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I don’t know how to make the world understand what it’s like to live with longterm illness. To wake up each day never knowing if you’ll be ok, to have your dreams and plans constantly disrupted. What it’s like to never feel rested and to always be in pain

> For the thousandth time, it's not just mortality we need to be concerned about. https://t.co/ATzgR2t7qU
>
> — Dr. Tara C. Smith (@aetiology) December 5, 2020

I have EDS. 79.5% of people with Ehlers-Danlos have significant fatigue (Anne Krahe, 2017, Systemic Manifestations and Health- Related Quality of Life in Joint Hypermobility Syndrome/Ehlers- Danlos Syndrome-Hypermobility Type)

“Chronic pain has been documented to affect up to 100% of individuals with a diagnosis of JHS/EDS-HT, while 85.7% report experiencing progressively worsening pain.” (Ibid.)

I am just...so sorry for all the people who survive COVID-19 trying to find condition management that doesn’t exist or is unaffordable. I’m so angry at all the hooks and lures set out by shills and charlatans that’ll cause so much iatrogenic harm

I want you to know that you won’t be the same person after you become chronically ill. It changes you and forces you to find new ways to live. Embrace that transition but know it’s ok to grieve for what you’ve lost

Just because someone is family doesn’t mean they’ll be a trusty support when you’re ill. Find the ppl you can rely on.

Tell people about how you feel. They’re not psychics or mind readers. Most ppl won’t know how badly you’re hurting unless you let them know

Minimise the things you can no longer cope with. Let it go

Find the things that help you feel better or help you cope: consider trying to learn ways to manage chronic illness a painful budget adventure. Try new things. Aquatherapy. Meditation. New meds. New doctors. Don’t go broke doing it. Plan rest days in among your “adventure days.”

If something isn’t working or is making things worse, stop

Doctors are supposed to be professionals, not gods or masters. Always be polite but consider saying “thank you for your advice,” leaving and never returning if a doctor gives bad advice or behaves inappropriately

Get a routine. Write it down. Track you meds and pain

Use the kindest voice you have on yourself to help yourself get through the hard times (like when you have to stand up first thing in the morning)

It’s ok to let some stuff slide when you’re unwell but institute a “redline.” Mine is stuff like “garbage must go out when necessary, dishes must not sit in the sink for more than 24 hrs”

Prioritise the stuff you enjoy and that reduces your pain levels

It’s ok to say no to doing stuff when you’re not well enough

And if it promises a miracle cure and costs the world, get a second opinion before paying up. Try to find some actual irl ppl the proposed treatment worked for. Check the side effects as well

Collectively, the best thing you can do to long term help yourself and others is to lobby together for better specialist care. Support groups aren’t enough.

I know you’re tired and it hurts but you’re either going to have to win the lottery or engineer your own healthcare (eg. @4ThievesVinegar) or go without unless something radically changes. Get political. #LongCovid