

Ms. Heather Grace, July 2022

**The Impending Demise of Pain Management — It's Not Too Late, YET
An Open Letter To "The Powers That Be"**

Effective Pain Management Heals, I'm Living Proof: My Story

My journey into what would become debilitating pain began at age 19 when my neck was injured in a head-on collision caused by a drunk driver. Being a backseat passenger in an older car meant there were no headrests. I healed as best I could after the accident with chiropractic care and exercise.

I was young, so even though I told myself "I'm ok/I'll be fine," I knew I wasn't quite the same as before. Nearly a decade of work in the IT field worsened the severity of my injury. It was all due to faulty ergonomics. Between the reasons for my condition, the horrors of the worker's compensation system and the onset of severe pain, it began to feel like I was in free fall. Somehow that kept going, until I ended up in the 7th layer of hell: A neurological problem so severe that on my first visit with the preeminent pain management specialist in the country, he said: "Normal is out the window for you."

It was the worst thing I'd ever heard, so I began sobbing. What he said wasn't actually cruel, it was honest. He could see that my body was pretty broken after 7 long years of workers' comp care that included TWO botched neurosurgeries and ONE spinal discectomy + fusion surgery which came far too late to be a good thing whatsoever.

Although I didn't know it back then, I'd lived with the genetic illness Ehlers Danlos Syndrome my whole life. After everything that happened, I was also left with severe nerve damage and neurological pain. I was diagnosed with Intractable Pain and Complex Regional Pain Syndrome Type II. CRPS II is in fact not regional at all but has spread to the whole body thanks to the impact on the spinal column and brain.

In case you've never heard of Intractable Pain, I'll explain...

Differences Between Chronic Pain & Intractable Pain Syndrome

Intractable Pain Syndrome (IPS) isn't understood in mainstream medicine because it's not very common. This makes it even less likely that the average person has heard of it. In fact, until I was diagnosed, even working in Continuing Medical Education for 10 years, I'd never heard of it! So unfortunately, I didn't know that it was possible to be in severe unceasing pain, much less understand the complete picture. People with Intractable Pain experience major health problems over many decades of their lives because of the toll this magnitude of pain takes on the body.

IPS must be known, recognized, and treated in like any other long-term medical problem such as rheumatoid arthritis, diabetes, or asthma. Physical, psychological, and pharmaceutical measures must be taken. Treatment for this complex and disabling diagnosis must be taken seriously and done correctly. Most people don't understand that there are vital reasons for the use of pain medication beyond its use in cancer treatment and hospice settings.

Use of pain meds must be acceptable to all concerned parties in the patient's life for the treatment to be successful, including their physician and their close family members. That's true even if the doctor &/or loved ones themselves don't fully grasp the need for the use of high dose pain meds that are (unfortunately) abusable.

Characteristics of Intractable Pain Syndrome

Pain is Constant, 24/7

Treatment is Daily, Around the Clock

Elevated Blood Pressure and Pulse

Elevated Temperature & Breathing

Anorexia/Malnutrition

Insomnia

Depression, Hopelessness

Endocrine (Hormone) Abnormalities

Elevated Inflammatory Markers OFTEN

Restriction of Life Activities, Such as Mobility

Decreased Capability for Requirements of Daily Living

Intractable Pain requires a different approach than Chronic Pain because it is a totally different condition. IP patients need specialized care that's beyond the level of most physicians who treat pain. A doctor who's knowledgeable about this condition and how to treat it is crucial. The above information provided by IntractablePainSyndrome.com

After everything above was explained to me by my phenomenal doctor, I realized I was indeed living in the past. To move forward with my life, I had to stop pinning all my hopes on the idea of "normal."

Because of all I'd been through and the fact that I was so focused on getting back to that life, I couldn't move on. I had to grieve the loss of my former life, my normalcy. Once I did, a door was opened to a meaningful future for me.

My Life Today: From Pain Patient to Advocate & Beyond

Thanks to amazing treatment with a physician who also helped me focus on a future full of possibilities, I'm living again in a way I'd didn't think was possible when I first sat down with my doctor in January 2006.

My doctor found the right treatment for me as an individual. As a result, I've reduced my medication dose slowly over the years. This was at my request, because it was time — it was not because the change to dosing set forth by the CDC was forced upon me. I'm now taking less than 1/6th the pain medication I did at the outset. That's because I've experienced neurogenesis, aka healing. Just reduced my dose again this week!

That's right, it's possible for people like me to heal, albeit very slowly over time when they get the care they need. Despite the severity of my condition(s) and my even requiring pain medication in the first place, I'm doing well.

Contrary to popular opinion, patients who get the proper dose of pain meds don't require more and more medication. The opposite is actually true! While some patients' dosages stay the same, many of us can lower our doses when our health improves. For me, that's happened 8 times to date. I believe I will continue this trajectory.

I've come so far already. In 2004 when I left the job I loved, awaiting 2 major surgeries, I believed I'd never work again. I was finally able to obtain a full-time job (with benefits!) and sustain FT employment for over a year beginning in March 2020. That's a major accomplishment!

In the past I'd tried and failed to keep a full-time job many times, but it's finally worked out for me. It required major effort to get to this point, but I got here because I had a foundation of long-term effective pain management which lessened the impact of pain on my overall wellness.

In case you're wondering, pain medication has always been but one part of my treatment. It does not define my care, nor my life. Pain meds are merely a tool I've used to get well and it's a tool that's worked for me. Each patient should have access to individualized pain care with the treatment options that best work for them. It's crucial for patients if they're ever going to see their health improve.

I couldn't imagine how far I would have come all those years ago, and yet it happened thanks to a pain care regimen designed to meet my specific needs. I'm thankful for the tools I was so fortunate to have because they helped me get my life back on track.

I'm much more thankful to my doctor, and to the wonderful pain & chronic illness advocates I've met. They helped me find meaning at the lowest point in my life. I won't lie, it's been a struggle and I have had my share of setbacks too. Yet I know without question that pain medication was required in my case. It has made a serious difference to my overall health, and it paved a way to my future too. I believe the day will come that I'll no longer need pain medication. It's something I'm now looking forward to!

It's hard to believe that I'm the same person who was once so desperately ill that I believed the only way to end my pain might be by ending my very life. I didn't want to die, but that's how severe the pain was back then. I wouldn't wish those dark days on anybody. That's why I'm so thankful I survived, and finally got the care I needed before it was too late.

Everyone should have the same sort of care I did: the best treatment protocol for each one of them as individuals. Look how it turned out for me!

Intractable Pain Must Be Managed, Like All Serious Illnesses — These Are Patients, Not Addicts!

It's crucial to understand: Effective pain management for someone with Intractable Pain is as vital as care for any serious illness requiring long-term treatment. You'd never tell a diabetic that an arbitrary maximum unit of insulin was all they were allowed to have. If that meant patients' diabetes being undertreated and dire medical consequences, including their eventual deaths, the world would be up in arms.

Why are pain patients any different? None of us asked for the pain, nor do we like having to take a prescription that's become so socially unacceptable. We're like diabetics. People in severe pain *depend* on medication for their survival. That medication happens to be opioids instead of insulin, but it's an apt analogy for those with IP. What's more, the fact that its pain medicine doesn't somehow make it wrong, just different.

The tragedy is that people like me are not addicts. This is, in fact, a very serious chronic medical condition. It isn't an addiction we're living with, it's a massive amount of pain.

Most people simply cannot understand what it's like to have pain that never ends, because it's incredibly rare. In a way, that's totally understandable. But to doubt someone you've known for years and were close to merely because they've got severe pain and require a serious form of treatment doesn't make sense to me.

I'd never doubt someone's suffering because it's cruel. It's also emotionally devastating to be seriously ill but instead be thought of as crazy, a liar, attention-seeker, or addict. Yet pain sufferers continue to be maligned by the media/public, their loved ones and even doctors.

The Long-Term Consequences of The CDC's Pain Med Limits

These judgments exist nowhere outside of pain management, so why must they exist at all? Why are people in pain being treated so differently, with such suspicion? The fact is, when the CDC's guidelines were released in 2016, the consequences were far-reaching and dire.

Countless patients have needlessly suffered and died. Many of these deaths have been due to the pain finally overtaking the body. Far more patients have chosen to end their immense pain via suicide. Imagine being so ill that you were forced to make such a choice! This nightmarish situation continues to plague people just like me.

Choosing to battle misuse, abuse and addiction in this way wasn't worth the price to far too many in my community. We've already paid too much. It's not worth the devastation yet to be caused by continuing to stifle physicians' ability to treat pain either.

If I were able to, I'd love to speak to all "the powers that be" face-to-face. I'm living proof that with the proper dosage of pain medication, people who are severely chronically ill can and do get better. Our pain can lessen, and our lives improve!

The long-term impact on pain management is yet to be fully understood, but I know it will continue to cause serious systemic problems. For instance: How many medical school students will choose to specialize in pain management, knowing it could very well end their careers if they merely follow the Hippocratic oath? Not many.

The End of An Era: Great Pain Doctors Pushed Out of Medicine

I feel for anyone who's been diagnosed with Chronic or Intractable Pain since the CDC's guidelines were released in 2016. I know the sort of physicians they'll face, who'll tell them even more vigorously than was I told: you're wrong, you're crazy/lying, it's all in your head, etc. How many people survive the torture of physical pain in addition to a cold system that has no intention/ability to treat their severe pain? Very few, and that's just plain wrong!

My situation isn't typical, I know that. It's a miracle that I've gotten back so much of what I believed to be lost forever. It's all thanks to amazing pain care. I am so grateful that I found the doctor that I did. I credit him with saving my life as well giving me the ability to return to work again — to be more like my old self against all odds.

Prior to the overzealous prosecution of caring physicians like Dr. Forest Tennant, doctors were far more willing and able to assist patients like me, the most seriously ill among us, who often only found the right doc after years of abuse and subpar care.

We came to these good physicians like beaten dogs who barely had enough life left in us to beg for help. We were all so mistreated even then that each of us came to believe our pain was a problem that couldn't be solved. Yet before the CDC guidelines, we were still able to find someone to provide us with real help when we needed it most!

To my dismay, Dr. Tennant, and many like him, were pushed out of their positions because of the CDC's guidelines, and the way the DEA chose to make examples of them. Dr. Tennant is a good man who didn't deserve a forced retirement despite no wrongdoing. The greater tragedy is the loss to patients who won't have anyone to help them find their way back to a meaningful life or continue the one they'd already found. These patients won't learn, as I did, that with effective treatment, quite literally anything is possible.

The Ripple Effect

It's more than just patients who lose because Dr. Forest Tennant was forced to retire. He taught countless other physicians, nurses, and pharmacists how to understand & care for people with pain in a way too few do. For example: He knew there were objective signs of severe pain. How many people even know they exist? I do, because of Dr. Forest Tennant!

I believe wholeheartedly that without access to effective individualized treatment by physicians whose options aren't stifled by a system that doesn't understand pain, many more people with serious diagnoses will develop Intractable Pain. The difference is no one will be there to help them find a way back to health. That means a lifetime of suffering needlessly, or else it means their eventual demise. How incredibly sad it is to me that one particular type of patient is treated so differently than those with any other ailment!

If the CDC/DEA et al continue to force arbitrary rules onto everyone, unfortunately more and more people will end up with serious life-altering pain. It doesn't have to be this way! Thanks to my doctor, I know that miracles can and do exist, even for the sickest among us. That'll only continue if those treating pain are equipped with the ability to make the necessary & appropriate decisions for the wellbeing of their patients. They must be able to utilize pain medication the right way before their patients reaches the end of their ropes and take their lives. This is a possibility if and only if pain management can be practiced unfettered. Those outside the treatment setting have no business undermining patients' pain care protocols. They simply don't have the knowledge to be involved on that level.

That goes for the CDC, DEA, medical boards, and insurance companies — along with anyone else who gets in the way of patients having effective care, and thus meaningful existence. I say this not as the average patient, but as someone whose medical knowledge and experience rivals that of many physicians. I worked in online continuing medical education (CME) for 9+ years. To this day, I read medical journals like any physician would.

Due to the severity of my condition, and the fact that I was at the mercy of a broken system like workers comp, my condition got far worse than it ever should've. I lived through the hell of both medical neglect and overtreatment. Sadly, I know it's the workers' compensation system that led to the severity of my illness, not the damage to my neck itself.

Because of my experience, I got an extensive education on how an overburdened system that's not designed for people with serious healthcare needs can quite literally cause permanent disability in someone like me. These days, treatment under the Affordable Care Act is much the same as it was for me when improper treatment left me with severe neurological impairment. Since the CDC's 2016 guidelines were released, the powers that be have all but destroyed appropriate pain management. After this document was put forth, laws changed across the country and around the world. Restrictions on pain care seriously impacted people who rely on Medicare & Medicaid. Because of the changes to the pain-related care policies, effective pain management is far too difficult to access for the people with the least agency: those who are impoverished, over 65 or disabled. They deserve more protection against ineffectual treatment for acute health crises and long-term conditions, not less.

It's not just those patients who are suffering. Most HMO/PPO insurance plans have followed suit. These days, the options for any newly ill or injured person in pain are limited. Serious harm is being done to those with serious diagnoses who need real help.

The statistics show this to be the case. As time goes on, the number of preventable cases requiring longer, and longer-term pain management will grow exponentially. The end result is more Chronic and Intractable Pain patients — and thus, more serious disabilities that burden an already overburdened healthcare system.

The CDC all but provided an instruction manual for creating pain patients, not to mention causing needless suffering and death to existing chronically ill patients. That includes far too many dying via suicide, as I'm sure you have seen. This will end up killing the practice of pain management eventually. If you've been paying attention, you know: We're already well on our way to that possibility.

End This Problem Now, While You Still Can

Maybe you don't need a pain management physician now, but what if one day you do? Will it be too late for you to find a doctor that's both willing and able to help you? I sincerely hope not. But it's possible.

Ask yourself: In this climate, who becomes a pain management physician today? More importantly, who will become one tomorrow?

Remember: These are human lives on the line. Everyone knows someone living with Chronic Pain. Yet for such a universal experience as pain, we've lost our way. It's time the powers that be returned the humanity and compassion to care for all patients, regardless of diagnosis. People who live with pain deserve that much, do they not? After all, the universal code of physicians is to "first do no harm."

Please don't jeopardize the future of an entire branch of medicine any further. Make the changes needed to continue treating people like me — people whose lives don't have to end because they have a serious injury or illness. It's crucial to roll back the damage done by the 2016 CDC guidelines before we all lose access to pain management forever.

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