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Grief and Neurosurgery in the Time of Coronavirus

MARY A. JACKSON, PH.D.

IT IS NOT AN EMERGENCY. NOT NOW, AT least. Instead, it could be another year or more of insidious degeneration before it may become that. Yet a slip on the ground could spell emergency or worse. "Avoid whiplash," the neurosurgeon says each time. Avoid everything that was once fun, I always think.

At the time of my hEDS diagnosis, my cervical spine was a concern. Like most of my pain, I had pushed these sometimes debilitating symptoms to the back of my mind. It's not that bad, I would tell myself. I internalized what most doctors to that point had told me, the familiar "I don't know." But since I was a little girl thinking painful feet were normal, my body has always known. It has known since those first surgeries and through various illnesses.

When I went to the Mayo Clinic in 2016 for my diagnosis, my husband was with me. Two years later, he unexpectedly died. At 34 years old, with a chronic illness, I found my body numb to any physical pain. The

emotional anguish was all-consuming. I ignored every symptom and pain and pushed myself beyond limits I had long since set. For six months, I felt nothing; I hiked, I climbed, I ran, I lifted boxes, I never slept. As the merciful shock of the loss rolled away and panic attacks became my normal state of mind, my pain and fatigue stormed back with abandon.

For 18 months, I did as the physical therapist said. I did as my psychoanalyst said. I did the grief work, took my meds, tried to carve out a life without my caretaker, without my love.

As the dust of sudden loss settled and my nervous system calmed, my body was laid bare to the crux of my genetics. The neck pain that returned I knew was not the same. Something had changed.

In January, I saw my new neurosurgeon for the first time. He looked me in the eyes and said: "I'm worried." What a contrast to the years of stumping

doctors. Once speculative surgeries for my spine were now more concrete.

Before the pandemic took hold in the United States, I was given injections. Hard on my body, and bringing no relief, they were diagnostic hoops to jump through. I was proud to do the first one without help. But for the second injection, I had to accept I could not do it alone as my baby-boomer parents came to Colorado to help.

The last injection came on the eve of lockdown, and I waited out the four weeks until my follow-up. No longer able to visit the clinic in person, I held a Zoom call with my surgeon. In the comfort of my own home, I found my nerves calmed. Figuring if I were to trust this doctor with my spine, he should see a little side of my personality beyond the fidgety, nervous widow in his office. So, I selected a Zoom virtual background to bring levity to the call: enter the cockpit of the Millennium Falcon from *Star Wars: The Empire Strikes Back*. In between fairly serious descriptions of my conditions, he paused with a chuckle to remark how Han Solo was glaring at him. Relieved to have more answers, a plan, and a doctor whom I implicitly trust, we exchanged science fiction novels as the decision for surgeries was made. And now, a month later, it is simply “hurry up and wait.”

The hospital is not allowing voluntary surgeries yet. My son is home from school. I work from home when I do work, and my parents, who I will need for help, are in a vulnerable age group.

The surgeries are happening, but when I am not sure. They say perhaps June. I will need to quarantine beforehand, but that will not look much different than life is now.

While friends are looking forward to getting back out after the lockdown lifts, I look forward to surgery. I truly do. There is a slight absurdity to that fact, but as other Zebras may know, the possibility of relief and the prevention of worsening symptoms is a gift. No longer being told “I don’t know” but to have a realistic plan is more than I could hope for right now.

My grief and new normal since my husband’s death have, in a way, prepared me for lockdown and my looming surgeries. Many tools for calming my anxiety, self-care, and rest have been vital to managing life in the pandemic. I adapt well to abnormal challenges. I am approaching these surgeries in the same way. I’m ready for the challenge of post-op recovery, and the next problem areas of my far too bendy body.

Perhaps when life is normal for everyone else, I feel more of an outsider. Now, with everyone at home and managing grief and anxiety, I feel less abnormal. We do not know when the quarantine will be lifted, when life may return to some semblance of normal. But for those whose life is never normal, who have heard “I don’t know” time and time again, there is a resilience that we can draw upon. My body always knows, and it knows how to get me through the pandemic and beyond. ■■■

The Patient Physician

MERIDITH ANNESS

You are
the future of medicine
they say.
Look at the sacrifices being made.
These physicians are called to serve
& one day you will be, too.

More than anything
my heart longs to
give—
care—
do what I was put here to do
create hope where there was none

But
my body isn't like theirs
I am bound by the same ache
I one day hope to heal in others

I am flesh & bones
behaving
uncooperatively.
How will I
pour my soul into something
when my body says
please
rest?
I pray to God
that my calling
won't be my undoing
But
let
me
take
away
your
pain
while I live mine
every day.

—An EDS warrior and future doc

“You call me a hero”

JULIANNA WENINGER

You call me a hero, brave, an inspiration
And I try so hard to live up to your expectations
But there's a war going on inside of me
A constant battlefield that no one ever sees
Torn between what my mind wants and body needs
Knowing that tomorrow is never guaranteed
I have so many big dreams and wishes
Taking all my shots but always ending up with misses
The constant struggle inside of me is never ending
My entire day is just filled with pretending
I'm fine, I'm okay, it only hurts a little
My body's wants and needs always leave me trapped in the middle
The middle of my desires, my passions and my fires
Choosing whether to keep pushing on until my body tires
Or to take it easy, knowing my limitations
Has always been my biggest frustration
Twenty seven surgeries down, a lifetime to go
Gonna plant this seed of inclusivity and watch it grow

The thing I got.

KAT MILBERGER

It sucks being stuck
in a body
that won't hold this
endless
energy.
Dance with me!
Can't you see the quickness in my spirit?
Sickness, come to fear it
Fix this, for the moment
But it won't be but a quick fix.

Grease it up, stretch it like gum in a bubble.
Pick out the rubble.
Constantly fumble with a braid you can't hold.
Hands too big, brittle cold
Cards not great, go on, fold
Grocery fruit, growing mold
Scrambling to preserve it
with a first aid kit
that's starting to rot.
And complaining never got
us anywhere.

The restaurant chairs are the worst.
And the thirst for the gym becomes the tireless god

tainting my every thought
and no one seems to get the thing I got,
but a puff of pot sends me *flying* for a sweet moment.

Wake up groaning

Starting over

Will the next day come easy?

Doesn't matter. Leave me
with this body.

It's mine though.

And I know it better than the weatherman's weather
But the forecast's severed to the bone.

Give it time,

trying,

Spit and grime,

prying,

Fingers stiff,

sighing,

Hair slipping, hold tight,

Nails gripping, keep sight,

Teeth gritting, pull, fight,

This time I really might

Finish.

Managing Chronic Pain with EDS and Co.

JEANTIQUE @UNIQUELY_JEANTIQUE

MAY IS EDS AWARENESS Month – a month dedicated to raising awareness and understanding of all things EDS. Of course, living with Ehlers-Danlos syndrome, we know about the struggles of chronic pain all too well. It is one of the main symptoms of the condition, and for many is one of the main challenges of living with it.

Personally, my pain started in my neck around the age of 11, and over time became more widespread so that now (aged 25) it is rare for any part of my body to be pain-free for long. The pain directly caused by having EDS is mostly related to my joints, muscles and nerves. But just like many others with EDS, I also have a number of comorbid illnesses that cause their own types of pain too. For example, my PoTS (postural orthostatic tachycardia syndrome) causes severe migraines, my MCAS (mast cell activation syndrome) causes horrific bladder and cystitis-like pain, and my stomach issues lead to daily gastrointestinal pain.

Living with so many types of pain, it can be tough not get completely taken over by it. Especially being aware of the permanence of our conditions, it makes sense that sometimes we might start to feel completely hopeless and defeated. This is an experience shared by most of us in the chronic pain community, but it doesn't make living with the pain any easier. Over the years, I have tried every strategy under the sun to alleviate my pain, and have developed a personal "toolkit" to help me manage my symptoms as best as I can. I hope that by sharing some of these practical strategies, it might provide others with some new ways of managing symptoms too, making day to day life just that little bit less painful.

Supports and aids

Using braces and splints for joints that are unstable, sublux or dislocate easily help provide support and minimise pain and injury. Knee braces (hinged, strapped, or elastic) are popular for those of us with

EDS, as well as wrist supports, neck braces and finger splints. I often wear a soft neck collar on public transport or in the car, because my neck is especially unstable. I use oval-8 splints for my thumbs and fingers which over-extend, and a thumb splint for my CMC joint pain – a pain that many of us with EDS are familiar with. I have also found kinesiology tape to be a life-saver. I frequently tape my thumbs, wrists, knees and ankles, using YouTube videos as a guide. There are taping strategies for pretty much any part of the body, so get creative seeing what works for you. Some tape is expensive, but as a tip, there are cheaper options on eBay.

I also have a whole selection of body supports. My best recommendations include a U-shaped pregnancy pillow at night, which protects and stabilizes my joints whilst I sleep, keeping them in a neutral alignment. Neck supports such as travel pillows, or special orthopedic memory foam pillows can be especially helpful at night or on long journeys.

Medication

For me, there are some medications I find especially helpful on a daily basis, such as my long-acting muscle-relaxants, tricyclic antidepressants, SSRIs, and topiramate, all of which can be used to treat chronic pain. For more acute pain flares, I would suggest keeping an emergency supply with you. These might include OTC painkillers such as paracetamol (acetaminophen)

and codeine, anti-inflammatories such as ibuprofen and naproxen, opioids, benzos, anti-emetics and tryptans. Of course all medication-related issues need to be discussed with your medical team, and medication regimes will look different for all of us and might take some time to refine.

Cold and hot therapy

Ice and heat are two of my best friends when it comes to pain! Cold therapy (ice-packs, cooling gels) is great for reducing acute inflammation or injuries, and has the added benefit of numbing the area so that the pain is felt less intensely. Heat therapy (heat packs, hot water bottles, deep-heat gels, microwavable wheaty bags) are helpful for soothing pain, relaxing chronically inflamed or tight muscles, or calming inflammation in the affected areas. Heat is also great for soothing other forms of pain such as stomach, bladder, and pelvic pain. You can even buy warm or cold patches to stick onto your stomach or back, making this form of pain relief portable.

TENS machine

Another form of portable pain relief is the wonderful TENS machine which is my number one necessity. These work by delivering small electrical impulses to areas of pain by electrodes on the skin, reducing pain by changing the way that pain signals are transmitted to the brain. I use the Elle TENS Babycare machine, which is around £50. It might feel like a

hefty sum but it is definitely a worthwhile investment; mine is pretty much attached to me all day providing constant pain relief. It is especially helpful for long periods of standing or sitting, and can also be used on various parts of the body, from the back and stomach, to legs and buttocks.

Physiotherapy and exercise

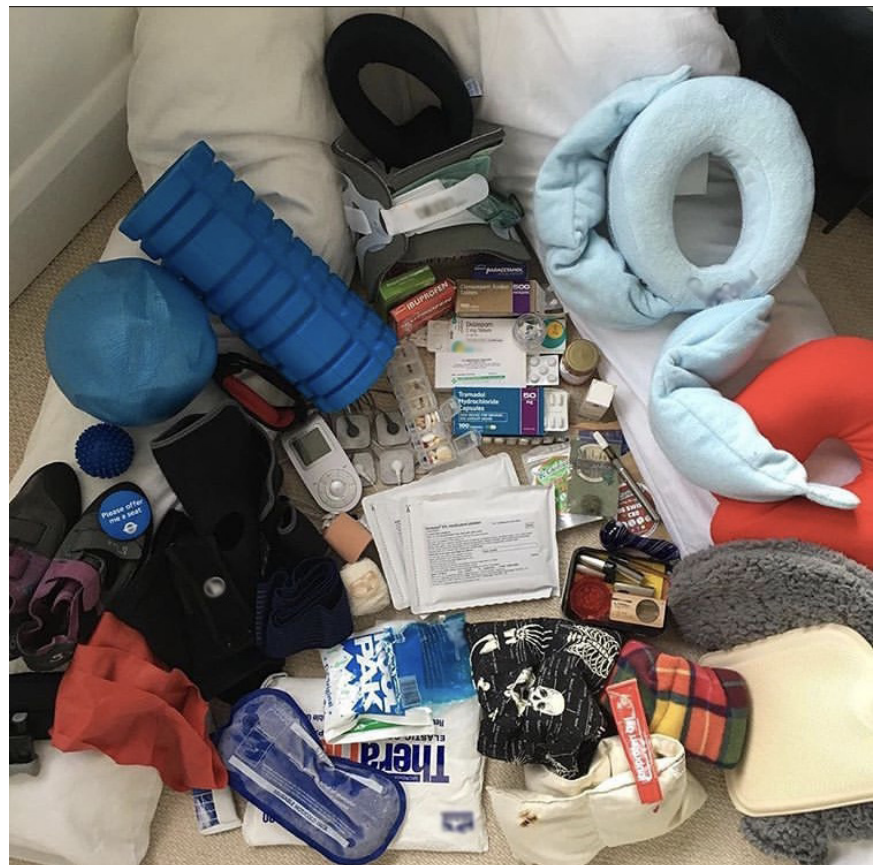
Physiotherapy and strengthening exercises help to strengthen the muscles around our unstable joints and do the work our stretchy ligaments aren't able to do. I am a paraclimber and have found my number one form of strengthening to be through rock-climbing! Of course many people with EDS won't be able to do sports like this – and that is totally okay – but staying conditioned and having a regular strengthening regime can really reduce pain in the long-term. There are numerous videos on YouTube of how to strengthen every muscle in the body, including from a sitting or lying position. Although we have to be careful with stretching (typically avoiding hyper-extending/over-stretching, impact, and dynamic exercises that put stress on the joints), isometric, resistance exercises, and those that activate multiple muscle groups at a time are recommended.

Trigger point relievers and massage

Obviously it's not every day that we can have a massage, but there are strategies that mimic it which are incredibly relieving. I've found foam rollers for grinding tough knots out beneficial, and the same goes for prickly balls, which are particularly helpful for my TMJ pain – and are portable too! You can find automatic massage chairs or machines, some of which include a heat function, and acupressure mats are amazing too. For my chronic migraines, life-long neck issues, and TMJ, I've found Botox injections life-changing!

A support system

Although this doesn't directly relieve the physical symptoms we have to deal with,



having a strong support system around us is absolutely fundamental. The pain might be the same, but the support of others to be patient, accommodate and adapt to the needs of someone living with chronic pain can be invaluable. Having psychological input from a therapist who works with chronic pain patients, receiving unconditional support from family and friends, and meeting others with EDS and Co. who get exactly what I am going through have made me feel so much less alone. The mental pain of having EDS and

Co. is just as important to alleviate as the physical pain, and I am very grateful to have found such a solid, compassionate and holding group of friends through The Ehlers-Danlos Society support groups who get exactly what I am going through. Especially in the current climate with corona causing daily disruption, the virtual support groups online have been a welcome tool bringing me closer to others in the community thanks to the wonderful world of technology! ■■■



Autocaptioning Meets Medicine

THE EHLERS-DANLOS SOCIETY

We've been asked why we don't simply turn on YouTube captions. Here are some of the results when medicine meets automated captioning. If you can figure them out, send your answers to stories@ehlers-danlos.com. The first person to successfully translate the list will get a (small) prize.

1. Classic 80s
2. Reptile dysfunction
3. Bite & score
4. Cash stall
5. Hi, permeability!
6. Hey! Dan lost his drone
7. The – beauty spectrum
8. The Earl of Dan Loss
9. Wider sum due?
10. "You're not dislocating your joints, you're subletting them"
11. Mark, A Cat Story
12. Hypocrite ease
13. Hype a mobile. Earl is Daniels
14. Mark crotch a story
15. I'm in control
16. New clay is hides
17. Creature shot
18. Pack eraser scars
19. Pie so generic, pop you rules
20. High bubble
21. Sir Ringo, my eel, yeah!
22. Dissident Omiya
23. Earnest and all syndrome
24. I'll pull him & lower him
25. Clear Frank banana
26. It wasn't a Cronus
27. Jack, he late son
28. My tad ring
29. 2000 levels
30. Sudden Terry lifestyle
31. Super high
32. Yes eye bell
33. The SEC Tamizah
34. Honor immunity
35. And Willie D.S
36. That without animals
37. Die affirmed strengthening
38. Effects of ABS and anxious Dion mail
39. Cycle logically
40. Air loose, ant lows
41. U.S. positions



I am a self-taught artist and for several years, though I have found many struggles and pains within my physical body, art has always been something it has been able to do well. In February, I sustained a shoulder injury and for the first time, pain greatly impacts my ability to paint. However, being that art is my number one coping skill and source of self-worth, I have refused to let it stop me from doing something I love. I listen to my body and let it guide me through both the pain and the art. This piece, appropriately entitled "Pain," is just one of many pieces I've created recently while pushing through significant discomfort. It represents both the new pain from the shoulder injury, as well as the many, constant, daily pains I live with. The bear, though injured, fiercely fights on and its strength is not withered by pain. I have always primarily painted animals because they are quick to adapt and let very little stand in their way of survival. I like to think of myself being like that way, strong and not marred by the pain in my joints.

enigma

TIFFANY NAJBART

I am flesh and bone,
held together precariously,
cautiously, peril always near.
The slightest misstep,
an avalanche I might never
 recover from.
Loose ligaments, cranky collagen.
What are limits?
I leave prescribed guidelines
 in the dust,
stretching far past what is good, right,
the way it should be.
Too much laxity, never
 enough discipline.
Limits exist for a reason.
But my soul?
Oh, it longs to soar past the
 confines of mere existence.
It dances to rhythms my body
 could never keep up with,
would certainly end in pain
and further things to fence
 myself away from.

It is life and brilliant color
 and triumphant song,
relentless
indefatigable
uninhibited.
How to reconcile these
 two impossibilities,
coinciding as if unaware of each other.
Limitless, lively, and so limited.
Free, vast, containing multitudes
 and constrained.

I am flesh,
blood,
precarious,
cautious,
limited,
soaring,
dancing,
color,
song,
relentless
enigma.

You in the Mirror

EMUNAH STARK

I look in your eyes and say:
You got this! Smile!
But you just shake your head and sigh
Looks like this is gonna be a while.
I watch as the tears stream down your face
And I say:

You are stronger
You are braver
But it's so hard
You're so tired
So depleted.

You are stronger
You are braver
But it's so hard
You're in so much pain
So defeated.

You are stronger
You are braver
But it's so hard
You don't think you can go on
Been crying for so long.

You are stronger
You are braver
But it's so hard
You can't see the end
Only where you've gone wrong.

You are stronger
You are braver
Yes, it's so hard
Yet you keep climbing, keep trying
And came this far...

The tears finally begin to clear,
I see the beginning of your smile
And I say:

You are stronger
You are braver
It's been hard, that was today
You're a Fighter...

I know you'll be OK!

The Challenge of Adventure

S-JO RITCHIE

“YOU’RE NUTS!”

That is my parents’ normal response to my harebrained ideas, and especially so when I told them about taking on the Adventure Challenge. Even though they were not fans of me taking on a 300 km (186 miles) bike excursion across Cambodia and Vietnam for EDS (Ehlers-Danlos syndrome) and HSD (hypermobility spectrum disorder) awareness, they still were 110% supportive – and were

convinced I would fall off the bike and injure myself. (Joke was on them! I didn’t have to fall off the bike to get hurt!)

I’ve always wanted to see the world. Experience different cultures. Fully immerse myself in a world so different than my own. But with EDS, I never thought that would be a reality. This was an opportunity of a lifetime and there was *no way* I was letting EDS interfere.



After a flight that I was convinced would never end, we landed in Cambodia a few days before the bike portion began. The trip from the airport through Siem Reap to the hotel was truly sobering. Ignoring the hundreds of scooters zipping around without a traffic light or stop sign in sight, it was clear that we were very far from the comforts and privileges of home. The poverty level was heart-breaking. The “hospitals” were nothing more than open-air clinics. Stray dogs everywhere – still every single person we met was one of the richest individuals I’ve met – not in the traditional sense, but some of the most caring, giving, and hospitable people I’ve ever met. Everyone welcomed us with open arms and were eager to share their culture with us. Of course, as we all know, life with EDS is never boring, and boy did I start the trip off with a bang – err, crack.

One of the reasons I went on the trip was to find perspective. After a fall that very first night, I got a lot more perspective than I bargained for. I fell pretty hard and wrenched my ankle; it’s not every day you look down and see the sole of your foot – well, maybe if you have EDS or HSD! Thankfully after icing and adding a brace brought from home for me by Susan, the chair of our Board of Directors, the pain seemed pretty under control and I was able to walk, so there was no way I was letting this get in my way.

The next day we ventured out to the Kulen Elephant Forest and spent an entire

day with the elephants at an amazing sanctuary. We fed them, walked with them through the jungle, interacted and watched them enjoy the freedoms they now had. It was one of the most amazing days of my life, and even though you couldn’t see them, there were tears of pure joy behind my aviators. When we returned to the hotel, we ventured out again, explored some of the markets, and went on a few tuk-tuk rides, before the biking portion of the trip began.



That first day of biking was surreal. We started the day watching the sun rise at Angkor Wat, the oldest religious site in the world, and spent the rest of the day riding our bikes to various temples in the area.



We saw history. We squealed over wild monkeys coming to say hello (followed by me running away in terror). We spoke to complete strangers about EDS and HSD in these ancient religious sites. Unfortunately though, as the day rode on, I started noticing my ankle screaming at me, more and more. I soaked it in the cool pool water that evening, which helped, and was back on the bike the next morning.

About a third of the way through the second day of riding, my body was really starting to let me know something was up, and no matter how much I wanted to push to accomplish my goal, my body was not budging. I finished the rest of the day on the follow bus.

EDS tends to put limits and restrictions on what and how much we get out of life. Sometimes the physical pain or dislocations aren't the most painful parts of EDS. Many times the hardest part is having to sit on the sidelines of life and watch the rest of the world go by. Even on my worst days, when asked how I'm doing I usually answer with, "Hanging in there, could be worse," but this time I couldn't. I couldn't fake being OK. I had to let walls down and show a vulnerable side of myself that few have ever seen.

While exploring Cambodia and Vietnam from the back of a bike would have been my preferred challenge, I realize now that that was not the challenge I needed. Stepping back and forcing myself to listen to my body, not being out on the bike,

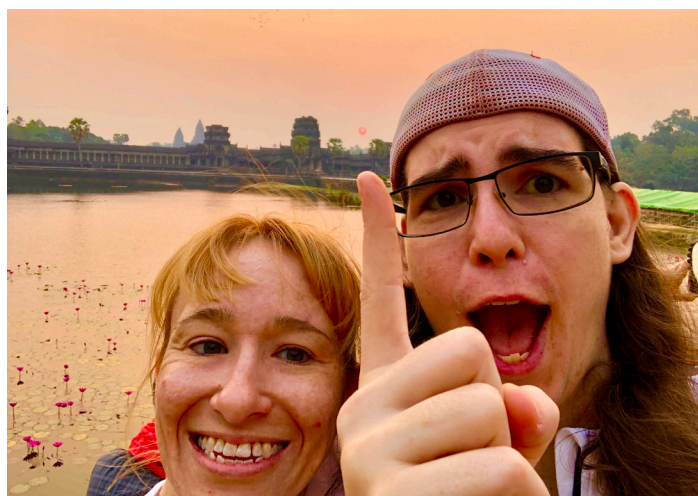
and dealing with the pain and frustration reminded me of what #ZebraStrong truly is. Zebra Strong isn't completing a huge physical feat, or something extraordinary. It is about doing what you can manage safely and smartly, and I was definitely reminded of strength I have.

While I didn't get most of the ride in, I had a once-in-a-lifetime experience, and I wouldn't trade one second of it for anything. Not even the injury. I got to fully immerse myself in new cultures, try new food, learn a different side of history, and spend two weeks with some amazing individuals.

I saw temple ruins and historical sites, that until now, had only existed in books and on TV.

I ran screaming from a scorpion, that upon further investigation was actually dead and gave the group a really good laugh.

My roommate for the trip, Carissa, and I had many evenings that involved us just collapsing on the bed in much needed hysterical giggles.



I learned some of the languages. Granted my Khmer and Vietnamese are limited to “Please,” “Thank you,” and “No thank you. Please get that spider the heck away from me!” (Spider Market. Nightmares. Don’t ask.)



I stumbled up a mountain to find some of the most amazing scenery I’ve seen, and celebrate a feat (feet?) with my bus buddy and fellow injured rider, Linda.

We ate amazing food, took a boat ride down the Mekong River, and wore our EDS jerseys with pride.

We all came to realize that “Adventure Challenge” ended up meaning something different to each of us by the end of the trip. For some it was completing the

biking portion of the trip; for others, it was stepping out of their comfort zone and trying something new, or it was finding an inner strength they didn’t know they had.

My challenge was finding balance. The balance between wanting to do and experience every moment of the trip, but still acknowledging and accepting my limitations. As I write, I am recovering from surgery for damage that resulted in that fall. I may have some unwanted souvenirs from the trip – two screws in my ankle and more surgery in a few months – but I also have memories and lessons that will last a lifetime. Little did I know that by not experiencing the trip as I had hoped because of what happened, I wound up with the trip (literally) that I didn’t know I needed. ■■■



striving

AMARA GEORGE PARKER

I've been where you are
treading water
afraid to rest for one
moment, knowing
that to stop would mean to drown

tattered rags hang to your legs
love-woven tethers bind and
drag at your limbs

I can see the sea's fast-building torrent
snatching your vision, breath, heart.

trust
underneath frothing tongues
and dragging tides
it eases

slip under
drift

let go of the flotsam you cling to

let the current take you
rest those sinews and
struggling bones

beneath the churn and drama
and that skin-clawing
undertow, the water is clear
and even from the blackest depths
if you lay back and look up
you can see sunlight

silence and sunlight

eyes open
eyes fixed
on that dappling light
that pure peaceful joy

your own heart will melt the
weight from your body
let you float to the surface
and beyond
into sun-soaked sky
and you'll wonder how
you ever got so
burdened
so tear-weighed and heavy
that sad fingers pulled you down
and you forgot you were meant to fly.

Cossacks Again.

MARK C. MARTINO

I TRIED TO MAKE MY MOTHER'S MG Midget fly when I was a teenager. Early morning after prom, I fell asleep on the drive home, just before a curve going up a hill. The MG made a valiant attempt at flight, sailing off the edge into space... and fell to rest barely a foot away from a gas pump. When I came to, I was completely hysterical. There were a couple of onlookers. They didn't come to my aid. They didn't offer to call someone. They walked away and left me. On my own.

Every time one writes, it might be for the last time—which seems a bit more urgent during a pandemic. I've had a lot of memories surprise me during sequestration. Some have been gifts—seeing a photo, and not just recognizing a wall of all things but suddenly reliving a five-decade old sensation of being in that museum room. Coming across an photo I didn't know even existed, of me aged 19 or 20 playing harpsichord, brought me another rush of memory. Wonderful gifts.

Others have been less welcome. I've discovered with age that some memories echo over the decades. I've found myself revisiting the weight of life during the first decades of AIDS, not knowing if, when, who to trust, people I loved dying, and realizing I survived because of blind luck. Here it all is again with a different virus, even to my being high-risk yet again.

On March 11, part of my gums were peeled back, roots cleaned, and sewn back up. A couple of hours after I left the clinic, it and much of Houston shut down. After getting home that Wednesday, I haven't left again without doing as my doctor ordered: mask, gloves, disinfection protocols. The only post-surgery care has been by phone; the teeth this operation was meant to save are now worse off for it, but there's nothing more they can do. I removed the traditional suture myself; the resorbable stitches haven't, and are gradually being ejected. On my own.

(echo) Watching the rain fall everywhere, the ditches fill up, water rising in the yard and first story. No one else at home. Left to me to save what I can before the garage goes underwater—for the second time in two years. On my own.

((echo)) Trying to drive home on a minor street during a storm but stopped in the line of cars, I heard a tornado warning on the radio. I looked up to see a funnel cloud descending directly overhead. No way to get around the cars, no shoulders and ditch, no buildings nearby. Nothing to do but watch it descend and wonder about my luck. On my own.

((((echo))) I was in a small boat with an outboard motor preparing to leave the dock, when a towel I had wrapped around me caught in the propeller and pulled me underwater towards the spinning blades. Deathly calm is real: either I got myself unraveled or I died. On my own.

(((((echo)))) I held the driver's car door open for my grandmother, closed it after she got in, and she drove off before I could get in, leaving me standing there. She realized fairly quickly, and if you asked, I'd say it wasn't important. Yet to this day, after I open the driveway gate I instinctively steel myself against the car driving off without me. On my own.

(((((echo)))) I was barely a teenager and baby-sitting my brother and sister. She

swallowed a large part of a bottle of vitamins. It was overwhelming to find my parents (before cell phones and in Franglais) while trying to figure out if my sister was going to die because I didn't know what to do. On my own.

My biggest fear. My worst nightmares. My mother once described me as being 43 when I was six. Always the responsible one, the one who makes decisions, the one who knows what to do. And also, the one who realizes how little control there is and how even small choices can change outcomes, but decisions have to be made anyway, because as my father said, leadership is making decisions. No matter how alone one feels, no matter how terrifying it is, on my own.

Except—I keep surviving. Each time I find myself wondering if this will be the time I can't manage, I still keep managing. I have these moments of lonely despair that nearly paralyze me, but I pull together and do what needs doing. Some day that may fail me, but not today.

Generations echo too, in complex ways. Traumatic experiences are unexpected heirlooms.

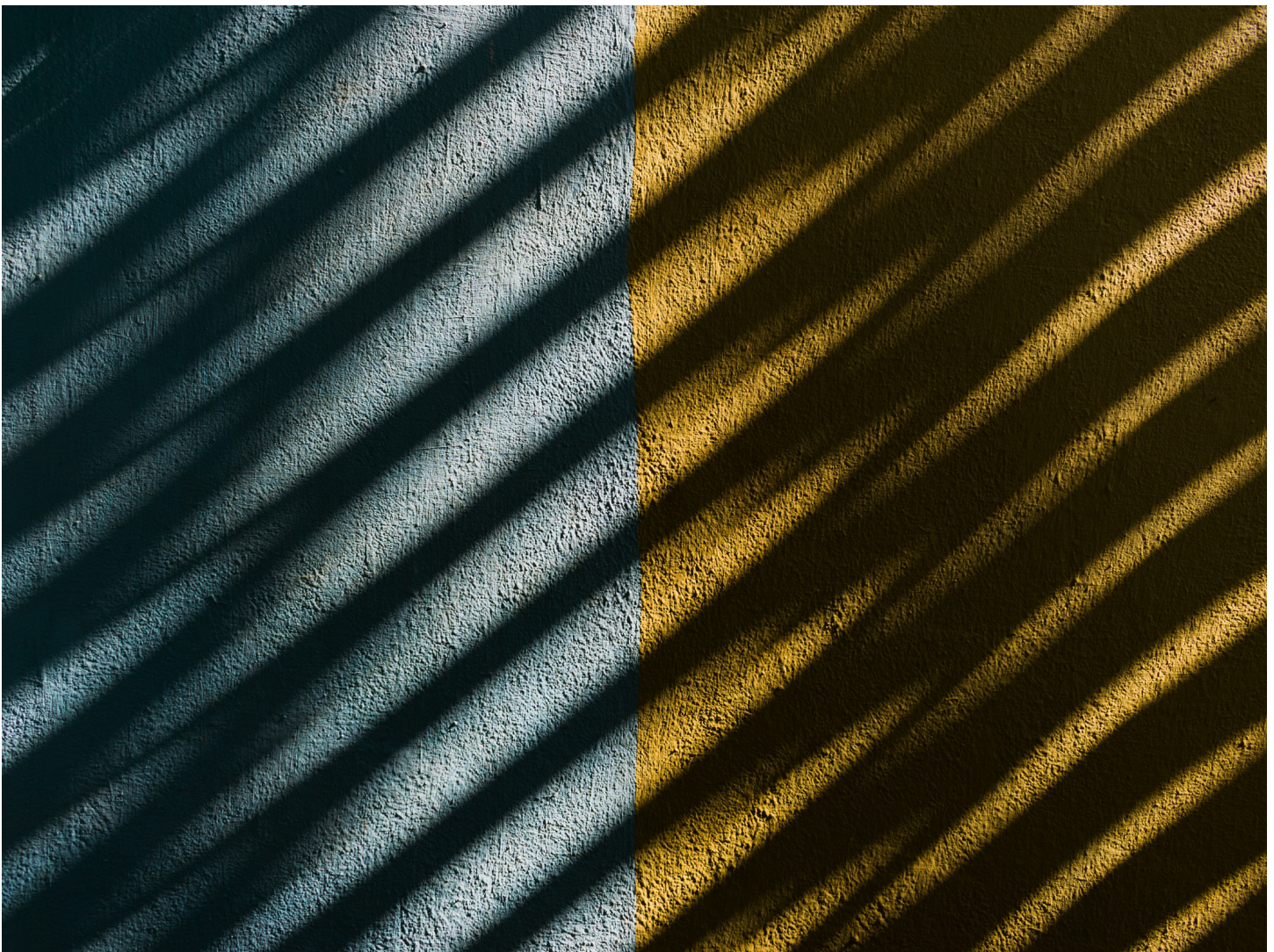
(((((echo)))) The most remarkable thing about my grandmother was her ability to just get on with it, to discount anything but what needed to be done. That drove my mother crazy growing up; but another

generation on, I find something admirable
about how, whether to someplace
better or not, she just...kept...going.

And I remember her when I find myself
doing the same. My grandmother was
a child immigrant from Poland. I think
of this resilience now as centuries of
my family watching waves of order
and chaos, wars and invasions, and...

(((((((echo))))))) Cossacks again?

Ah well. Next. ■■■



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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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