The
**Ehlers
Danlos**
Society

LOOSE CONNECTIONS

BRINGING TOGETHER
THE VOICES OF OUR COMMUNITY

OCT 2021 ISSUE

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Cover photograph by Marcus Lange

What I Meant to Say

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the sun set every minute

pride was a river that wouldn’t run dry
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at night shadows drifted across the hardwood floors & i dreamt about light
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cicadas call out after years of silence
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throw the curtains open   morning is coming

In the Long Run

BETHANY JANE McCARTHY

I'VE RECENTLY BEEN REFLECTING ON running—yes, I'm obsessed with running, it's definitely my most enduring Aspie special interest. Next year is my 30-year anniversary of running, and I recently had a reality check when I was forced to take three months off to recover from an ankle injury, after a very long injury-free running streak of eight years.

There's a joke about vegans: How do you know if someone is a vegan? They'll tell you. As an ex-vegan of twelve years I always hated the stereotype, but I was often guilty of it. Runners can be similar. I've always thought that workout clothes were, well, for exactly that. I've never worn running shoes unless I was actually running. I was the one in the dress at the awards ceremony after races. I also wore makeup to races. It helped me feel like I was "being me."

Just a few weeks ago I had an interesting experience at work.

Customer: Oh, I love your hair/outfit/makeup, you look great! But I could never look like you, I'm a runner.

Me: Thank you...me too! Running is my favorite thing in the world, next to dogs.

Customer: Oh really?

The customer proceeded to quiz me, possibly to make sure I did in fact qualify as a runner; she enthusiastically continued to tell everyone at the work event currently taking place that I was a runner (including informing them of just how many marathons I have run) and, "Wasn't it incredible!?"

I got a good giggle out of the experience, and I do know that stereotypes exist for a reason much of the time. I really don't look like your average "sporty person." I like makeup and fancy hair, I'm heavily tattooed, I have piercings, and I don't wear active wear as casual attire.

It's for a very good reason that I don't identify as a "sporty person." Running is not a sport to me. It far transcends being a sport in many ways, ways that have been written about by authors such as Haruki Murakami,*What I Talk About When I Talk About Running*, 2007; Christopher McDougall, *Born to Run*, 2009; Alan Sillitoe, *The Loneliness of The Long Distance Runner*, 1959; and my favorite comic, Matthew Inman, author of *The Oatmeal (The Terrible & Wonderful Reasons Why I Run Long Distances)*.

When I reflect on all of the things to which running is inextricably linked for me, the list is longer than I anticipated. Sport didn't even make the list. While I do have an interest in running as a sport, largely due to my love of the science of human performance (I have a degree in Exercise Science) and my somewhat Type A personality, my list was dominated by topics that would be considered psychological and philosophical in nature.

Following the 2012 Sydney Marathon, I took three months off due to yet another stress fracture. Other "life stuff" was happening at the time, so I didn't plan any races or events for when my stress fracture healed, and I returned to running casually, roughly three times a week. For the past eight years I have enjoyed an unbroken running streak, injury-free. I didn't wear a watch, I didn't keep a mileage log, I just ran for running's sake, because I love going for a run.

I have not returned to marathons, or any other event or race for that matter, but I kept running, sometimes every day, sometimes just five kilometers, sometimes 25 kilometers. Don't get me wrong, there's always the idea of another marathon nagging in the back of my mind. I always wanted to run my 50th marathon on my 50th birthday, or something significant along those lines. I had some very high-achieving role models in the CoolRunning community back in the day, and once ran a friend's 100th marathon with him on his 60th birthday.

However, I've learned many things about myself in the four years since 2017, including that I have a connective tissue disorder (hypermobility spectrum disorder, G-HSD type). I've always had some good party tricks thanks to my excessively bendy joints, but it wasn't until recent years that a lot of dots have been connected regarding many life-long physical and mental health experiences. Having HSD has significantly impacted my experience of, and relationship to, running—even when I didn't know it.

Now, without the external signifiers—the finish-line photos, the medals, the personal bests, training plans and mileage logs—the respect I have for running and the significance of running's relationship to my body and mind has grown enormously.

Things that I think about while running, and things that I think about because of running, include the serious, the silly, the self-indulgent, and the insane. Topics that could be expanded into essays in their own right include: how fascinated I am by the relationships between discipline and running, and the philosophies of minimalism, existentialism, and identity; running's relationship to the experiences of addiction, depression and anxiety, and ultimately, running as catharsis; the runner's high; the dopamine of anticipation, and the meditative-like feeling when you hit that magic, effortless flow of a good run.

Running can also be intimate. A meaningful conversation with a training partner, sharing tough kilometers of a race with a stranger, and intimacy with your environment. I've moved my home a lot, and everywhere I've lived I feel like I've gotten to know my suburb and city with a degree of intimacy shared only by the daily runners, walkers, dog owners, and curious explorers. It feels like there are secrets to be shared by your environment if you earn it with your dedication to running.

In 2022 I'll turn 45, and it will be 30 years since I started running in 9th grade when we were required to train for the school cross-country in our physical education class. I wasn't a great runner, definitely not fast, and running was mostly my side-gig when it came to activities until my early 20s. But I was enamored even then with the concept of being a runner.

Now, reframing my relationship with running in the context of HSD's impact on my health has given me greater motivation to do what it takes to ensure I get another 30 years of being a runner. ■■■

I was challenged by a friend to practice my photography and take my mind off my EDS on a day I didn't feel well enough to leave the house.

Stairs
The view from my bedroom door when I finally got out of bed after crying in pain. The light was shining through the bannisters.

Sglodion
My pet rat. Her name means "Chips" in Welsh. She has dumbo ears and curly whiskers.

Lightbulb
A solar lightbulb in my garden that had filled with water.

Open the Doors.

TOYIN DAVID

Everything is not black and white;
If only it were simple, like the color of my stripes.
People look from the outside in,
but never know what happens deep within.
How rare, how define,
If only the practitioners could be more inclined.
Awareness is key, it opens doors to what could be?...
a diagnosis maybe?...
Oh, the pain
A pill we take again and again.

Society only sees what they want to see
Call me invisible like my disability.
With EDS society we are a community.

Hope and light,
No matter what, we fight.
For the strength is what helps us maintain
the ability to live on again.

@toyindx on Instagram

Captain’s Log: Endurance

HANNAH

In the end
I am shackled to you
My bones are made of you
Greenheart
Arch enemy
Myself

Over time I have learnt
You are indifferent
Deceitful
Unreliable
Unresting
Or is that me?

Duration of our journey
Forever
Always
But not in a love song kind of way
Constant companion without end
Wishing you would leave

“By endurance we conquer”
Mourning this sinking ship
Wanting to hurt you
Give you frostbite
Leave you in the ice
But fed up with hurting me

What is there to win
except peace of mind?
Sign me up
Don’t want to conquer anymore
I’m done
Enduring

@densjungandesjalvhushallaren on Instagram. “By endurance we conquer” quoted from Ernest Henry Shackleton, captain of the polar exhibition ship *Endurance*.

Paint pouring technique on canvas of an up-close view of the back. There are ribs in colors gold and white and EDS vertebrae made with black, white, and copper with two red dots that indicate pain.

Endurance

MIEKE SOBOLEWSKI

Endurance,
There is no middle or end.
Sometimes it's innate,
other times it's pretend.
It's stillness and waiting.
It's calculating, advocating.
A light in the dark,
a comma, an ellipsis mark...
To feel nothing and everything,
all at once, yet again,
amongst another pop, twist, and bend.

Endurance Alongside EDS

GRACE CARNEFIX

ENDURANCE, PERSEVERANCE, AND resilience are concepts not lost to those with chronic illness. My journey to diagnosis for Ehlers-Danlos syndrome has meant enduring the unbelief. At 14 years old I was constantly told I was "fine" by doctors who didn't care to listen to my symptoms fully. Being forced into a system that expects textbook answers took a toll on my mental health. No young child should ever be told their pain is not real.

Now at 18, I look back and am proud to have endured all I have to be diagnosed. I am now able to advocate for myself and encourage others to do the same for themselves. I have endured difficult surgeries, procedures, tests, and skeptical doctors. Ehlers-Danlos creates many comorbidities that range from mild to rare. I unfortunately suffer from MALS, SMAS, renal nutcracker, POTS, endometriosis, TOS, and a valve disease in my left leg. Finding doctors who understand these have come few and far between. However, now that I have my team of specialists helping me, life has become much more hopeful.

Endurance means different things depending on perspective. For those of us with chronic illness, endurance can become suffocating. I have days where I crave normalcy over endurance. Endurance presents like a cage with no way out; We see the outside world but can never enter it ourselves. But is that really a bad thing? I used to view endurance so negatively—it was all I heard from those who didn't have any idea of what I was going through.

However, now I am able to see the community around me who does understand it. We are not alone in this journey of endurance. Wherever one of us lacks in strength, our community has the ability to encourage, and lift in up in support. The bad days are real. Don't ever let anyone convince you otherwise. I also encourage you that the good days are just as real and are coming. Find what is worth enduring no matter how difficult the journey is. ■■■

Inspirational Acts

PAMELA MATHISON LEVITT

It’s easy to speak of pain.
I advise others to do it often;
here’s a passport or a dictionary

to phrases that rearrange
parts into order.
As if conveyed, pain will pass,

hopping along, like if I say it,
it will have a body of its own
and won’t occupy mine.

I tell myself I have to live with it.
Like my face or my brain,
it can’t be exchanged for another.

I tell others that it’s important to sit with it,
to notice it moving,
to accept its presence.

What would it mean to resist?
What words can exorcise
myself?

Meditate on it, follow the synapses,
all the signals it points toward.
Trace the pathways through the body;

touch it to know, to know
You can hold it;
You can hold onto it

because letting go isn’t a choice.
What would surrender look like?
There are no opposing forces here.

There is no one, but we talk about pain
like a shadow or a light or a guide or an opening.
We make infinite connections;

We reconcile, we abide with, we describe,
we attempt to pass it like a torch
we must cling to as if it illuminates.

My tongue is swollen with words about pain.
My arms are strained from writing them;
My brain pulses and my chest heaves.

Others say words to describe the acts I perform.
I say words for them. We exchange the words.
But the pain returns.

Endurance and vEDS

MAUREEN McGOWAN

WHEN I WAS A LITTLE GIRL MY mother used to say I didn't have much endurance. I could often be found curled up asleep behind a chair or a TV set at family parties. In second grade when I took the deep water swimming test, the instructor stood close by in case I couldn't stay afloat. As I grew, I began to dislike gym class and impromptu games of dodgeball because I just didn't have the strength to keep up with my peers. As chronic pain and injuries became commonplace in my teens and twenties, my ability to endure was further tested.

After my pregnancy at 32, the pain continued and the ever present fatigue and exhaustion took over.

I felt as if I had been finally beaten. I could no longer work or care for my child independently. Thus began the assault on my mental endurance. I felt this was somehow my fault. My ability to function was sorely tested as I searched for a diagnosis. It finally came after four long years of barely getting by. The diagnosis of hypermobile Ehlers-Danlos syndrome was little comfort as there was no cure and little treatment. Eight years later, the diagnosis was changed by DNA testing to vascular Ehlers-Danlos. It was not easy to accept the new diagnosis, especially because my beloved daughter was affected also. With my physical and mental endurance declining I attended a month-long pain management program.

As I learned about my illness and the tools to manage it, my physical and emotional endurance began to grow. I learned to accept this new version of myself. I grew proud of myself for all that I had endured. I was no longer just functioning but actually living again! I was able to care for my family and do volunteer work. I was even able to travel a bit.

Now, well into my fifties, I have outlived many with vascular Ehlers-Danlos syndrome. Endurance is becoming an issue again. It is hard to deal with the increasing pain, fatigue and disability. It is hard to come to terms with my own mortality. Because of this journey, however, I have become emotionally strong and resilient. I have earned the endurance I will need to face the road ahead. ■■■

LEFT ANKLE 2020: OS TRIGONUM SYNDROME ■ NATASHA WEIN

Graphite and white colored pencil on brown paper bag, June 2020.

Natasha Wein is an artist working out of Stockbridge, MA. For more on her work, find her on Instagram @nweinart and @berkshire_resin_art or visit her website www.nweinart.com.

THE EVENING I BOOKED MY ANKLE surgery, I cut up a paper grocery bag and sketched my left ankle. The small triangular bone in the back of my ankle failed to fuse to the larger bone—called the talus—from overuse playing soccer competitively in my youth. I wore clunky lace-up braces under my socks and have known since I was nine years old that I might need this operation if the symptoms eventually interfered with my ability to get around.

Though I did not receive the cEDS and hEDS diagnoses until my early twenties, my adolescence was riddled with unusual, lingering, and easily-acquired injuries: my ankles were chronically swollen and painful, my knee caps failed to track, my pubic bone didn't fuse, my low back and neck hurt and sent radiating pain down my limbs, and six of my ribs subluxed when I swung a baseball bat in middle school physical education. All of these injuries affected my developing body and mind as I attempted to act my age, play, compete, and find comfort; pain and mistrust left its mark and made memories in my nervous system, disconnecting me from my bodily experience the more I got frustrated with the aches and pains. Medical providers were baffled, my parents were frustrated, and I was alone in a painful experience that would prove atypical and unsustainable. I now have severe spine pain and radiculopathy, joint instability and pain, chronic inflammation and fatigue, daily migraines, POTS, and more grief than I can bear. If I sleep on my side, my ribs twist and press out of their sockets and I feel like I am twelve again. Each injury takes me back to an all-too-early beginning and I move forward with it, creating new tales of breaking and mending.

After surgery, I taught myself to walk a second time; using my walker, I took up every opportunity to shake my fist and tell the people in my life to get off my lawn. I jest about my aging and degeneration as if it isn't happening rapidly and in real time. I fear how bitter, jaded, and disconnected my conditions are turning me. I have tools now—awareness about my condition, the ability to educate others, daily physical therapy and other treatments—but they are not enough. In addition to practicing accepting pain and the physical limits that require more dependence than I'd care to admit, I must also practice making beautiful things and exercising my sense of play and humor.

My parents are not frustrated anymore; they are sad and so am I. I do not always know how to continue to endure and persevere when the suffering is not time-limited and respite is rare and precious; each farewell to momentary relief feels like a new loss each time.

A mentor once told me that when everything feels rotten, remember: sunrises, surprises, and harvests. I hold this guidance close because it leaves room for the unimaginable to unfold and surprise me with its delight. I practice saying to myself, whatever you are working on right now is important, especially on the worst days; keep talking, keep laughing, and keep hoping. ■■■

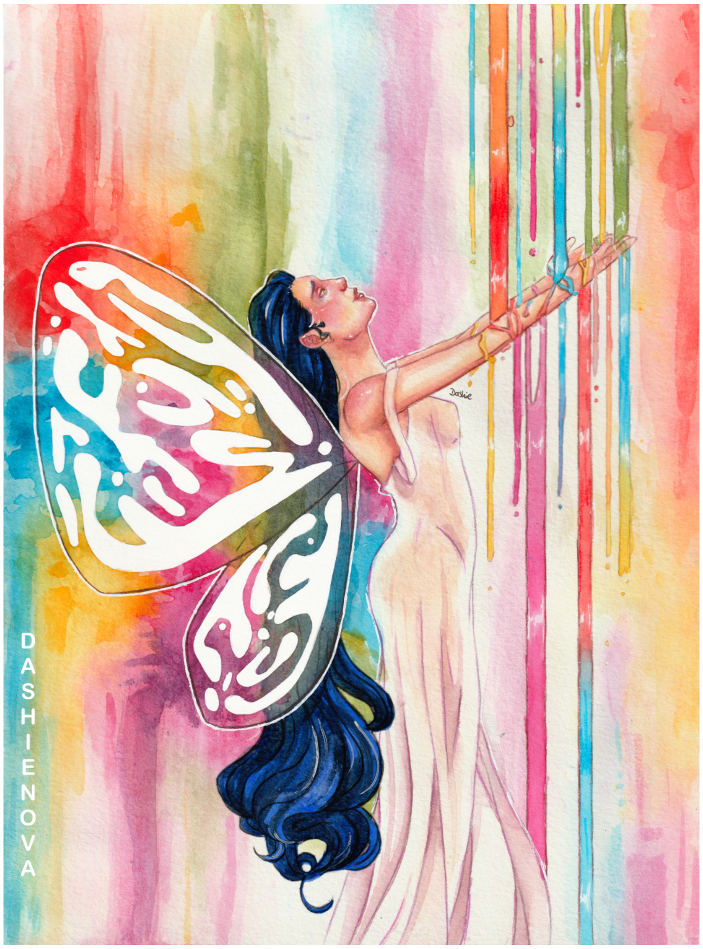
Disjointed

MEAGAN

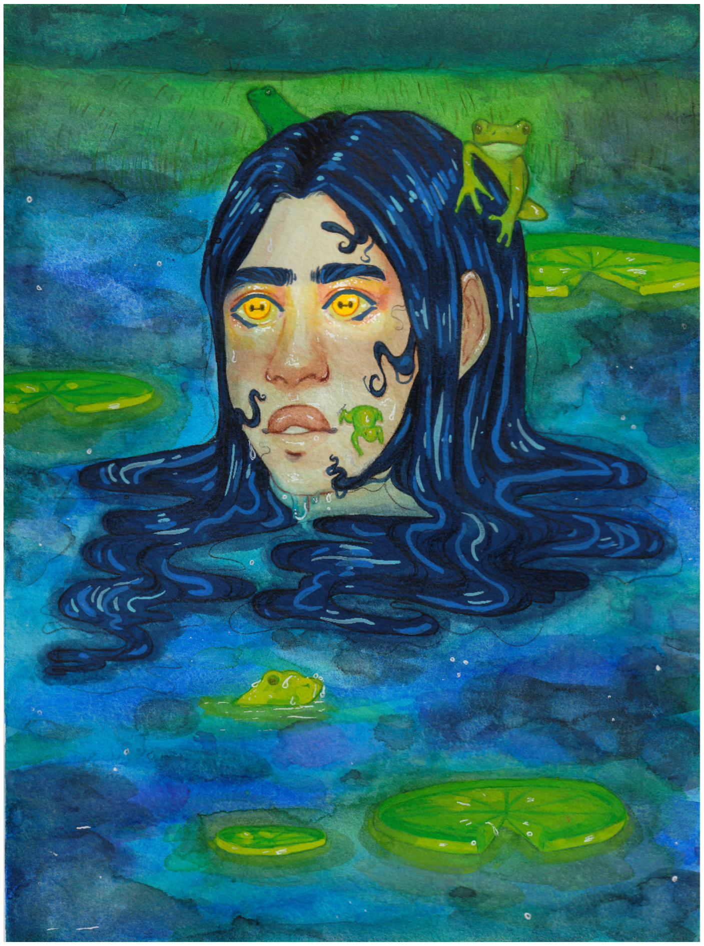
Is it possible I
Matter
Weak, protected
Can
Cast off a body defective
Flex a mind once afflicted
Freed, insurrected
No longer disconnected
From matter deemed infected
Ready to be
Resurrected
Healed by perspective
Mind and matter allied
Reconnected.

ENDURANCE ■ DASHIENOVA

The piece I made specifically for *Loose Connections* depicts a pale girl with dark hair, and zebra print clothing draped over her. It explores what endurance means to us, as people with EDS and HSD.



Made in April for Autism Acceptance month, “Spectrum” is a piece I re-paint every year to abstractly demonstrate the autistic experience. It includes all of the colors of the rainbow, since those colors represent autism, and a girl with butterfly wings.



“Child Of Frogs” is of a girl with frog eyes, peeping out of the water of a pond. She is surrounded by frogs and lily pads, and glistening water.

We Are Giants

ELIZABETH LATHAM

Endurance presupposes that we have a threshold and,
when reached, our body can go on no longer.

What happens when this threshold is ever-changing?
Constantly pushed beyond what we once thought possible.

What can break us one day passes without notice on another, depending
on a multitude of factors such as pain, sleep, and symptom flares.

Like a muscle, our endurance builds over time.
This is the very definition of growth.

We shouldn’t have to endure such suffering, but the strength we build
while chronically ill is immense.

This strength often goes unnoticed by a society that can't see beyond
what is visible to their own eyes and experiences.

A quiet strength builds, a vital skill transferrable to every aspect of our
lives. We are the unseen giants.

@inspiredbyelizabeth on Instagram

Day by Day

KAIA COBURN

I started having knee pain when I was eight,
Being fine one day and wearing knee braces the next,
Not knowing that for the rest of my life it would be my fate,
As the years went on, EDS got more complex.

For it's not just my knees,
But other joints as well,
One minute I'm walking with a breeze,
The next my hip subluxes, but how long will this pain last?
Only time will tell.

So I take it slowly, adjusting things to fit my needs,
Knee braces or not, a pain free day is not guaranteed.
Whether I run with a fast or slow speed,
I go along with it day by day
and regardless of my condition when the sun sets,
I feel that I succeed.

Endurance

JIM BARNARD

I HAVE BEEN MARRIED FOR 15 YEARS THIS month (September 2021). I was pretty scared about getting married back in my dating days because I came from a broken family. I wasn't sure I had much of a roadmap for marital success. When I finally worked up the courage to ask, my then-girlfriend, Alisha to marry me, I felt like God had prepared and called me for this step. Little did I know what any of this was going to look like.

Three months into our married life, Alisha became horribly sick. She could not keep any food down. I didn't panic at first because I was certain she had just come down with the stomach flu. Only this bug didn't go away. There was something seriously wrong with her. The honeymoon came to a sudden halt and the next three months were spent at the Mayo Clinic with her undergoing dozens of the weirdest and most invasive tests we could imagine.

That experience was unspeakably hard on both of us. The doctors didn't agree on what was wrong with her. One doctor told her she had Ehlers-Danlos syndrome (EDS). I had never heard of EDS before, but basic Google searches seemed to affirm this diagnosis. But another doctor, her managing practitioner at Mayo, felt there was a different explanation for her sudden lack of health.

"Well, I think you are a ruminator."

"What does that mean?"

"It means if you got some counseling, your physical problems would probably go away."

"So, you think I'm nuts?"

"No, not nuts. I just think you have not dealt with your past well and it is causing your body to have some issues."

I had never seen Alisha with an expression of pure anger before. I thought she was going to explode or possibly pick this man up and bend him into a pretzel. I wanted to say or do something to make it better, but I couldn't determine anything that would actually help. I seriously imagined myself punching him in the face, but thankfully that's not really my style. With us being newly married, I wasn't sure how to advocate for her, so I just sat there as a confused witness. She handled herself great and did not really seem to need my help, but my lack of fight on her behalf remains one of my greatest regrets in life.

She asked him what would lead him to the conclusion that she is a ruminator. He told her that since she was abused by her dad, this was the most logical conclusion—he declared he sees this frequently. Her anger started to hit an epic peak as she explained that, no, she and her dad did not have a good relationship and he was not a good husband to her mom, but truly outside of genetics, he did not cause this for her. He wasn't the most loving father, but he didn't cause her guts to suddenly stop years later. She also explained how much counseling she has sought out over the years in an effort to be healthy. That was the only thing I actually spoke up about, saying something about how emotionally solid she is, but he was not trying to hear any of that from us. I should have gotten aggressive to defend her, but I felt as though a sudden outburst of legitimate frustration would potentially turn his focus to potential abuse by me because abused daughters always marry and become abused wives. I just sat there frozen.

She filibustered him for a few minutes, refusing to let him leave without providing other options or answers, but he had none. He had made his conclusion during the first 15-minute meeting several months prior, and nothing was going to convince him otherwise—no test results, no diagnoses from other doctors. He had made up his mind and needed to move on to the next patient. I was so mad because there seemed to be no actual reason for him to put Alisha through all those terrible tests, just to make the decision he was going to make from the get-go. I wondered what the tests would have needed to show in order for him to feel like he was wrong about his hypothesis. Clearly, she had done about as bad as anyone could do in all those different tests.

We left the clinic very confused and frustrated, especially after that one doctor dismissed the results from all the terrible tests she went through, only to suggest the problem was psychological. Over the following seven years we saw EDS take a real toll on her body: Alisha lost half of her body weight, spent hundreds of nights in the hospital, had countless surgeries, and essentially died on me twice. Our marriage was full of expectation gaps.

Years after the experience at Mayo, she got an opportunity to be seen by a specialist who we believed could help provide a new treatment option for her. This particular doctor worked at Dartmouth College's Medical Center in New Hampshire. I wasn't sure at first about making the trip. I was having flashbacks to our Mayo experience. But that wasn't fair; this person wasn't that other doctor after all, and Alisha was told there was the possibility of participating in a case study after our visit, so it felt like it was worth the investment.

There she had a slew of tests run again which put her through the wringer. The doctor affirmed her illness at the end of everything, but didn't feel like she was a good candidate for his trial. As we drove away from there, Alisha seemed oddly tense. Eventually, she asked me if I could pull over on the side of the highway. I assumed she needed to throw up, so I quickly got over onto the shoulder so she could get out. She jumped out of the car immediately.

I would normally jump right out alongside her to rub her back as she got sick, but this time I stayed in the driver's seat and took a moment to appreciate the field of wildflowers that adorned the area where Alisha was standing just off the highway. We were listening to the new (at that time) Coldplay album, *Ghost Stories*. Track number five, "Midnight," had just started playing when I heard screaming.

I jumped out of the car and ran around to the other side to see what was wrong with Alisha. She was yelling so loud and intensely. It didn't take me long to figure out that this pit stop was to let out her rage. I joined right in. I stood beside her and yelled with all my heart. The two of us screaming at the top of our lungs with the most methodical Coldplay song providing the soundtrack while standing in the middle of a random field packed with wildflowers as cars zoomed past...the moment felt so full. As the five-minute song ended, so did we. And we held each other and laughed so unbelievably hard.

Alisha was battling bitterness. All the tests and questions, the charts and notes, the surgeries and recoveries, the lack of answers—she was weary and needed to let it all out. She wasn't done trying to find much-needed answers, she just needed to beat the bitterness that had suddenly grown inside of her. I am so proud of her for recognizing what she was experiencing. She couldn't "keep her arms up" anymore and was (quite literally) crying out. I was thankful I could hold her arms up on that day by using my voice and screaming alongside her. There was a battle happening in the valley of suffering: was bitterness or endurance going to win? She was battling for endurance, but defeat meant risking slavery by the opposition—in this case, bitterness.

When endurance wins, the pathway becomes clear—from suffering to endurance, which builds character, ending in hope. This is victory. Conversely, it is possible to choose another path, the path of bitterness. This destructive path moves—from suffering to bitterness, which builds doubt, ending in hopelessness. This bitterness path exists with the presence of isolation, and it creates victims every day (people just like me).

We might not get to choose what we endure, but we can choose *how* we endure. Endurance requires discipline. All of my back-and-forth emotions over the years existed as I was working on endurance. I would occasionally tell people who honestly wanted to know how I was doing that I felt like I had been training for an emotional marathon for way too long. Endurance pushes you beyond what you would normally believe to be your capacity. Endurance doesn't have to be pretty; it just has to be. It looks like taking the next step when you absolutely don't want to or don't think you can.

When we head down the wrong path, it's not too late to walk it back. Halfway along our 6,415-mile road trip, Alisha found herself needing to *turn around*. She cried out, or screamed out really, and I was able to be there and hold her arms up. Endurance is always easier when we aren't isolated. I am so glad she didn't hang on to the pain of bitterness for another moment. She needed to let go of it before things could get worse.

Later that same day, when we arrived at Nantucket, we rented a convertible Jeep and drove up and down the beautiful beaches, soaking up all of the summer sun. Well, the final test Alisha had gone through that morning at Dartmouth required adhesive to be stuck to her nose in order to keep a tube in place. They failed to clean off the glue properly afterward. She is extremely allergic to adhesive, so think about adding several hours of direct sunlight to the situation. Her entire nose blistered up big and fast. She was miserable. Good thing she had let go of the ensuing bitterness and knew she wasn't alone. I am so proud of her for how she endured that very painful situation. It clearly wasn't the worst thing she had ever experienced, but she was fragile and could have easily moved down the wrong path in isolation toward hopelessness. Any of us who has EDS or loves someone who does runs this risk themselves. I pray that you are battling off bitterness and isolation and finding your voice to endure and hope. ■■■

Jim Barnard is an "expectation gap coach" with tiller coaching, and the author of *The suffering guy* (released May 2021) which shares our story of suffering caused by Ehlers-Danlos syndrome.

Changing Positions

PAMELA MATHISON LEVITT

My child becomes ill from playing:
one moment, hair in the wind, smiles radiating,
the next, grey and flat,
pain wadding up the smile
like someone crushed it in their fist.

I feel like using mine on something.
Instead, I bring all the comfort I can carry,
water, electrolytes, pills, ointments.
I make the air smell lovely and massage
her feet with oils.

She asks me not to leave her;
the words are unnecessary.
I wrap myself around her, one in fetal position
around the other, willing her pain
to disperse with my heart rhythms,

until she rests, quiet and still in my arms.
I ease out of the room, cracking the door
so I can hear her calling my name,
calling my name, so I can fix things,
so I can rewind, unknot some gene sequence,

and let her spin on the merry go round,
standing in the middle if she wants to,
hands splayed wide in the air
no need to cling to anything for balance,
just the joy of movement without consequence.

Endurance!

GAFSA BUX GARSON

Endurance!
Some human beings endure no hardship;
financial constraints, bad health, nor pain!
And
It is sad that those that those that experience severe hardships,
financial constraints, pain, and are ill,
get no help from those who can't even fathom or empathize
and show no mercy to those who did not ask to become ill
nor to endure hardship!
It is such a pity that humanity is gone!
No one realize that anyone can become ill or bankrupt with a blink of a eye!
The Almighty sees those who suffer on this Earth
And
Blesses them with love, light, abundance
When the time is right!
So I implore thee to have hope and faith
Because the Almighty is always there and that is
more than enough assurance!

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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