Two Systems in Collapse

What illness can teach us about responding to climate change

JULIE REHMEYER

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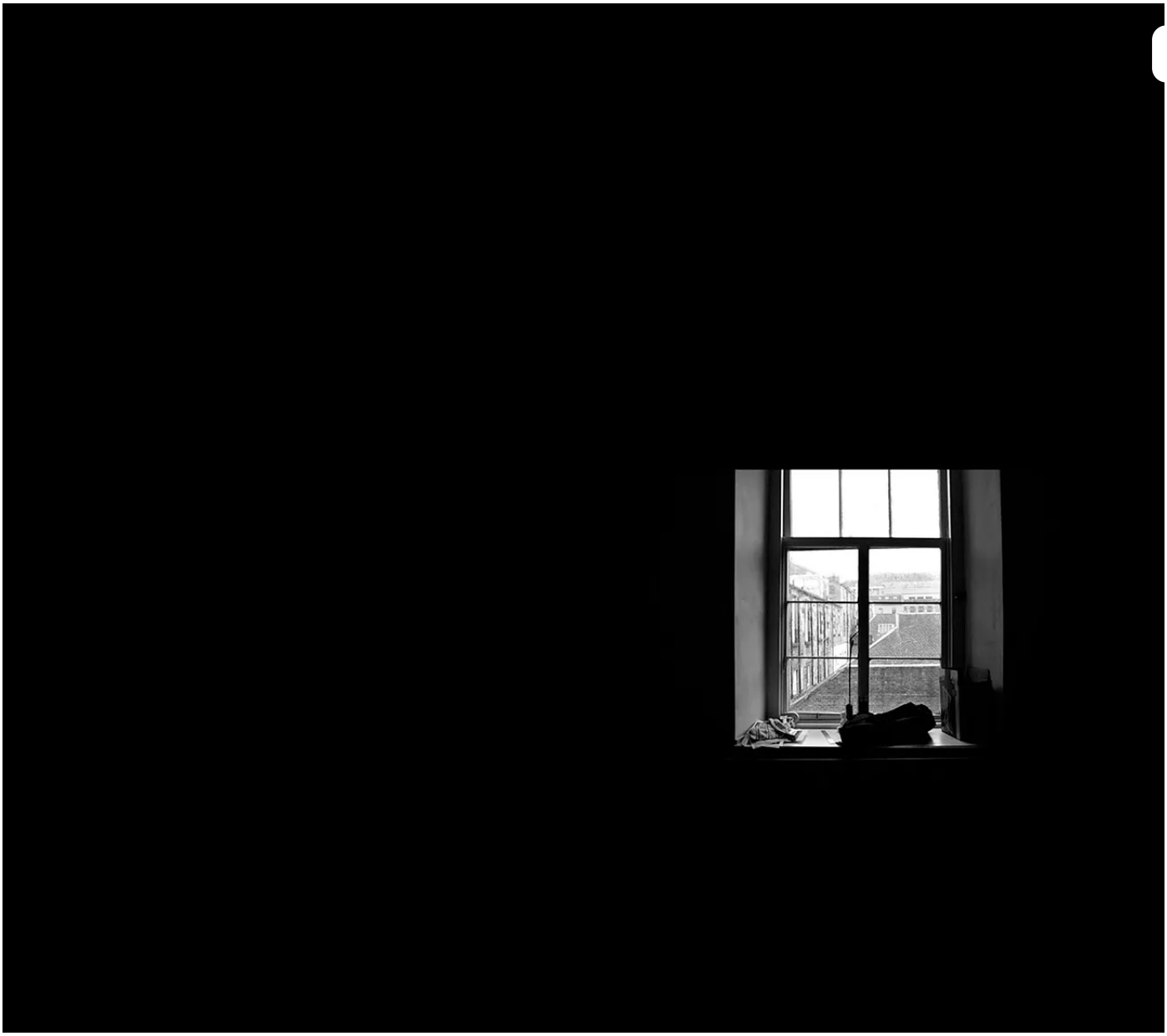

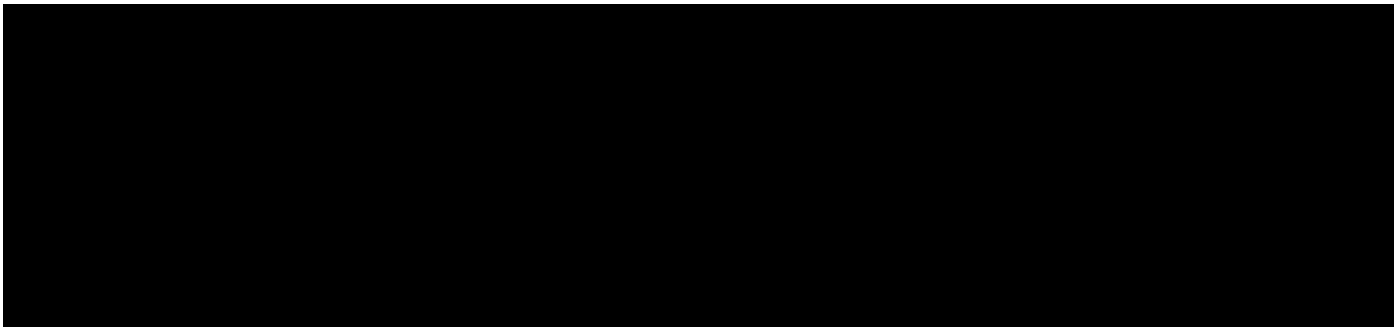

By Josh Nutall

It's been a little while since I last posted — my health took a dip for several weeks. I'm and grateful to be back writing. — Julie

Recently I came upon Emily Johnston's essay *Loving a Vanishing World*, and it simultaneously skewered and inspired me. She is unflinching about the costs climate change, taking in the whole picture of devastation in a way I frankly st to — I look away.

But Johnston doesn't allow herself to either turn from the truth or to become paralyzed. Instead she does in the piece the emotional work so many of us stru do ourselves, and she issues a challenge: Use whatever leverage you have — ev feels puny in the face of saving the world — and act.

Reading it brought up two responses for me: First, I felt, *I am not doing enough.* second, I felt an eerie kind of comradeship. In the community of those sufferi severe myalgic encephalomyelitis — an illness that punishes exertion and that make even thought or touch unbearable — we, too, face devastation so great it to look at. Our suffering is so intense that many of us spend years motionless darkened rooms because light and sound are excruciating. People often turn a yet somehow, we must not be overwhelmed. We have to do the same internal w Johnston demonstrates: facing what's real, holding it without flinching, and th our limited energy to sustain ourselves and one another. Our leverage is tiny, b still exerts force.

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I highly recommend reading Johnston's essay in full — I feel forever changed l here's a taste. She begins the essay reveling in British Columbia's shoreline, bu can't rest in that beauty. She knows what lies beneath: a garbage patch the siz Texas, microplastics in every drop, fish populations crashing, phytoplankton d percent since 1950. "The truth," she writes, "is that the ocean that looks so bea and unchanging is well on its way to becoming a vast garbage dump full of pla of heavy metals, where little survives but jellyfish. It will not smell the same. I will change. And most sea-birds, of course, will die with it."

I know, I know, I want to stop reading too — it's so painful that I want to pret not so, or tuck that knowledge into some deep recess of my brain. But keep go her: "So I want to ask you the same question I ask myself every time I'm entra the beauty of this world: what does it mean to love this place? What does it me love anyone or anything, in a world whose vanishing is accelerating, perhaps b our capacity to save the things that we love most?"

These same questions echo in the experience of living with severe ME. This il also a collapse, in miniature. Every action must be metered, its value ruthlessl countered by its often brutal cost. You become acutely aware of your brain as a of flesh, one that must be managed and coddled to eke out a bit of functioning existence flows through a straw that can be choked off to almost nothing. Eve you're lucky enough to recover some ground, the life that has gone can't be reg

So the same questions Johnston asks about the planet, we ask about our bodie

does it mean to love this life, when so little life is available to us? What does it love anyone or anything when we haven't the capacity to even engage with the

Hope isn't a reliable ally, as Johnston points out: "We cannot expect to feel *hop* least not very often, and having any *particular* hope is likely to end in heartbrea patients know this all too well. Most of us became severe only after years of tr that failed. A few of us have an emotional constitution that allows for optimis each successive effort, but most of us learn not to attach expectation to any on experiment. Instead, we practice a kind of hopeless action — we keep trying b trying itself is a form of faith, a muscular type of prayer. And even without exp any particular treatment to work, we hold the possibility that something migh eventually.

And sometimes it does. Sometimes ME patients have big improvements or eve into remission, as I have more than once. Similarly, sometimes climate action spectacularly effective, as in Johnston's inspiring story about climbing into ka shutting down the Port of Seattle to delay Shell's Arctic drilling rig. When the only delayed the rig by an hour, Johnston wondered, "All of that work and love what?" But a few months later, Shell abandoned its Arctic drilling quest, in pa because it was surprised by the protest and aware of the risks to its reputation

But such victories are rare, and as Johnston writes and ME patients know well with the knowledge of certain and devastating loss, sometimes it's a struggle t breathe." She goes on, "But the incredibly freeing truth is that life on Earth isn concerned with my sorrows, and those who are already struggling to save thei lives or their homes aren't interested in whether I'm grieving or uninspired. T me to *do* something."

The particular agony of ME is that it attacks precisely the ability to *do* someth anything. It enforces an involuntary self-involvement, when so much effort is

consumed by the act of survival.

And yet, one of the things I find most inspiring in the ME community is how people find ways to contribute to this world beyond themselves, even when th almost nothing to give. Advocacy and supporting other patients are obvious a important strategies, but patients' ingenuity is astonishing: writing a cookboo Political commentary! Dance! The need to offer something to the world doesn disappear under duress; it sharpens. That offering is a thread that keeps us tet life.

I read Johnston's essay at a time when her question already haunted me: How love what you can't keep? I had just written an essay about my dear friend Bet — a brilliant ME advocate who ended her life while visiting me. Beth had pou life into others: building systems of care, connecting researchers, challenging power. But she could no longer bear her own body's demands.

Her suicide forced me to confront the same truth Johnston names: that someti has to exist without hope of rescue. After Beth died, I found myself saying yes choice—not approval, but a willingness to accept her decision and keep loving even through it, though I would certainly have said no if she'd asked. That stra of consent loosened any judgment or resentment. It allowed me to center love when saving is impossible.

I've come to think of that posture as holding an empty bowl, one wide enough contain everything—grief and gratitude, ruin and resilience. It doesn't deman resolution. It doesn't tell a story with a tidy lesson where everything comes ou the end. It just stays open to the full reality of our world.

Johnston's essay and Beth's death converge on the same question: What do you you've looked at the devastation without flinching? Johnston's answer is actio

context of ME, the action is often so small one could miss it entirely. It lies mo
simply keeping going.

For myself, I now have a sliver of aliveness beyond mere survival. I constantly
myself how best to wield that sliver. For now, I've chosen to use it on this Subs
lies in my personal Venn diagram of what I'm good at, what the world needs, a
brings me joy — and, critically, what fits within my current capacities. I figure
world needs the devastatingly hard-won wisdom of severe ME patients. It also
knowledge of what's happening in the energy transition at a local level.

But I continue to wonder. Is writing my little Substack, with fewer than a thou
subscribers, really very effective? Should I be doing more direct advocacy? Sho
creating structures of support like Beth did? Something else entirely? These a
questions I just have to keep asking.

And yet — this is the practice, isn't it? Loving what's vanishing requires actin
without knowing if it's the right action, choosing without the comfort of certa
You hold the empty bowl wide enough to contain doubt, smallness, the possib
you're getting it wrong.

The discipline of ME — and of climate response — is to keep going, even whe
realm of action is far smaller than necessity demands.

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Discussion about this post

Comments Restacks

Write a comment...

Anna Nov 1

Liked by Julie Rehmeyer

I love your writing and get excited every time I see something new. I hope you keep writ
if it is this profound for me, it will be for others. This piece beautifully expresses though
had when I look (flinching too) through my screen at the impact of climate change. I fe
by it but not immersed because I'm so rarely in nature. I am alarmed by the ferocious s
from my bedroom. Howling winds and a cyclone warning never before experienced in n
the world. Out-of-nowhere flooding downpours like the sky itself is bawling in grief. Ca
cracks of huge hailstones, then a blast of blistering heat radiating through the (curtain
mirrors the lurching changeability of our illness, the chaos of symptoms, the unpredict
fluctuations of never knowing, forcing us to stay in the present. And never being able t
enough to protect ourselves because of the nature of this illness itself. In some ways it
is an embodied climate crisis.

Keep writing when you can. Please. Your unique voice is so precious. You put into word
I thought unwordable. And you find just the right heart words to put to such complex e

LIKED (3) REPLY

1 reply by Julie Rehmeyer

eric zeitlin Oct 31

Liked by Julie Rehmeyer

Very poignant. I think you could write a wonderful book on the topic. And with ME caused/exacerbated by environmental illness, these two topics are indeed intertwined, even one and the same? Moving myself to the forests of southern Colorado was by far thing I ever did for my health, better than 30 years (and hundreds of thousands of dolla alternative medical treatments. I take care of my land, and it takes care of me.

I can't help but wonder if nature has decided that humans don't deserve to live on this planet, and has revved-up our self-destructive tendencies in order to get rid of us all.

During a period of particularly low energy and dark mood, the universe recently remind as you wrote, I could contribute to the world in a small but meaningful way- I found son abandoned kittens and raised them in my little camper. All I really needed to do was lov of the few things I can still do. All of them have been adopted to good homes. One of th has recently been torn apart by a divorce, and I have watched two of the kittens mend hearts of the children in this family. Just like you said in this post- a small action that I c perform that changed the world for the better.

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