Author Full Name: Anonymous Received Date: 01/19/2025 10:58 PM

Comments Received:

As a person who has Ehlers Danlos Syndrome and several other medical conditions causing me to live with chronic pain, I've had to navigate a world not equipped to treat me with the handcuffs placed with the severe restrictions to opioids. Although opioids are just a part of my treatment plan that encompasses many other working facets, they are an important part... not only for my physical well being, but for also my mental wellbeing. Both of those have greatly suffered in recent years.

Orthopedists are terrified to prescribe opioids except post op. Relying on steroid injections (which are contraindicated for EDS as they have the potential to rupture our already faulty tendons and ligaments, yet sometimes we roll the dice anyway because we feel there's little other options) and frequent use of NSAIDs which have lead to other medical problems. I've had to switch doctors because they don't prescribe them under any circumstances. Going to the ER because you are in a pain crisis is a joke and a known joke among our chronic pain community. You will wait hours (if you live in a metropolitan area like I do... likely 6-12 hours) where you may or may not get anything more than ketoralac..depending on the doctor you get. So, unless you'be been at a pain level of 12 out of 10 for hours or days on end... you lay in bed in agony and pray sleep. I use to judge, but now understand why some people turn to street drugs such as heroin. I hope I never make that fatal decision.

Pain interrupts every part of waking and sleeping life. It's greatly contributed to Complex PTSD. And although I don't take opioids every day, I need the option every day because I never know what my body is going to feel like from hour to hour. Imagine never really being able to plan your life because at any moment, life is too debilitating to participate in and you have to carefully ration what medication you have and decide "do I take it now? What if I hurt even worse tomorrow or next week and I don't have any left before I am able to get more? If I wait and it get worse, will it be too bad to get under control?" There's constantly a million questions and decisions. It's exhausting. I missed a lot of things as my kids grew up into adults because I was unable to participate due to pain and lack of proper pain control. I'm praying for changes so I don't have to miss those same things with my grandchildren.