonged in a group of people. I was accepted.

Acceptance is powerful. Theater became a calling; there was little I didn't do at some point (I never costumed a show). And the Houston gay community was just starting to organize. In 1978, Houston's first Gay Pride week included Town Meeting I, a gathering to set up a broader political and

structure for Houston. A memory again of a specific moment, when I realized I was in an arena full of people who – were like me – a realization untinged by the casual fear of being in public, being fully myself without hiding. That feeling helped sustain me when I came out to my family, even when my father disowned me and I stopped talking to them for years. I have no doubt I would have had a very different life without acceptance by wider communities.

Those communities sustained me as we crawled through AIDS in the 80s and 90s. They helped me avoid the doctors who refused to treat AIDS patients, the doctors who were actively discriminatory. They helped me find a place in history; I remember particularly one wake at which a handful of us talked about the history of gay life in Houston and the country. Well. They talked, I listened. Most of the group were gone by the turn of the century. Without the gay community, without the theater crew, I doubt I would still be alive either.

My second community awakening started in 2000, when Google said to me, “We can’t find Ehloss-Danlen syndrome. Do you mean Ehlers-Danlos syndrome?”

I very much did. I’ve talked before about the summer when my body decided it had had enough, and presented me with what I now know was most likely my first transient ischemic attack. Despite being told I’d suffered a panic attack, I decided it was time to figure out what a doctor had meant when he told me I might have something he wrote down as Ehloss-Danlen syndrome, but I didn’t “have stretchy enough skin for it.” Google knew what he meant, taking me to Ehlers-Danlos National Foundation, and I was on the way to perhaps identifying the cause of at least 500 years of “family joints.”

Soon afterward, I attended my first EDNF conference. It was exhilarating. Hundreds of people with problems just like mine, people who didn’t even notice when you had to sit on the floor for a minute, people who took care of each other easily because we understood each other. There is no joy quite like the realization that not only are you no longer alone, you have found a group of people who understand you in ways you never believed possible, and accept you as you are. Acceptance.

“Acceptance of one’s life has nothing to do with resignation; it does not mean running away from the struggle. On the contrary, it means accepting it as it comes, with all the handicaps of heredity, of suffering, of psychological complexes and injustices.” — Paul Tournier

Acceptance by others can help you journey to accepting yourself. It’s easy at first to think you’re fooling yourself, that you’re an imposter. You question if you are valid, if you really belong in a group, or anywhere. But you find others who affirm your own experience. When a community holds out their hand to you and invites you in, they’re telling you they recognize something that they feel means you are a similar spirit. That’s powerful; once you accept that part of yourself, you’re no longer alone. It can be easier to have some compassion for yourself when you see that others like you deserve compassion. Because you are accepted by others, you can affirm that part of your self. Acceptance becomes affirmation. And as you were welcomed on your journey, you have the community to support welcoming others. Yes, you are real. Yes, you belong. ■■■

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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