Twitter Thread by Julie Rehmeyer

Julie Rehmeyer
@julierehmeyer

It's been 13 months since my craniocervical fusion surgery and 7 months since my tethered cord surgery. My diagnoses were craniocervical instability, tethered cord, ME/CFS, MCAS, POTS, and mold illness (which may or may be fully explained by MCAS). 1/n

Before my first surgery, I couldn't sleep inside a house b/c of mold illness/MCAS. I got paralyzed, unable to speak, and barely able to breathe, sometimes 8 or more times a day. This could result from tilting my head back, speaking too much, a loud sound, a tap on the head. 2/n

Traction (pulling my head away from my body) brought me back from these episodes. I couldn't ever be left alone. I wasn't bedbound, but I could do essentially nothing for myself. 3/n

By that point, my symptoms were extreme even for CCI, and they were quite unusual for ME/CFS. But I started out with classic ME/CFS -- PEM, POTS, unrefreshing sleep, cognitive impairment, low NK-cell function, wacky cytokines, sky-high IGGs for a bunch of viruses. 4/n

The last year has been HARD. These surgeries are brutal and hard to recover from. Needing a second surgery when I hadn't yet fully recovered from the first was emotionally and physically rough. 5/n

But... Yesterday, I went for a three-mile hike with a friend. I was tired afterward, but no PEM. I can do strengthening exercises and push myself, hard. I'm starting to be able to write again. I can talk to people for as long as I like. I can care for myself and my new puppy. 6/n

My POTS is now under control with a fairly low dose of Mestinon. It's surprising that the POTS is still there, and it may be that I was getting tiny CSF leaks that self-healed. I'm hoping that I won't need the Mestinon after a while. 7/n

My mold reactivity is SO MUCH BETTER. I still have MCAS and I'm taking MCAS tx. But I can now live in my own house, which hasn't been possible for the last four years. I spent many months essentially homeless. I'm inexpressibly thrilled to be in the house I so love. 8/n

For me. I think the mold/MCAS was the primary driver of my illness. I believe that mold exposures led to inflammation, particularly around my brainstem. This inflammation involved the release of cytokines that are known to damage collagen. This damaged my neck ligaments. 9/n

That led to craniocervical instability. My neck ligaments *may* have gotten damaged initially from a couple of bad concussions I had as a kid -- not enough to cause sx, but enough to decrease the space for my brainstem and make me less tolerant of inflammation in that area. 10/n

I no longer meet the criteria for ME. 11/n

I don't believe that surgery is the solution to ME. Only a subset of ME patients have the same problems I have, and unless you do, and unless your sx are quite bad, you wouldn't be a candidate for surgery anyway. No neurosurgeon would operate on you. 12/n

I do think my experience, and that of other pts like me, suggests that we should be looking hard at the role of MCAS in ME, and also at what's going on with ME pts' connective tissue. Many ME patients have EDS, but I don't, and connective tissue was still my problem. 13/n

I also think we really need to look at the role of mold in ME. My MCAS sx were nearly exclusively in response to mold exposure, and before I developed CCI, I recovered almost completely through extreme mold avoidance. Mold plays a key role for many many ME pts. 14/n

I think one of the key lessons we're learning from ME is that these contested illnesses are closely related to one another. ME, EDS, IBS, Lyme, autoimmune disease, CCI, MCAS -- they're all pieces of a bigger story. 15/n

And long Covid is part of that story too. 16/n

So I think we need to break down the silos between these communities, ones that divide patients from one another and researchers from one another. 17/n

I don't have EDS, but EDS research is relevant to me. EDS patients are my brothers and sisters. 18/n

Doctors and researchers who want to help pts with one of these diagnoses need to learn about the rest too. 19/n

This is a project of co-liberation. Solidarity, friends. Let's work together. /fin