

PATIENTS' STORIES OF HARM

There are ten-million patients in the United States with rare and painful diseases who require daily pain medications. These patients are not addicted to their medications. Nearly 70% of the 10 million painful disease patients have been forced off their daily medications, without their consent, by doctors who believed the 2016 Center for Disease Control (CDC) Opioid Guidelines were legitimate and passed into law, which is not the case.

The CDC Guideline was unauthorized and not peer reviewed, fitting the definition of an illegal attempt to rewrite federal drug dosing policy by the CDC, while overriding Food and Drug Administration (FDA) authority. Federal laws establishing each federal agency and their rule making authority was violated by the CDC in its transparent attempt to indirectly regulate opioid medications. The National Pain Council (NPC) views this as a violation of federal law.

The misconception stubbornly remains that the CDC has the “power of law” to regulate the use of FDA approved pain medications. The “power of law” was “pro forma” denied by the CDC but was believed to be law in the minds of the doctors carrying out the draconian policies by refusing proper treatment for chronic pain.

In fact the CDC can make suggestions about anything they wish, but cannot write medical practice policy. Medical textbooks make clinical suggestions, the CDC makes suggestions, and medical conferences also make suggestions. Doctors evaluate suggestions but are not mandated to follow them. Doctors must follow state and federal laws like all citizens. The CDC cannot make laws.

The CDC Guideline was created to appear as real regulation, but in an unrelated paragraph in the 2016 CDC Guideline is the single occurrence of the word “voluntary” seemingly to hide the fact it was not really a regulation at all.

The Federal Drug Police (DEA) “adopted” the Guideline, inappropriate for a law enforcement agency to be adopting any medical policy. The U.S. Department of Justice (DOJ) and its enforcement branch, the Drug Enforcement Agency (DEA), is using the CDC voluntary suggestions as a fixed truth to arrest doctors.

The DOJ then argues “bad doctoring” as evidence the doctor is a drug trafficker in order to prosecute doctors for “overprescribing”, which is not a crime anyone can find on the books. The DEA appears to be driven by their belief that doctors caused the “opioid crisis” by overprescribing, an incorrect assumption.

When doctors go to prison, or lose their licenses to practice medicine by being falsely accused of prescribing for too many pain patients, who then cares for their patients?

The answer is no one, and worse the patients become pariahs as former patients of a doctor “charged with federal drug crimes”. At one time it is reported the DOJ had a service to find new doctors for patients abandoned, however this appears lost in the past.

Only one in five doctors in the U.S. will NOW take patients on opioid pain medications. These patients then become "pain refugees", a term coined by Dr. Mark Ibsen, a Montana physician who had his medical license taken because he was caring for too many patients and that worried Montana's government in return creating the false concept of “overprescribing”. Overprescribing is a relative term and is without precise definition.

Doctors anxious to please the federal drug police and state licensing boards, while avoiding getting into trouble and losing their careers, are going one step further and forcing their patients off their long-standing opiate pain control medication(s), which they themselves prescribed. There is only one instance when this is legal, during an FDA recall. The FDA has not recalled opiate pain medications.

Doctors are so terrorized that they are refusing to refill effective medication regimes and do so without the consent of the patient they have cared for. There is a requirement for written consent to take opiates but no consent to have them taken away without a legitimate medical reason.

This occurred in seven million pain patients in the United States since the original publication of the CDC Guideline for Opioid Prescribing and Chronic Pain.
See [NPC Publication #051 “Seven Million Harmed”](#).

These are First Hand Accounts of what happens with the government interferes with the doctor patient relationship.

Ed: Numbers following entries are National Pain Council confidential case numbers, since these were original accounts submitted by our members and other painful disease patients, we did not edit their stories.

The stories below represent the “pain refugees” struggling each day with unimaginable pain and loss of daily activities that we all take for granted: standing at the stove or work table, playing with children and grandchildren, riding in cars, driving a car, going to religious services, shopping, being intimate, going to the movies with family, taking a shower, getting off the couch, getting dressed, getting out of bed. It's time we hear from those harmed by government and government consultants, and here it is:

Alabama. I have taken pain meds for 30 years for chronic back pain. I had Harrington rod surgery for scoliosis at age 12. My family doctor retired. I cannot find a new one, who will prescribe my pain meds. I have had three doctors turn me down for treatment, and I don't know what to do. I had to miss work, important family events, and woke up worried and crying each morning. I took my meds as prescribed with no trouble. I don't know what to do now. (53a)

Alabama. I was diagnosed with primary, Generalized Dystonia, in my late teens. I couldn't tolerate the Parkinson's medication. The ones I could tolerate were opiates. For the first time, resulting in less body rigidity and jerkiness, my fingers are no longer clenched and I no longer lean to one side. The doctor started tapering my pain medicines and no longer participated in my insurance. This cost me \$150 per month/out of pocket. I am back to where I was. (64a)

California. I have CRPS/RSD and am currently seeing a doctor that monitors my progress and medications. After trying every treatment modality including physical therapy, anti-seizure medications, biofeedback, etc., I was put on oxycodone

LA. I had 8 brachial plexus nerve blocks and 5 lumbar nerve blocks. My neurologist/pain management doctor kept upping the dosage because I was getting no relief and we could not figure out why. He ended up upping the dosage so much that I was only experiencing side effects; no pain relief. I changed doctors and the new one performed neuro-inflammation, blood tests, and found a genetic malabsorption defect. He put me on a trial of subcutaneous Dilaudid, and I experienced instant pain relief. I got my life back. The restrictions that are already in place are making it harder for legitimate chronic pain patients to get their medications. These medications give back the quality of life for many. (84a)

California. When I started Duragesic, I made a point of making it clear that I expected to continue treatment. The CA Medical Board sent a letter to my doctor, questioning my pain meds. I was forced tapered until I was bedridden and suicidal at 95 MME. He stopped tapering too but now wants to get it down more. People who are in excruciating pain on a 24/7 basis, aren't trying to "escape from reality", they're trying to survive this reality of severe, debilitating, constant pain. (92a)

California. At the beginning of the year, my PM Doctor completely stopped prescribing opiates. When I asked why, I was told that the county, where I live, was bombarded with inquiries from the DEA. All this because of one doctor who was prescribing. It made our county have the highest number of opioid scripts written in the state. The doctor lost his license for a few years, but I heard he is now practicing in a different state. (95a)

California. With extreme anxiety and debilitating pain, I was seriously giving up. Thank you for allowing me to be your patient. You have given me life again.
(Written to her doctor, she had to go 200 miles to see) (99a)

Colorado. I had a hospitalized friend with terminal cancer, who was in intense pain. She called me for help. The 15 mg of oxy, every 4 hours is not working. Nurses treat her like a drug addict over a pain complaint. She is dying. She is not a complainer. (63a)

Connecticut. To live with pain, is to live not much of a life at all. Without proper pain control, it becomes hard to do anything. It's lying in bed for 8 days straight, knowing you need a shower, but being in too much pain to do so. It's crying yourself to sleep and biting a towel, in hopes your family won't hear you crying. When you are laying in a ball, choking on your own tears, and begging God to just end it all. Meanwhile, knowing that doctors have the tools to help, but they won't. The issue of corresponding responsibility has pharmacists scared and refusing to fill prescriptions. All because of fear of reprisal, arrest and jail time. (59a)

Georgia. My neurologist told me that because Georgia State is cracking down on hospitals, and/or doctors prescribing pain medication, that I would need to go to an Advanced Pain Specialist, in order to continue the prescription of Oxycodone. I was referred to one and the first day of my appointment, I was required to sign a drug contract, take a saliva swab and a drug test. The test came back with a false positive for methamphetamines, because of the Prozac I take for Multiple Sclerosis. Now she will no longer write prescriptions. (22a)

Louisiana. I am currently having my pain medications forcibly reduced. Louisiana has decided to follow suit with the CDC, without thinking of how to handle chronic pain patients. I have over 12 herniated discs, along with Fibromyalgia. I follow every rule and have been on pain medication for over 10 years, without incident. I live with always feeling like a criminal for (1) getting monthly pain meds from my spine doctor, (2) every pharmacy that WILL fill pain RX, will only do so when they can treat you like a degenerate, (3) family and friends that don't understand or really care. I have started wondering what my options will be, when I can't move or even think clearly through the pain. (23a)

Maryland. I did a concerted effort to commit suicide after my involuntary removal from pain meds. I was in the hospital for 3 days, and then I was kicked out. I tried once more. I was unsuccessful both times. If I ever try again, it'll stick and I will be successful. (111a)

Massachusetts. In 2017, I was diagnosed with Chronic Pancreatitis. I could obtain no pain management, sufficient to treat the disease, and in fact, was treated like a "pill seeker". After contacting numerous doctors, organizations and even the National Pancreatic Foundation, I received NO help. I called legislators' offices and left multiple messages about my plight. Later that year, I found a new Gastroenterologist who retested my pancreatic function, and his findings confirmed

that I had lost 11% of my organ function. Numerous medications were immediately changed to include 5 mg of Oxycodone. My health improved and I could finally eat and gain strength. After a short period, my prescriptions were stopped due to CDC guidelines. Without this medication, people will suffer severe pain and consider ending their lives. I want my life back. Why should people suffer this way? Doctors are afraid of losing their jobs. I fear I can no longer have the children that I long for. (65a)

Michigan. My wife has Rheumatoid Arthritis. Her medication has led to other problems. She's getting biologic infusions monthly. She has visited 3 pain clinics for two shots, the other was raided and was closed by the DEA. My wife broke her foot, bad enough to require surgery, and a plate. Her podiatrist prescribed MS Contin and Vicodin. The pharmacy won't fill this anymore. (94a)

Mississippi. I am a medically retired police officer, with over 22 years of service. I have been in chronic pain management for many years now. My condition will never get better. I have been examined by no less than five medical doctors. Unfortunately for me, the conclusion is my condition is progressive and will only get worse. I've had four neck surgeries and one lower back surgery, due to on-the-job injuries. For the past few years, I have found a pain regimen that allows me to have somewhat of a normal life, though I still experience pain 24/7. The recent upswing in deaths from opioid abuse is tragic. However, the guideline by the CDC for doctors to reduce opioid doses for pain patients like me, will cause more problems than it solves. This could prove a disaster, as we know many street drugs contain powerful opioids, such as fentanyl, which the DEA has been very unsuccessful in stopping. Some of these street drugs are counterfeit. Some patients may tire of the constant pain and commit suicide with street drugs. I believe the effort to stop drug abuse and addiction is very noble. However, the route to solving this opioid problem, should not include violating the rights of our disabled citizens, or causing some patients to become criminals while trying to maintain what little normalcy and quality of life they have now. (68a)

Mississippi. The D.O., I found out a year ago, is taking care of me. After 3 years with no options, they tell me, "We'll do injections" for your epidural fibrosis. Nope, it aggravated it more. (12a)

New Hampshire. I've been a chronic pain patient for 23 years after being rear-ended by a tractor trailer, which left me with a broken neck in two places, a double concussion and a herniated disc in my lower back. My doctor of 23 years deserted me, and did not help me find a new place to go. (131a)

New York. I have been sick with Pancreatitis since 1985. It became chronic a few years later. The doctors started me on different pain medications. The medication made the pain bearable, so that I could function and take care of my three children. In 2016, I had a flare up that lasted 6 months. I was admitted to the hospital. The doctor wrote orders for pain medication, which was half the dose that I take normally. I was treated like a drug seeker. The pain is never ending and the pain medication helps me live as normally, as possible. Restricting access to these medications, punish the ones who really need them. (101a)

New York. I am a 45 year-old, retired New York police officer. I have chronic abdominal pain and have difficulty eating. The pain radiates to my lower back. The doctors have diagnosed me with MALS. When I seek help for the pain, I am treated like a drug addict. The pain is so intense that I've fainted and have had numerous trips to the ER. I should not have to fight with doctors for pain relief. Most days I can't get out of bed. My pain pills allow me to at least have a life. (102a)

North Carolina. It is hard to get out of bed in the mornings. It usually takes over an hour to get moving. I sleep in the recliner all day, except when needing to use the restroom. I take my pain meds regularly, and do not skip a dose anymore. I can't let the pain get out of control. (67a)

North Carolina. My doctor just dropped me, and said that my pain doesn't match my MRI and x-ray. The doctor I had before this one, retired last July. I have been without pain meds now for a year, because the pain clinic said I didn't need pain meds. I'm dying. I can't sleep and my BP yesterday was 175/100, I need help. (161a)

North Carolina In 2011, I had a tooth extraction that led to permanent nerve damage and Trigeminal Neuralgia. Those painful conditions are very hard to treat. I have had all the procedures that were recommended to me, yet none worked. I

also tried all the 1st, 2nd, 3rd, etc. line meds that can help with these issues, but none of those helped either. My PCP went on maternity leave. No one would prescribe meds, to help me eat or take a shower. The water hurts so bad hitting on my face. I want to get my life back. (107a)

North Carolina. My pharmacy has been “flagged” by the state for having too many opioid prescriptions. I have to try and get my script filled, somewhere else for this month. This isn’t a forced taper. It’s a forced cut off. I thought the CDC nonsense, didn’t apply to DPPs? (30a)

North Carolina. In 2018, I went to a doctor for chronic pain. He couldn’t see me on the pain side until he got updated records. He already had my records from 2016, so he only would treat my withdrawals with Subutex and \$250 cash. He then sent me to the pain side of his practice, to give me injections but no medicine. He then sent me down the street to another physician, who treated me the same way. He treated me like an addict, not having seen one x-ray. He threatened to cut me off. The next doctor did the same. Finally, a pain management doctor said I was high risk and he wouldn’t treat me. They never did any tests or asked for my records. They seemed terrified to prescribe. (49a)

Ohio. Myth: Alternatives to pain medicine are safe and effective. “I’m no longer living”, “I’m barely existing.”, “I need more help now.” I’m taking 5 Tylenol every hour. I never overdosed on the Fentanyl I took, along with Vicodin, every 4-6 hours. Now, my back is so bad and compounded by Lupus, Fibromyalgia and Sjogren’s. It is a living hell. Getting off Fentanyl, didn’t make me go out to the streets for illegal drugs. (52a)

Pennsylvania. A friend from Pennsylvania, says that her rheumatologist gave her a script for pain medicine through December. He told her to start to cut back on them. This was to prepare her for the cut back that is coming in January. The State is cutting back on all patients and that there was nothing the doctor could do about it. (55a)

Pennsylvania. My GP admitted to me this week that the hospital chain has bought out all the small rural hospitals in NW and North Central PA. They are not allowing PCPs to practice the art of medicine. They have received letters from the Attorney General threatening his practice, if he prescribes opioids, soma or benzos. I used to get all three and was high functioning. Now it’s off to Pain management for Percocet with no chance of getting soma and/or benzos period. Instead, I have been prescribed Vistaril. My doctor told me there was no way he could put his practice in jeopardy, in order to treat my pain.

Ohio. I am a refugee pain patient. No doctors will take me in the state of Ohio. I no longer have the one thing that gave me a quality of life. That was pain medication. I no longer have a life. (14a)

Pennsylvania. I stand with chronic pain sufferers off in the shadows. We have been forgotten. No research. No treatment. Now there are laws and a movement of public outcry condemning opioid use. Our pain medicine is being taken from us. We have been treated without compassion, humiliated, and stripped of dignity. People don’t understand that we are not abusers but simply seek temporary relief from our endless pain. We are always tired, often depressed and feeling hopeless. We are just trying to overcome the obstacles presented to us. We are made to feel shame, because we need to use pain medicine to cope with everyday life. I am on the other side of the opioid crisis. I am not an addict. I take pain medication to function at a minimum level, and allow my chronic pain to get the better of me. It lets me feel normal for a short time every day. I never feel high from taking it, I just feel almost normal. It allows me to focus and to do simple tasks that I could not otherwise perform. (100a)

Virginia. I am desperate. I was involved in a motor vehicle accident with injuries to my spleen, liver, femur, malleolus and talus. The list goes on. It has been 20 years since that time and even after rehab, physical therapy and tai chi, I am still in a great amount of pain. At first, I was prescribed opiates, and the pain was tolerable, and I could function in my everyday life. Not now. The DEA is out to destroy our lives. I have a GP, but she doesn’t believe in opioid medication. I always took my medications as prescribed. (98a)

(ED: Some patients did not want to give their location, in fear of reprisals from their doctors, we have the details in our confidential files referenced by the number that follows their reports).

- I don't even tell my doctor how I really feel anymore. It won't change anything. I just tell him what he wants to hear and leave with my measly script of pain medicine, which was lowered. Of course, after peeing in a cup. (15a)
- What does the pain feel like? It feels like smoldering bits of lava infused with razors. It rips through the core of the spinal canal, through the nerves and into the musculoskeletal system. The pain rests in the skin, only to return via the same passageways, back to the core and repeating the process continually. From the bottom of the skull and into the tailbone and hips is another myriad of shredding agony. When at rest, the heart beats out of the chest. The limbs are heavy and uncoordinated. The memory is nonexistent, without lists. Sharp and stabbing sensations from the jaws and into the neck and shoulder are felt down the arms and into pinkie and ring fingers. These fingers go numb at night. Bending forward causes intense pain in the lowest injuries of the spine, but also brings relief after the initial fiery burn. Standing up cause's pain in the same areas within a few minutes, so I must change positions often. (16a)
- My surgeon said he has to find out whether or not I have an umbilical hernia. The results from the CT scan showed I did. I asked if he would take care of postoperative pain, with a palliative care patient. He said I would have to be determined after surgery. (1a)
- I had kidney surgery and had a total nephrectomy. The surgeon tried to send me home with 15 oxycodone tablets. I was given 2 every 4 hours while in the hospital for 10 days. When I complained, he gave me another 25. (2a)
- Threats of tapering opiate pain medicines. Its medical malpractice and cruel. Taking my own life is the only thing left to do. I am assisted living. I don't know what life I have to look forward to, since they are NOT treating my pain. Instead they judge me and call me a "bad person" for needing pain medications. My life is destroyed. (3a)
- I'm slowly getting better. Thank God. I cry every time the pain lessens. It's very strange to have moments of no pain. (4a)
- I have spent the entire day, trying to improvise, to get enough pain relief to walk. This is so tiring and not a healthy way to live a life. I do hope that CPP and IPP, in the future, will not even have to give a second thought to this. (5a)
- Thank you so much for your continued work and advocacy on behalf of pain sufferers. I am 71 years-old and have fought this battle for 44 years. I've had 28 surgeries. I have never felt so betrayed by our own government. (6a)
- I was able to get my medication back after being tortured for years. I found one doctor who knew what they were doing, and I appreciate them. They saved my life. (7a)
- If you are unaware of forced tapers, it's a 4-year, 24x7, nightmare for 20+ million chronic pain patients. We are treated like abusers and addicts, while the government supplies the streets and targets doctors and their patients. (8a)
- My pain is so debilitating and without meds, I am not functional. I am stuck in bed, a physically tortured hostage, writing in pain. I watch people's mouths move and I'm not hearing them, because the pain is too much for comprehension of anything else. (9a)
- My pain meds were cut, because I chose pain meds. Now they are tapered. I smoke a lot of marijuana, if not, I get very moody. (10a)
- The VA took anxiety medicine away with no notice, just cold turkey, gone. So I switched to illegal cannabis, a street drug in Mississippi. I'm not going to stay home, kick my dog or scream at my wife because some drug enforcement agency doesn't want to do their job. (11a)
- Going through this mess has convinced me to never go to the ER. I told my kids, neighbors and friends that if I am lucky enough to have a heart attack, to just let me die alone. This would be kindness and love. (13a)

- My doctor is ruining my quality of life by withholding needed medications. The end result is that I'll be bed bound for the rest of my life. It's not just the pain but also the agony and hopelessness of being dismissed, humiliated and ignored by the medical professionals. The medical community is holding us hostage because they have all the control. A gallbladder surgeon told me she wouldn't be able to give me pain meds after surgery to control the pain. A pain management doctor agreed to prescribe them for me. Then my pharmacist refused to fill the RX, even after talking to my doctor who Okayed it. (17a)
- The pharmacy is now making me deplete 100% of my medications, before refilling them. It lasts 28 days, then fills on day 29, since I take it at 3 a.m. going through withdrawal becomes the norm. (18a)
- Spent 6 hours on the phone today with no hope. Time is running out, along with meds. We just can't win. I have visited over 34 doctors in my area now. Was driving over 200 miles one way to refill RX. Now the pharmacy won't fill. I have a RX and can't fill it. Problem used to be finding a doctor. If you can find a doctor, you may not be able to fill a RX at a pharmacy. Why are the disabled community being attacked and treated this way? (19a)
- For a while I had no choice but to use my insurance company's mail order pharmacy, which turned out to be another hell. (20a)
- When I first moved across the States, I had been on pain meds for over 10 years. The new pharmacy wouldn't fill the new RX. This went on for days, while I was out of my fentanyl patch. My old pharmacist even called the new pharmacist. No luck. Finally, my husband and son went in and raised hell. (21a)
- I've only had opiates intermittently over 19 years for severe pain. I never had issues, but haven't been allowed any pain relief for the past 18 months. I was told to exercise and meditate. As a sports masseur and naturopath, I was meditating 10 years before getting sick. (24a)
- I will be needing opioid pain control for the rest of my life. I've been on generic Percocet for 10 years and have a 20-year relationship with my doctor. These guidelines or laws have made my life a living hell. I have to drive monthly to the doctor's office and twice to the pharmacy every month or find someone to drive for me. The government has no damn business barging into my doctor/patient relationship. (25a)
- Sadly if you say you want "pain medication", you're likely to be prescribed off-label antidepressants, anti-inflammatories, anticonvulsants or anything and everything, except for analgesics that actually work and are FDA approved for pain. (26a)
- Injectable Toradol in the ER, has more side effects than safer more effective opiates. Doctors are too timid and afraid of the federal drug police. They are willing to harm you. (27a)
- I was given Toradol in the ER for an ovarian cyst. I was in agony and even told them, I can't take any NSAIDs. The doctor gave it to me anyway, by IV without my knowledge. I learned once I was discharged and read my take home papers. (28a)
- The VA ER's have been pushing Toradol for decades. The last PCP I saw refused to consider hydrocodone and tried to push Lyrica on me. I took 60 mg morphine 3 times a day and 20 mg of hydro for breakthrough pain for the last 17 years and never had any issues. I'm going to give up. No one will help me. (29a)
- This is sickening and has been going on for 4 years or longer. I went to 7 different CVS stores one time in the same county. All of them said they didn't have generic Norco, which is a common drug. I knew that they were all lying, when they claimed they didn't have it. This is discrimination and intentionally causing me pain. (31a)
- I had an issue at a CVS store, concerning Norco. The head pharmacist would fill it with no issues. The other pharmacist just flat out refused to fill it. I then tried a different CVS. They have no problem filling it, are super kind

and pleasant. I've filled all of my scripts for the past five years at this CVS. They know I've never gotten more than one script and mine is always from the same doctor. We shouldn't be treated like criminals and yet we are. (32a)

- The BS, I went through, when I transferred my opiate prescription from one pharmacy to another. The new pharmacy (Rite Aid) claimed they could not accept my script because “they did not have any.” I was not going to leave that store, until I got some answers. I told them to look up my medication history (all of these, no matter what pharmacy, are a matter of record by state law). When they saw that I had been prescribed these for a long time and that I had been using them in a responsible manner, (no weekly refills of 100 pills, for example) they finally admitted that they did, in fact, have them and could fill the prescription after all. (33a)
- So many times in the past, I lost count, I knew they (the pharmacist) were lying. I have a decent BS radar. I'm an old lady. You never get to be old without having a good BS detector. Their body language, looking away when speaking, saying they are on backorder. Once we waited a whole week. Thank God, I hoard a few for emergencies like this. (34a)
- I was told that when I went to my pharmacy, they were out of stock, for the pain medication that I needed. I honestly don't know if they were or not. I wouldn't be surprised if they lied. (35a)
- I physically had to go into the pharmacy over and over again, or long enough that the pharmacist recognized me. Then, she had a leave of absence, and it started again. Another time, I had to start over as an “opioid native” patient at different pharmacies when Medicaid forced an insurance change. (36a)
- What's wrong with this? Pharmacies are refusing to fill prescriptions. No attorney will take a case to stop it. Politicians won't get involved. News/media won't air the story. (37a)
- Distributors are now not sending orders to pharmacies, and even telling them how many of each dose they can dispense. Since when did distributors practice medicine? (38a)
- I have been living with bilateral Trigeminal Neuralgia for 15 years, have had 2 craniotomies (MVDs) and 4 glycerol Rhizotomy that resulted in Anesthesia Dolorosa. I have tried every medication out there and finally found a treatment plan that provides me the best quality of life. I currently take Alprazolam and Oxycodone. Recently, I broke my back tooth and had to have two root canals. They set off a severe flare up. My dentists prescribed pain medication. I told my pain management doctor that I had to take more pain medication to treat the flare. His response was that most people take ibuprofen for dental procedures. He said that I broke the pain contract and wants to put me in an inpatient detox, and on Suboxone. I am being handed off to another doctor now and would like information on the dangers of rapid detox, and how Suboxone is not recommended to treat pain. (39a)
- The CDC is requiring two or more prior authorizations for chronic pain patients and people like my husband who are diagnosed with Stage 4 Prostate Cancer. I have felt like banging my head against the wall, after talking with so many insurance company reps. I tell them over and over that the guideline is not meant for cancer patients and does not apply to physiatrists, only to primary care physicians. My husband was almost without meds, because they wanted a quantity limit on his Fentanyl, which already had a prior authorization. This was on a holiday weekend. I feel a lot of empathy for people who cannot have access to pain control. It is barbaric and so unnecessary. (40a)
- I was literally days from a planned, dramatic suicide. I had hoped it would have been public enough to shine a light on our plight. I was told about Kratom. I'm alive a year later. It got me through, until I found a pain doctor that actually treats pain. (41a)
- This is a tedious disease. Arms are not out in front or upright. I watch TV lying down. I read on my phone because it's lighter than a paperback or tablet. I recommend getting an Echo and retinas checked. 5 mg Repan really helps with reflex and motility but tardive dyskinesia would be bad, so I don't take more. I take lots of Gaviscon and Phillips tablets. Botox and occipital blocks didn't seem to help the constant migraines, nor did they prevent. I think a major factor is my neck and I get acupuncture/medical massage every two weeks. Tizanidine, Ondansetron,

Hydrocodone, and Rizatriptan are my migraine go-to. Most plans let you have 12 Rizatriptan per month, but I've also found some plans will let you fill the maximum of two different trip tans monthly. Stretching only stretches the ligaments and tendons and not the muscles, so I avoid it. (42a)

- My dad was a chronically ill patient. He was 75 and underwent multiple back surgeries and nerve decompression, along with recently a broken hip and spine. He fought like hell to live, but his family doctor told him due to the CDC guideline, his pain meds had to be controlled by a pain doctor. After months of waiting to get into a pain doctor, he was able to get his medicine. The following visit, his doctor cut him down ¼ off his dosage. He was not cut down slowly. My dad suffered. He went back to see his doctor the following week, but the doctor was only interested in giving pain shots, which didn't work for my dad due to scar tissue. The doctor refused to up my dad's pain meds, even though he told them he was suffering. Five days after that visit, my dad committed suicide. I blame the doctor as well as whoever decided to play God and not allow proper dosages of pain meds to chronically sick people. (43a)
- As a chronic pain patient who has been taking Tramadol for over a decade, the last few years have been terrifying. I worry every three months, when I have my prescription refill appointments, that this will be the time my doctor decides he will not prescribe my medications and that he's done. My husband worries more about what's going to happen when my doctor, who is older, retires. (44a)
- I take pain medication and have been on the same amount of pills for over 20 years. Sometimes it works better than other times, but I can't go to the doctors and say they aren't working any longer. I just have to suffer in silence. If I say it's no longer working the way it should, they'll take my pain medications away. (45a)
- I have been bed bound from pain for the last 2 days. I was forced off my pain meds, when my doctor of 20 years retired and then I moved. Every new doctor refuses to prescribe and I am labeled a drug seeker. I was an athlete and owned 2 restaurants. They are all gone now. (46a)
- I remember sitting in a hall, on a gurney, screaming while my radial bone stuck out of my arm. It took 2 hours for them to give me a shot of morphine, and it didn't work. Maybe I needed another shot? (47a)
- I had severe bladder pain with frequent and urgent urination. I was given antibiotics, hydrocodone, oxybutynin and elm iron. After several hospital visits and a variety of tests, Interstitial Cystitis was identified. Lesions and metaplasia were found and removed. Doctor injected Botox and the symptoms became worse. The only thing that worked for the pain was hydrocodone. In 2018 the medicine mix was changed, although it still worked satisfactorily. I was not consulted. Also, my current doctor had me performing favors at her house, working with contractors. When I finally refused because I was in pain, she basically told me, "too bad." She stopped prescribing to me. (48a)
- I'm stoned right now from MMJ, to answer intelligibly. I told my adult children how sick the government is. They would rather I be stoned on MMJ, than take safely prescribed opioids that do not alter me mentally in any way. (50a)
- Could someone kindly please email me each morning and tell me not to do it. A recommendation to suggest, don't take a Beta Blocker, Gin and Tonic and Morphine together. Currently, I'm being force tapered off my pain meds and I don't know what else to do. So this is my cocktail to survive, for now. I have hope that one day the government will decide to stop playing doctor and allow my doctor to be my doctor once again. I know my "cocktail," is a cocktail many chronic pain patients take, unless they are willing to chance buying pain pills off the streets. Some days I think about it. I want to say "Screw It" and go buy some pain pills, just so I can get out of bed in the mornings again, take walks outside or maybe cook a meal for myself instead of heating up frozen, pre-made, TV dinners. Basically anything except sitting here, hoping I can get my pain low enough, so that I can just take a short walk outside. Once I'm completely tapered off all my pain medications, I may decide to finally try buying pain meds off the streets, hoping it's only pain meds, and not illicit fentanyl. Although if I die, at least I chose to try and live, instead of wasting away while sitting in my chair - alone, waiting for the government to get out of my doctor's office and let my doctor once again be my doctor. (51a)

- I don't want to die. I have been under prescribed for 2-½ years. All I can do is just lay in bed. I don't know what to do. (54a)
- I'm so tired of the pain and am ready to give up. I'm not living, just existing. (56a)
- My pain doctor wrote that he recommended palliative care in my file, but I cannot get it anywhere in my area. Both my pain doctor and PCP refuse to give it to me. (57a)
- I've never been treated so badly. All the doctors in my area are blaming the patients. Never say "pain" in your hospital or you're screwed. (58a)
- Patients with chronic pain, who are stable and arguably benefiting from long term opioids, face draconian and often rapid involuntary dose reductions. Consequently, patients have endured not only unnecessary suffering but some have turned to suicide or illicit substance use. Others have experienced preventable hospitalizations or medical deterioration. Perhaps most alarming is the FDA's assessment that the withdrawal symptoms associated with an abrupt discontinuation of too-rapid taper can lead patients to seek other sources of opioid pain medicines, which may be confused with drug-seeking for abuse. Patients may attempt to treat their pain or withdrawal symptoms with illicit opioids, such as heroin and other substances. (60a)
- Dr. Thomas Kline, its doctors like you that still give me hope. Mine, on the other hand, has made me go into probably the deepest, darkest depression I've ever been in. This is really saying something. (61a)
- Before my medication redemption, I lived on the edge each day. I lived frustrated in pain and it affected my relationship with my family. Socially, I didn't want to do anything. I could not sleep and still struggle with it, but its manageable now. I can now focus at work and can get my job done, even after the 3-hour drives and long conference room meetings in bad chairs. I had to get up and excuse myself during long meetings from the pain, to stretch out. I can now participate in coaching my son's sports, being able to play sports with my son, ride bikes with my girlfriend and help my mom around the house and yard. I was depressed at who I was and my lack of value to these people. Surgery is too risky because of heart issues. I've had zero side effects related to the meds and they have single handedly changed my life 100% better. (62a)
- I have sought help from 4 pain doctors. They each told me, "your problem is everywhere" and "I can't do anything for you." My last doctor left the practice and didn't refer me to anyone. We were addicts. There was nothing wrong with us. The doctor wanted to do a stem cell transplant and recommended hyperbaric oxygen. He decided to taper with medication that helped the withdrawal symptoms. (66a)
- Lady Gaga denies making up her chronic pain. She suffers from Fibromyalgia and it has created severe, physical pain that has impacted her ability to perform. While some critics have questioned the severity of her pain, saying it was a publicity stunt, she says her suffering is real and it has changed her life. She also has pain from Synovitis. (69a)
- For the first time in a 30-year nursing career, I'm starting to think chronic pain is a life-limiting illness - a body under constant stress from unrelieved pain, cortisol, uncontrolled BP, adrenaline and patients being forced to take alternative meds with many more side effects than opioids. I'm now taking Cymbalta, diclofenac, Robaxin, Neurontin and Amitriptyline. I feel like my kidneys will be shot and at the risk of a stroke or heart disease. My depression is worse. When I had opiates, I could get up and be present with my child. (70a)
- Recently, my doctor cut me off mild pain meds, without notice, after an MRI showed no spinal herniation. I have severe Scoliosis, nerve root impingement of the neck and lumbar with resulting Neuropathy and Arthritis Arthritic Bursitis in both hips -- the list goes on. Science no obvious herniation, obviously the pain was not real. He was done, leaving me with undiagnosed pain. Doctors are completely missing diagnoses, as they are too afraid to address pain -- the primary indicator of a serious issue. Doctors have lost their collective minds and all their gonads. (71a)

- I have an extensive medical background and was a medical social worker for seniors and the disabled. In addition, I am disabled myself. I'm having a boatload of unfortunate and unfixable diagnoses that all cause pain. I am only 58. My future as I age, and as I medically digress, is terrifying given the medical environment today. (72a)
- Medical PTSD is all too real. Thank you for addressing these difficult topics and being a voice of reason in the midst of Opioid Hysteria. It is important to identify what is really going on in people's minds and what is actually motivating them. This is key to affecting change. (73a)
- A reading of the government briefs in Doremus and Webb reveals a complementary strategy: statistical manipulation. The documents assert that Congress was wrestling with a massive social problem. It involved as many as 1.5 million addicts, concentrated in urban and industrial areas. These figures were frightening, but also were fabricated. (74a)
- A study finds only 1.3% of overdose victims had an opioid prescription. Postoperative opioid dependency is 20 times more common than the Type 2 addiction gene. This implies that surgical complications are 20 times more likely than addiction. This is a sound argument for conservative treatment of injuries that may heal without a carving knife or stapler. (75a)
- I can't take any more pain as it is. The fear of being dropped to 200 mg is terrorizing and has driven up my blood pressure 20-40 points. I know 360mg may sound like a lot, especially given what other people get now, but with my Cytochrome P450 defects and extremely high constant pain levels, 360mg only gives me a small pain reduction. I'm not ready to pull the plug yet. I'm still taking it day by day, hoping for some good news. (76a)
- How was PROP allowed to create the 2016 CDC guideline with no pain management doctors, advocates or pain patients input? Why was this done in secrecy? It's very unbalanced and biased. There is scientific proof that they are wrong. They can ignore it all, because they are the makers of The Guideline. How do they get away with it? (77a)
- Myth: opiates don't work for chronic pain. No studies show this because there are no studies. Let's twist that around. (78a)
- Are opiate pain medications too dangerous to use? I have Adhesive Arachnoiditis. I went from having somewhat of a life, to unbearable pain and now I'm in bed, almost all of the time. The government stepped in and now my life is horrible. I am tired of living like this! Why must I be tortured daily? I have a rare disease with no cure. The only treatment is with medications containing opioids. (79a)
- I would love to see you tackle the myth that the majority of adolescents are abusing prescription opioids that they get from the doctor. It is actually a lot more complicated than that and what people have been saying and told. (80a)
- I have Adhesive Arachnoiditis and had somewhat of a life for over 10 years, thanks to opioid pain medications. The government decided to get involved with my treatment. My opioid pain medications were cut drastically, to the point where I spend most of my days in bed with unbearable pain. I am 62 years old and just want to live what remaining days I have. Is this too much to ask? What medication will the government decide to cut next? Will it be medications for my heart; will it be for my diabetes? (82a)
- I was born with a genetic abnormality (natural fusion). Since I was a teenager I have suffered with pain. Over the years it has gotten worse. A pain doctor put me on Percocet 5 mg 4X day and when there was no relief, increased the dosage to 7.5 mg 4x day. This relieved most of the pain and I felt like I could live again. Then it was cut in half; then cut in half again. I never got a reason why this occurred or results from any tests. I went to another pain doctor and was given two Hydrocodone per day, which was much less effective. Physical therapy made the pain worse. He recommended a spinal cord stimulator be surgically implanted, which I did not do. There was no guarantee this would work. I am taking, or have taken, Lyrica, Celebrex, Ibuprofen, baclofen, extra strength Tylenol, Valium and Zofran. I just want to enjoy life again, instead of dreading every single day. (83a)

- I was functional until 3.5 years ago. My doctor reduced my pain meds. I'm lucky I still even get meds. However, I can't do anything. I just sit around and watch TV or go online. My daughter was taking care of me, but she passed away two weeks ago. I don't know what's going to happen to me now. I'm scared! (86a)
- On Wednesday, I was admitted for on-call surgery. No OR was available. I was placed in a room, gowned and given an IV. No room ever became available, so I was sent home and was billed for the ER visit. On Friday, I returned again for an on-call surgery. This time the surgeon arrived, but he did not have trained staff or instruments. He actually trained the anesthesiologist on how to bring me back, so I would be awake and then back to sleep, as they tested the nerves for pain. The surgical area was from a botched hysterectomy. I was assured by hospital staff that my palliative care certificate would be honored. My doctor was not on staff at the hospital; therefore he could not order pain meds but would ask the Hospitalist to do so. I came out of surgery with no pain pump or pain meds ordered. After the hospitalist was called, he ordered morphine. I had informed everyone that I was allergic to morphine and it was on my chart. No one would prescribe pain meds. Ultimately, my surgeon got me discharged from the hospital. They put me in a wheelchair and rolled me to the lobby. Later, they took the wheelchair back and put me on the floor to await a taxi. By then, I was experiencing full body muscle jerks, electrical zaps across the side of my face, and I was in medication withdrawal. There is no way to describe the hell I endured. (87a)
- My grandchildren keep me going, but sometimes it's hard to even hold onto that when the pain is too bad. It's hard to even hold my phone up to look at my phone and focus on pictures of them. You don't suffer from your pains, so it's hard for you to empathize or comprehend what we go through. (88a)
- I want Dr. Kolodny to explain why I, a veteran with chronic pain from a botched back surgery, was on death's doorstep? I was in his preferred state of unmediated, but alive and well, up and moving, lucid and eloquent when on what he would consider high-dose opioid therapy. I am dependent but not addicted. It wasn't until I sustained an injury that required long-term opioid therapy that started me on long term pain medications. (89a)
- They had admitted me for back problems and a doctor wrote on my records, "I entered the patient's room and she had her face in her pillow and was screaming. She looked up at me and was crying. I do believe this is manipulation in order to get opiates, so I have decided to treat her pain with acetaminophen." All I had asked for was an ice pack and pillow. I never asked for opiates. This place is a nightmare. (90a)
- I think it's important to point out what my life has been since prescribed pain meds. The suicidal thoughts that had become nearly constant, ceased. I was alive again, resuming activities with my family. I've had my life back for nearly two months now, and I'm terrified of losing it again. (91a)
- At CVS I experienced judgmental/uncalled for comments, eye-rolling and snickering from the pharmacists and techs. Like I was a joke as they messed with my life. This is all because I'm a chronic pain patient needing pain medication to have a quality of life. (93a)
- I was an athlete while in school, became sick, and in college was diagnosed with Crohn's Disease. I was also diagnosed with Psoriatic Arthritis. My Crohn's is under control now. I drink a gallon of water a day to try and prevent kidney stones. About a year and a half ago, I was admitted for passing multiple kidney stones at the same time. They refused to give me any pain medication other than what I was taking on a regular basis. I screamed in pain and they wrote me down as drug seeking and told me that if I continued, they would put me on a psych hold. I did go to pain management about 8 years ago and was forced to take Suboxone, which did not help my pain and caused my colon to freeze. I was in the hospital for two weeks. My G.I. won't prescribe Lomotil anymore, because he said it is a narcotic. I do get pain meds for my rheumatologist, but it is a very small amount and I have to ration it. So I take Kratom regularly and save my pain meds for kidney stones and extreme flare ups. (96a)
- PROP had tried to limit the use of the opiate pain medicine by correctly petitioning the FDA, three years before the CDC Guidelines. They disagreed with the petitioners and declined to implement their radical changes, to limit the uses of pain medicine in the US. As it turned out, a policy so radical and devoid of rational thinking and scientific support. It did succeed in demonizing opiate pain medicines, to the point of the worst medical disaster in American history -- the pain refugee crisis. On March 15, 2016, the world of people with intractable pain was turned upside

down. The CDC agency abruptly announced to the world that 50 centuries of pain relief was wrong. Opioid alkaloids or opiate pain medicines were now useless and too dangerous to consider. The CDC does not have a medical practice charter. The question arose -- what was going on? (97a)

- I'm hoping and praying that my doctor will continue to protect his practice and his patients, despite the strong arm tactics by the DEA. I must stay on my medications for life. If these are taken away, as a result of dirty politics, I will have no choice but to walk into the arms of the Lord. Also, my pharmacy isn't accepting my doctor's electronic prescriptions anymore. (103a)
- A good friend of mine is 73 years old and a chronic pain sufferer for the past 20 years. He has degenerative disc disease. He is slowly dying because of these ridiculous guidelines. In addition to his pain, he has chronic anxiety. The new laws state he cannot be on alprazolam while taking opioids. He goes to a pain clinic monthly and they give him the maximum amount of opioids that they can. He is given half the strength of what he used to take. So not only is he suffering with pain, he has all this anxiety as well. Neither of his conditions are being treated properly. It's sad to see him slowly dying. He has lost 60 pounds since they took him off his medication. He used to be active and had a zest for life. Now he is a shell of a man who can barely walk. I have talked him off the ledge many times. (104a)
- I have been in Pain Management for 10 years. I was injured at work, and my injuries led to me developing terrible crushing bladder pain. Now the pain has spread throughout my body. CRPS, Interstitial Cystitis, Paralytic Bladder, Heart Disease, Esophageal Spasms, Inflammatory Bowel Disease, Raynaud's, PAD, Severe Myalgia in both feet and legs. My body is shutting down.
- It pisses me off. I literally have no bad habits that caused any of this. I just committed the crime of getting seriously hurt at work, and not getting better. Now I'm older and I've drawn the short straw, apparently. Yep, it pisses me off. I'm not ready to go yet. Until recently, I was one of the "lucky" ones. I had pain management and medication for pain. When my pain saga started, I wasn't demonized and belittled. I fought hard, and won lifetime medical care and medicine for the injuries that led to my becoming permanently disabled. But I have learned that this battle means next to nothing. It's "time to taper" for me. Since my pain doctor told me I was being tapered, I have been to the emergency room - twice. My fear and anxiety at being abandoned has contributed to the rapid decline in my health. My anxiety is past the point where I can cope and now they want tranquilizers banned. Who are these people? (105a)
- My sister, who had MS, shot herself in the head this past weekend. A doctor refused to give her medication for intense pain. She was only 61 years old. This is the death of compassion. (108a)
- A man faces manslaughter charges for helping his wife kill herself. Typical horrible reporting that stated she killed herself, because she didn't want to go into withdrawals. Instead of stating the truth, which is that she didn't want to live with untreated pain. (109a)
- Duke Orthopedic Clinic sent a copy of their new opiate policy that I just received ahead of my upcoming appointment. (110a)
- My elderly Ohio friend's husband, purposely went to the streets and committed suicide by OD after his doctor abandoned him, because he was in pain. An Ohio college professor's doctor gave her a hard time when she asked for pain medicine, while she was dying of Stage 4 bone cancer. Ashtabula. (112a)
- My sister took her own life last month. She was 29 years old. She was a professional dancer and broke her ankle. She was in excruciating pain, but no doctor believed her or would give her pain relief. (113a)
- What is intractable pain? IP is a severe, constant pain that is not curable by any known means, and which causes me to be in a bed and house-bound state and early death, if not adequately treated. Treatment is usually palliative with opioids and/or intervention procedures. (114a)

- Yay, I just received my Prescriber Report from Mass. Prescription Drug Monitoring Program, (PDMP) to intimidate me not to prescribe opiates to my patients. (115a)
- The NarxCare risk score lists 9 prescribers and 4 pharms. Six were proctors at the VA. One was my dog’s vet. I called MI PMDS office and asked to have it corrected. I’m bedridden now. Narxcare Fraud should be trending, but few know about the scoring. (116a)
- Any doctor who claims chronic pain is all in your head, is clearly a quack. Unless you experience soul-zapping pain that has you terrified to move, you have no clue what it’s like to suffer from chronic pain.
- Hundreds of years of medical research and results and tens of millions of pain patients, all wrong and “full of it,” because of the new crop of anti-opioid zealots. What a crock! (117a) Karen
- Saw my PC doc last Friday. I again didn't sleep the night before. I had to agree that I would titrate down if I wanted to take medical marijuana. Every time I go to my doctors, I’m waiting for the other shoe to drop. The Med Pot industry in Maryland is strain inconsistent, so what works for me, isn’t always available. (118a)
- This is what I hate, the anxiety that starts a week before my pain doctor appointment, as I brace myself to defend my steady pain regimen. (119a)
- I went to see a new rheumatologist and the first words out of her mouth was “You know we don’t prescribe narcotics.” I said, “I’m over this bs, because I know you’re not concerned about pain.” Wow! Even before an evaluation. I should have said, I will come back when your professional ethics return. (120a)
- I am so very sorry. I know a two-year-old with cancer. They are trying to control her pain with gabapentin. I’m suggesting to the mom to speak with a lawyer. My heart is breaking. (121a)
- I was at Walmart pharmacy and an elderly lady was in distress. Her husband's physician stopped her from filling his pain prescription. The doctor told her she had to bring her bedridden, incapacitated husband in for a urine test before she would allow them to fill the prescription. I told them they should call an ambulance to pick him up to get the urine test, if that’s what it takes to get a urine screen. I have seen it done and had to do it with a friend’s father. I was the end of life caretaker, as if there is any good reason for doing that to an elderly, bed bound patient. (122a)
- If anyone reading this is wondering “why doesn’t he just go to another doctor?” For almost all of us, there are no other doctors. They WON’T prescribe these medicines. They will treat you like a drug addict and a drug seeker, and will refuse you treatment, despite evidence proving you really are just a pain patient. Her doctor refused to continue treating her. He was prescribing morphine for several years. She never had a substance abuse problem and was very cautious. The doctor knew he was wrong for abruptly stopping her medications. He admitted it to several people, before he found out that she had committed suicide.
- Before the CDC guidelines came out, I was on 6 pills of opioid medication a day. I had been on this medication for 5 years and never once abused my medication or took more than what was prescribed. When my pain specialist cut my dose in half, I literally crashed and burned. Since then I have been practically homebound.
- I’m 48, a mother, wife, homeowner and voter. I’m also a chronic pain patient. I’ve had RSD for over 20 years. The pain has been managed all that time by the same dose of opioid medication that I took 20 years ago. Without the opioids, I’m unable to walk well, unable to do housework and unable to care for my son.
- My story of pain began 23 years ago. I was working at my desk, my muscles seized and threw me from the chair. As I curled on the floor, my body seared with pain. At the age of 30, I could barely stand, and sitting was impossible. So I began to conduct my life lying down. For many years I was bedridden. As soon as I took opioids, I improved. I could work again.

- I attended 2 years of college. Then my eye pain and Fibro had gotten to a point where I could no longer continue my studies or participate in activities I had previously enjoyed without meds. For the most part I am pretty much bedridden.
- I was forced off 75% of my pain medications. I began taking Suboxone a friend gave to me, for when I would run out of pain meds. Now I'm taking heroin, but fear I will get something laced and die.
- My 86 year old grandmother went in for a hip replacement after a compound fracture. They said the new protocol was to not do anesthesia and just do local nerve blocks with Tylenol for the pain during the entire total hip replacement. That obviously didn't work. Halfway through while sawing through the bone, she was screaming and thrashing around. So they intubated her and gave her proper anesthesia.
- She was in the ICU for 4 hours after the procedure. Her heart rate and blood pressure was all over the place from the high levels of pain. All the medical staff gave her was two Tylenol. This level of "healthcare" amounts to a series of criminal acts against the disabled and elderly. She already lives with 3 major diseases and they only were willing to give her Tylenol. (123a)
- This is truly genocide. There are glaring and horrifying similarities to what is being done to pain patients now, and what the Nazis did in their T4 Program to kill off the disabled and those considered "unworthy of life". It is still alive here in the USA. Stanford University -- home of many anti-opioid/pro-patient torture zealots -- has a long history with eugenics; nothing new under the sun, but is pure evil. (124a)
- My 33 year old daughter was cut off from her pain medication about 4 months ago. I had to get a job at night so I can be there for her and also take care of my 4 year old grandson. He has a heart defect and cannot attend daycare, due to his condition. Our situation has gotten so bad. My daughter is in constant pain and my grandson is showing signs of problems too. Why do we have to suffer like this?
- (125a)
- When I first went to this doctor, he said he would give me anything I wanted, concerning pain medication, up to 90 mme, and no more because of what DEA outlined. I thought that was strange; he kept me on what I was on. I asked for nothing else. (126a)
- In July I tested positive for Fentanyl. I know I did not take anything other than what I was prescribed. My doctor said he had no choice but to cut me off all my medications. I have had nothing for pain since, so have been self-medicating since July 2021. (127a)
- In May 2020, I received a call from my pharmacy that they could no longer fill my prescriptions. They gave no reason other than they "have to think of their business". I am in crippling pain, no longer able to care for my 8 year old son. I am constantly crying, hurting and filled with anger that this can be allowed to happen. For those of us who commit suicide rather than deal with the pain, the government should be charged with murder. (128a)
- I am about to lose my job, my career. I work from home, but my lizard brain is focusing on the pain. I feel everything every time I move. The clinical depression and anxiety adds to the suffering. Every day is a living night terror. And to think my own government is torturing all CPP's. My mind is not grasping the reality. I don't feel safe and I'm all alone. It's called pain medicine for a reason, and I am not safe. None of us are safe. (129a)
- With pain medicine, my life has improved to what it once was. I was alive again. I was a father and husband again. I actually went dancing. I've had my life back for 2 months now. But I'm terrified of losing it again. (130a)
- I have to schedule my life around refill appointments and forget any leniency if I have to travel even one day before my refill is due. I've had to cancel family visits because of this. Luckily I've been able to switch to mail order and get 3 months. A lifesaver. (134a)

- Medicare sure DOES put limits on what opioid meds I can get, how many and how often. Prior authorization was not mentioned in January and I spent 2 hours 32 minutes on a call with the pharmacist. They would not fill it without it. Doctor office failed to mention that I needed it, the insurance company didn't warn me, I missed doses and was very uncomfortable. (135a)
- Many people are leaving New York. They can blame COVID, but the reason I'm leaving next month is the medical system has been infested by anti-opioid zealots. They've tortured the incurable and elderly since Dr. Kolodny and PROP talked Tom Friedman and the CDC into backing the 2016 CDC Guidelines. But COVID revealed how barbaric we've become from this narcotic hysteria. (137a)
- Opioid pain reliever's work or the FDA would never have approved them in the first place. My mother used to take 3 OxyContin 80 MG, 4 oxycodone 30 MG and a morphine pump. She never had an issue. She lived like that for over 10 years. Unfortunately cancer got her. But she said many times, if it wasn't for the pain medicine, she would have ended her life years ago. Because of pain meds she was able to live a quality of life for a decade. (139a)
- I was never given a reason for being tapered off the pain medicines I'd been taking for 24 years. I was never told where it would end. The DOJ and state government got together with my doctor and decided on my "new" treatment. I had NO voice, no consultation, and no say in my own treatment. (140a)
- I believe I've been misdiagnosed with Fibromyalgia because my doctors didn't want to fully investigate what was going on with me. For years I was used as a guinea pig, trying new drugs that made me worse time and time again. Then when I finally started taking pain medications, they were effective and I thought I was getting my life back. But when I asked for more I was labeled a drug seeker. I have been using my grandma's pain meds that she gives me, because otherwise I would have taken my life by now. (141a)
- Just left the hospital with acute pancreatitis. My autoimmune disease has damaged four organs and I won't live much longer. In the hospital, they neglected to give me my long term opiate treatment as promised. After seven days of unbelievable torture I left the hospital in severe opiate withdrawal. (144a)
- I have been on Valium PRN since my first back surgery in the early 1980's. I use valium for muscle spasms and on occasion for the "Hebei Jeebies," a restlessness that makes my legs feel like something is crawling on them. I had no issues with 10 mg Valium, even when I was on and needed high dose opioids 1260-1460 MME. After 18 months from when I had stem cell injections in my spine, I am now down to 100 mcg Fentanyl patch with 10/325 mg Percocet and 10 mg Valium for PRN pain and restlessness. (146a)
- I went to the hospital for increased pain. A disk had popped out and I was in total agony. The attending ER doctor said to go see my PMD for an injection. It was Christmas Day.
- I asked my doctor if I had the "addiction gene" and if they could test for it, since my parents are both recovering alcoholics. He said there isn't one. He refused to treat my chronic pain, torn tendon and nerve damaged leg. (147a)
- I told my doctor that my quality of life has been destroyed by forced tapering and that I was just trying to get through each day of pain. He said, "You are not worth me losing my license. You're just going to have to get used to being in pain," and walked out. (149a)
- My pain doctor told me two days ago at my appointment, that he will start tapering me off my pain medication. He made an utterly insane statement, "It should be easy; you're not on a high dose." Why did he want me to get off them if it's helping me and it's the lowest effective dosage possible? I believe this is a way they get rid of patients that have problems or they can't figure out. I use a local pharmacy that has been perfect and has given me no issues about my pain medication. Again, the dose is low enough to take the edge off and function half way. (150a)
- I was cut off my pain medication for absolutely no valid reason in July 2020, after being on them for 10 years of responsible opioid use for chronic pain. I'm 60 and never have I diverted my prescriptions, nor failed their ridiculous

urine tests or random pill counts. All because Ohio is insane. Everywhere they scream “Opioids are bad!” All are anti-opioid zealots! Now they want me to talk to a Neuropsychologist. I can’t wait to see what this voodoo doctor has to say. I’m in bed almost all day every day and I guess I’m supposed to meditate my pain away? (151a)

- If I’m taken off my pain medications one of three things may happen: (1) I will die (2) a medical person may die (3) I will be forced to take my chances on the streets. Doctors haven’t been able to tell me what’s causing my neuropathic pain. They haven’t been able to explain the intermittent palsy. I feel all they do is torture me with needles that they put into my spine that do nothing. They prescribe drugs that sometimes make me drowsy, sometimes not, that may take my pain away for 6 hours during a bad flare. (152a)
- Unfortunately this is the norm in pain care. Last year when I refused to take any more Gabapentin, or take more ESI, I was shown the door. Harming me was not important to the PM Doctor, his license was. Does discharging me from pain care create a public health threat? (153a)
- I’m a 61 year old woman who has suffered my entire adult life with pain. Recently I questioned if I should continue with my current medications. It hurts so bad that I start vomiting and crying. I have something wrong somewhere, because when I get out of bed in the morning I have pain when I walk. It feels like something is going to fall out of my private parts. My feet and legs turn blood red and swell up with water. My shoes are always wet, where water runs down into them. Nothing is being done. Now I have painful shingles along my ribs on the right and left sides. My primary care doctor would not prescribe me pain meds. A pain clinic started to prescribe them to me, but it’s only 45mme a day. This is not enough, so the doctor tried to get me on something without acetaminophen because of liver failure. My Insurance said that they won’t pay for it and I cannot afford the \$1,400 copay. I guess I will have to stay on these current medications that are causing my liver to fail. Is this right? (154a)
- I have lost a decade of my life, bedridden in my forties. My heating pad is like an umbilical cord, keeping me tethered to the bed. My MRIs are proof of terrible degeneration and one disc pushing against the main nerve. I am ignored. I want Vicodin schedule III. Why am I being denied a medication that has worked for me in the past? (155a)
- My PCP is finally going to treat me for pain management with Suboxone. At first he said I would have to admit to addiction issues, which I have none. After he read my chart notes, he then agreed to treat my pain, calling my situation a “high tolerance” to opiates. Whatever that means. I’m spared (for now). Not looking forward to the urine screens and counseling. (157a)
- I’ve suffered from agonizing physical and mental pain since childhood. Now I have horrible Endometriosis, severe Fibromyalgia and Osteoarthritis in my neck and spine. I also have DDD and PTSD. I was cut off from all my pain meds, after being on them for 10 years. I’m labeled a drug addict. Please God end my life. Please. (158a)
- I’m from WV and I can’t get help. Online I hear of patients complaining, because their pain meds have been lowered. I’d give anything to have pain medication. One woman complained that she was cut down and only able to get 300 pills of Roxy’s. I’m in desperate need and I can’t take it anymore! I don’t care what doctors say, pain meds and benzos can be safely taken at the same time. If they couldn’t, half the world would have died a long time ago. I need a doctor to prescribe me the medications that I’ve taken correctly for over 28 years. I have no life. I need help badly or I’m going to die. (159a)
- My spouse texted me that his company is having benefit changes, including tracking opioid prescriptions and management. (160a)
- I have Ehlers-Danos, a disorder that causes dislocations daily. Without daily opioid use, I am not functional. The pain I experience is often a 9 on a 10 point scale, with opioids. The difference between two points is having a personality and being able to be present with my teens, give advice and listen. I am able to run podcasts for others with disabling pain. I can write my children’s books and chat with my friends. On good nights I can make dinner and talk with my husband about his day. (163a)

- I used to be an avid scuba diver and I traveled the world. Now my daughter has to push me in a wheelchair if we go to the mall and window shop. I would be okay if they hadn't cut my pain meds for no reason whatsoever, except that the CDC said so. I have never had a problem with addiction of any kind. There is no reason I should be living life like this, with no quality of life. (164a)
- I need a pain doctor in Oregon that will allow me to stay on my pain meds that are working for me. Recently I moved back to Oregon and Kaiser is only interested in reducing my meds that were monitored for 7 years by my previous pain doctor/clinic. I lived a high functioning quality of life when I was on my proper medicines. (165a)
- I have Klippel-Feil Syndrome, Syringomyelia, Scoliosis, Spina Bifida Occulta and I'm missing a kidney. I have osteophytes pressing on my spinal cord and my doctor told me that a positive ANA is proof that I no longer need my pain medications. I need to go to the Rheumatologist, but cannot get in to see one. I have been trying since November. My pain doctor lowered my medications by 50% and I am now on 20mme and my blood pressure and HR have been skyrocketing, because I was not weaned down. My pain is excruciating and I am no longer able to have a functioning day. The law in my state is 90mme for opioid naïve persons. People like me should not be dropped off my meds. I'm not opioid naive. (166a)
- I finally brought my pain down to a moderate level, so that I could walk. I quickly took advantage of that by doing several routine chores around the house. I am so ashamed that my wife does chores that I should be doing. When she gets home she will be angry. (167a)
- I was a hard worker. I supported my two children on my own. Working one full time and two part time jobs. I never took assistance. I worked at hospitals, doctor offices, foster care agencies, radiology, etc. What is wrong with me that I'm being denied (pain meds)? (168a)
- I lived in Houston when I became PM; had to move back to my smaller Texas hometown when I was too sick to work. In 2014, Walgreens in a small Texas hometown, said it was against the law for them to fill by prescription, and CVS said they didn't fill that. I asked the pharmacists if there was a CVS manager I could speak with about having CVS order my medication. He told me not to threaten him and hung up on me. I was so shocked and I didn't know what to do. Walgreens in Houston always filled my meds with no problems. I went to a small locally owned pharmacy and so far they've filled it with no problems. I talked with the pharmacist and told him I have chronic pain and offered to give him a copy of my PM contract, but he said it was not necessary. (169a)
- I'm in terrible pain. I would go to the ER but last time I went, they accused me of being a drug searcher. My own doctor is on vacation. My usual refill is being denied by the doctor on call and reduced it to only 5 days at a time. Usually when I have a huge flare up of severe pain, I take extra to stay stable, but so far I have been unable to do that. I work a fulltime job and I'm in so much pain I don't know how I'm going to do that. The on-call doctor won't write my refill. He's refusing my usual refill of 5 mg short term oxycodone #180. They didn't tell me anything just that they weren't going to refill my medications. My pharmacy told me what was going on. I believe my back issues and nerve problems have gotten worse. The pain is incredible. Why do they treat me so terribly? The nurse was not nice. It seems they are only worried about themselves. (170a)
- I am fighting with a doctor who cut my pain meds 70% because he received a complaint for over prescribing. No medical reason; just said he's not going to lose his license to keep giving patients the pain meds they were getting. Taking it to the State Medical Board. (171a)
- 15 years on 50 mg of Tramadol once daily was mirable. I have Lupus and was able to walk 3 to 5 miles daily, garden and work part time. It also eliminated a lifetime of depression, which my doctor understood as another benefit of Tramadol; it transformed my life. Now I'm bedridden after being tapered off without my consent. (172a)
- I am so afraid. I was hit by a car as a pedestrian over 20 years ago and I have multiple diagnoses as a result. I have taken pain meds for 15+ years without any problem. I was force tapered four times. The first two tapers I did fine. The third and fourth have left me in bad shape. After the third taper, my brother told me he was given

methadone, and that it worked well for his pain, and is more acceptable to the medical community. So he gave me 2 pills and I took them. Of course my urine test showed them, and I explained I was just trying to find an alternative. If I had asked for a switch to a new medication, I was afraid I'd be branded as an addict. Now my doctor, with whom I had had a good relationship for 14 years, treats me like I'm a dog. I'm hurt so bad by that. He reduced me again. Now I'm in pain every day, and now I'm terrified by my doctor. I'm labeled as a "bad patient". Nothing I say makes any difference at all. I am disabled. It doesn't matter. I tried to explain that I never had a problem until they kept cutting and cutting my medications. Pain was not a sufficient answer. I am afraid. (173a)

- For further irony, look no farther than chronic pain patients that arrived at this place because of what the medical community did to us. I'm not bitter towards surgeons since I sought them out and agreed to the procedures. Now I just want the medical community to help me cope. (174a)
- A friend had a cardiac ablation two days ago. Spoke to her today and she's in extreme pain. They told her to take Tylenol. Now her chest hurts and her arms are swelling. Now acute PO pain is treated as minor in the healing process. Opioids help the body relax so it can heal. (175a)
- I moved to Missouri in early summer. I'm still taking RX from my pain doctor in Florida. The doctors I've gone to, have been rotating me out from one to another, as they refuse to take over my care. I've been told to go on those dangerous drugs, FP + hydromorphone. He said I will remain in severe pain for 6 months and then I should be okay. Getting off my diseases (Arachnoiditis MS, Stenosis, spondylitis, Scoliosis, Spolsthasesm Osteoporosis) should cause my pain to disappear. I was also told that I'm going to be the reason my physician in Florida will end up going to prison. I've been treated horribly here. I've been on pain management for 30 years and I'm scared. (176a)
- It's retarded like I obviously have pain for uncontrolled Lupus, RA, and Fibromyalgia. I work full time and have a toddler. I have 2 cysts, etc. and I get 7 days of medication. It's not even Percocet or something good. It barely takes the edge off pain wise. It's just so dumb. I'm not a narcotic addict but I deserve to not be in pain. (177a)
- I had a neurologist stick that needle into my leg. Blood was running down my leg and tears down my face. He had the nerve to tell me "there is no way you can be in that much pain." Thank God my husband was with me to witness. Never went back. (178a)
- I have needed to increase my dose for many years. However, I'm told that this simply isn't an option. I sit at 90 mm indefinitely. I wouldn't say the pain is adequately controlled. (179a)
- I had suffered with such constant stiffness and pain for the prior 5 years due to Psoriatic Arthritis. When I herniated a disc and was given Norco for the first time ever, I was stunned at how I felt somewhat "normal" again. (180a)
- This is where our anger comes from. We hurt like hell 24/7. Our brains are wired to fire signals until we can't treat the pain. It's not a matter of feeling good. It's a matter of desperation to think straight and bring our pain levels down. (181a)
- After 17 years with one doctor, he walks in the exam room and tells me he realizes I need high dose opioid treatment, but he is not going to give them to me. Instead, he gave me 2 months of meds to find a new doctor. His practice is probably the reason I'm in this much pain in the first place. (182a)
- I have a patient in Sickie Cell Crisis and I couldn't even get her 20 days of pain medication, without jumping through hoops and being on the phone with Health Net for 4 hours. No one has the time for this. It takes away from patient care. (183a)
- Physicians and pharmacists would be reminded that opioids are used for indications other than pain. My wife had UC, had an ostomy and she had to go to a pain clinic for her bowel motility opiate script. (184a)

- He had years of health issues as a survivor of SARS, Diabetes, Kidney issues and Cancer, although chemo supposedly helped. He wanted more morphine, but the doctor lowered it instead to a lower dose pill. It was so obvious his pain increased. He died before his family could get another doctor. (184a)
- The problem is often chronic pain patients, especially a complex rare disease, are misunderstood. They are treated like drug seekers or worse, junkies when they end up in the ER. (185a)
- I'm not being treated with any medications for Lupus, RA, Sjogrens, Endom, Lyme Disease, etc., etc.. The last medication I was able to get, was 5 mg prisms, one time a day. Now that has been taken away, because I have developed osteopenia. I can go to a Suboxone clinic, if I pay cash. It's so confusing and I'm exhausted. (186a)
- I was taken off, less than the low dose of 40 mg. I was on 30 mg for 5 years and then force tapered. Now 3 years later, my life is basically falling apart, since these monsters tried to "help" me from overdosing. (187a)
- I breathed a sigh of relief from the pain dissipating. Then I realized how stiffly I'd been sitting and was able to relax into a normal position. I cried because I finally felt like my old self. Lastly I got up and walked around, went outside and came back in and cooked. (188a)
- I tell people that by the time I get relief from pain medication, that I used it all and there is none left for feeling anything else. My body used it all in pain. (189a)
- With medication, I felt immense relief. It was like a magic eraser removed the group that had often rendered me incapacitated. When it was abruptly "dosed down" to zero, my quality of life disappeared. And now I live around my pain. (190a)
- I've suffered from CRPS/RSD for 34 years. I've been through everything they could throw at me including two stimulators, of which the last left me with scarring on my spinal cord. I've been on/off opioids with no problems addiction-wise whatsoever, but opioids are by far, the best pain control I have ever had - bar none. I get a little emotional when my life is being stolen for no reason. I now can barely care for myself with what I can get. I've never failed a urine test, pill count, an office visit or anything else. Politicians just decided that I didn't need my medicine anymore. Why? (191a)
- I wonder how many others like me have been abused by doctors and have lost all faith in the medical community. This is my life now; constant torture. Have just given up. (192a)
- I can personally attest to the horrors the opioid pain refugees are undergoing, trying to find medicines and relief. (193a)
- My friend, Sherry, has Pudendal Neuralgia. Her physician had his office shut down. She was referred to another physician who refused to maintain her on her present medications. She's been sent to a pain management doctor to get a ganglion impar injection. Unfortunately, her pain is not mainly in the rectal area and steroid injections rarely provide relief for PN. She's very frightened. She is weaning herself down with what is left of her last prescription. This is the same story again and again.
- (194a)
- No legitimate chronic pain patient on opiate pain medication who takes this medication as prescribed, does not need Narcan. I am living proof, 8 years and up to the present day. I have been on and am still prescribed long term opiates for my rare, incurable and painful disease. Narcan is a wonder drug for street Heroin addicts who frequently overdose, but there is a world of difference between addicts and legitimate genuine chronic pain patients. (195a)
- I can get my pain meds now, but I must go to a pain doctor. I must go every two months and they count my pills. Also I have to do a pee test. (196a)

- After being abruptly cut off my higher dose pain meds, I took responsibility for nearly 15 years. I suffered permanent damage to my heart, kidneys, eyes and entire digestive system. My blood work ups are documented proof of the damage that was done within one year of being cut off. When I found a new PMP two years later, I was on about 1/6th of what I used to be on. I'm way under the 90 MME and its fear that keeps my PMP from prescribing any more. I'm grateful for what I have, but I'm still under-treated and I must pick certain times of the day to be in severe pain. (197a)
- If anyone reading this is wondering “why doesn't he just go to another doctor?” For almost all of us, there is no other doctor. They won't prescribe the needed medicines. They will treat you like a drug addict, a drug seeker and will refuse you treatment despite evidence proving that you really are just a pain patient. (198a)
- Her doctor refused to continue treating her. He was prescribing her morphine for several years. She never had a substance abuse problem and was very cautious. The doctor knew he was wrong for abruptly stopping her medications and he admitted it to several people before he found out she had committed suicide. (199a)
- Before the CDC guideline came out, I was on 6 pills of opioid medication a day. I had been on this medication for 5 years and never once abused my medication or took more than what was prescribed. I was able to play golf and worked out 3 times a week, which helped me keep my weight off. When my pain specialist cut my dose in half, I literally crashed and burned. Since then I have been practically homebound. (200a)
- I would love some info on this. I have been legally disabled for 9 years. I've intractable pain conditions and have gotten worse very quickly. Yet I can't get into a PM and get 60mme/day from an internal medicine doctor. I'm aware I'm luckier than a lot, but still no luck. (201a)
- I'm an RN, disabled from spinal surgery and living in a nightmare, by the way others are pushing their own beliefs/agendas on others. I shouldn't be punished like this. Opioid medication does relieve chronic pain if given at the right dosage. We're treated horribly for having pain. (865)
- I am one of those patients with chronic lower back, right leg nerve damage and severe pain. Can't do anything without pain. I promised my daughter I wouldn't harm myself, but truly don't know how much longer I can handle this existence. All my MRIs state the condition is worse each time a new MRI is done. Back surgery in 1993 is not a situation that physical therapy is going to help 20+ years later. (864)
- Chronic pain destroys you mentally and physically. Taking veterans and chronic pain patients off their pain medications is a death sentence. Stop the lies and stand up for veterans and pain patients. They all deserve better than to suffer until their death. (860)
- Nothing surprising in this study. I don't know anyone living in chronic pain who can take a long walk. That's unrealistic. And going to a movie or out to dinner is not possible, sitting too long or in uncomfortable chairs. (859)
- My partner had terrible pain during cancer treatment. Nurse navigator was positive we were taking it for drugs. Turned out the Rituximab caused acute liver injury. He died of liver failure a few years later. It was liver pain the whole time. The nurse was wrong. (858)
- You mentioned “I'm being tapered down too.” Many, if not most of us have been tapered or cut off unfortunately. Losing QOL and function sucks. There's no doubt about it. (857)
- 92% of pain medicine specialists said that they have been required to submit a prior authorization request for non-opioid pain care. Physicians and their staff spend hours per day on such requests. 72% of pain medicine specialists said that they, or their patients, have been required to reduce the quantity or dose of medication they have prescribed. (856)

- I am being forced tapered. I asked why they were doing this, because they never had a problem with me and they said they needed to get me to a safer level. This is unethical, immoral and medical malpractice. It is cruel. (855)
- I've found you need a lawyer, lots of patience and the ability to get through withdrawals without any help. I couldn't function correctly, but did ask the question why me, often while in tears hurting like no tomorrow. The doctors are scared of losing their license. Dr. Kline had balls big enough to follow through for those of us that have been living through hell. I'm lucky to be alive and if the news says you're an addict, then you must, according to most. They ruined my relationships with my family and friends. (853)
- When I was cut off, I was offered illicit drugs and I never once took them. I suffered horribly but I feared the poisonous drugs from the streets. I was on a high dose of fentanyl patches for over 15 years and I never had an issue. (852)
- I was prescribed Narcan via the pharmacy but then was taken off. I was told directly that current medical would not take me as a patient after 25 years of controlled dosages. (851)
- I've been lying here in searing horrible pain and other ailments day and night for 3+ years. How ironic that if I was an addict, I would not be in pain. (850)
- My brother is terrified to find a PM outside of the VA. The VA won't allow his current PM to appropriately treat his pain, even with new findings that he messed his back up even more in an accident and currently has a spine infection. (849)
- I have been on Klonopin for over 25 years due to severe tremors. I am fortunate that my pain doctor took over prescribing from my psychiatrist, who honestly didn't care. However my pain doctor keeps decreasing my dosage. Now I can barely write. (848)
- I was treated very rudely by the orthopedic surgeon for no lateral knee replacements. My knees are bone on bone, zero cartilage left. He said I'm taking high dosage of opioids and that would cause me to be a risk for infection during surgery. He wants me to taper down before surgery. (847)
- My primary prescribes me pain meds. I only take one per day. They want me off Valium, which I only take one per day. Ugh! (846)
- I was on codeine on and off for over 30 years. Initially I was allowed refills. When that was no longer permitted, my doctor gave me a new prescription each and every month for 120 pills. My family doctor wrote a prescription for 120 pills but the pharmacy would only fill a 7-day supply. We should all ban together to petition the FDA or CDC to change the guidelines. (845)
- The pharmacist, at her local Rite Aid Pharmacy in California, had berated her for her history of opioid prescriptions, then told her to come back later. She left without the refill, feeling that she was being treated like a criminal. She is the collateral damage of the opioid epidemic. About 17,000 people die each year in the US from a prescription opioid overdose's 50 million American suffer from chronic pain 1/3 of the adult population -- including 20 million who have what is called high-impact chronic pain, or pain that frequently limits their daily life. (844)
- What do you do when you're having a bad pain day? I've been going between forcing myself to do something small, like the dishes, because it feels like a huge win. I am sick of spending the day in bed. Some days after I've tried all the OTC junk, I cry. (842)
- What's wrong with treating acute chronic pain? The longer you go on with untreated pain, the more perpetuated the pain becomes, and the more difficult it will be to treat. So if you're treated in 60 to 180 days, your probability of being pain free goes to nearly zero. But if we can get you in the first 30 to 60 days, you might stay pain-free from that particular problem or the rest of your life. (841)

- My dad had 3 back surgeries and is on codeine for pain. His work is stressful. His doctor retired and the new doctor put him on Suboxone (good for his pain), but cut his Xanax without tapering. I've tried a substitute for pain, and the anxiety was 10 times worse on it. I'm scared anxiety/stress/panic attack will kill him. (834)
- The doctor accused me of trying to get more meds when he's only giving me 20 at a time and told me to slow taper. I told him there's a guideline on how to taper that he should follow. He told me he could do whatever he wanted to me. I've never been so frightened by a doctor's words. (833)
- I had been at the same dose for over 5 years with no problems. I begged. They gave me a script for 10 tabs 2 mg for a month (of the stuff they do not script) and sent me on my way. The withdrawal ruined me. Next month I told him how I wasn't doing well at all, but was told again they don't script it. (832)
- I went to sooo many places and most said they only took/took cancer patients. That is not the definition. Keep looking, it's a hassle of a fight and I know it well. Honestly, I have Medicare and it's nearly worthless. I still pay for my care and my scripts. (887)
- I am in constant agony. I don't know how much longer I can go on. My nerves are shot. I'm agitated and feel anxious all the time with no pain relief for multiple pain issues. (Fibro, RA, OA, 2 blown shoulders). I can't afford to take off work and my doc says the stress of denied pain relief is killing CPPs slowly as it's wearing out every organ in our bodies. (886)
- Medicare is joining in punishing pain patients and I should have known. I'm becoming a casualty without compassion. I'm on the front line and I am honored to serve. (885)
- How can I convince my pain doctor that the Guidelines have been so mishandled? I'm in trouble now, after a long battle. In a urine screen I showed up positive for Tramadol, which was obtained from a country where it's unregulated. They prescribed it to me, but my future is very uncertain. I've never been in any trouble in a decade of living in TX, but after 3 years of below 90mme I am losing my resolve and ability to manage. (884)
- First time a doctor said "it's all in your head", I said "Great, how do you get it out? Do you refer? Is there an organization?" His eyes grew at each question until he backed into the door and fled. I was confused, but finally I realized and yelled, "Oh, you were insulting me not diagnosing me." (883)
- My son has chronic pancreatitis. He is 40 years old and has had it for 11 years. He went to 3 ER's about a week ago and could not get help. He was in agonizing pain. The 3rd ER called the police and he spent the night in jail in pain. They charged him with disorderly conduct. (882)
- I had fibromyalgia for years. Opiates were the only thing that helped. I understand why pain patients commit suicide. If I had to suffer at that level of pain without opiates, life wouldn't be worth living. (881)
- I never understood how they could say one type of pain was worse than another. For example, things like CRPS and trigeminal neuralgia are considered "suicide" pain conditions. They rank higher than cancer on pain scales. (880)
- The stigma is the worst. No one in the chronic pain community should feel shame. Chronic pain is debilitating enough without the stress of "what does this pharmacist or other health care professional think of me?" (879)
- She says she can't get into pain management and is getting 60mme from an internal medical doctor. I asked her why she can't get into pain management to see if they could help, although results may not change from 60mme, but it is worth a try. (878)
- I am actually not a good driver if I am in uncontrolled pain. I have Fibromyalgia. My whole body hums in pain. Lyrica works but at \$1,000 a month, it's not possible. I barely have a social life at all due to pain and

fatigue. Even when I fall asleep, I dream that I'm in pain and wake up with the same pain. When is life going to get better? Why does everything in my life have to be either pain, broken, defective, dysfunctional or wrong? (1012)

- Chronic pain presents differently than acute pain. Doctors should know this, but yet we're still put in this position. We learn to hide pain for various reasons and just to survive. (1013)
- CPP's became a profit center. We get charged for the tox screen at every appointment, a copay to see a doctor for PA or FPN visits, \$25 per prior authorized fluoroscopic injections, unnecessary x rays/MRIs and then to sign documents that are no more a contract than my Toyota is a Porsche. The CPP's are bled dry. (1014)
- I cannot get off opioid medication. With it, my life is livable. I want to live, and without it I will die. Either my heart will give out or a 00 buckshot from a shotgun to the chest, into the heart. The pain will become unbearable. I will do anything to prove PROP has hurt so many. (1015)
- With Arachnoiditis, I am in severe pain 24 hours a day, seven days a week, and I'm not being treated well enough to help this pain. I am at my wits end and don't know what else to do anymore. (1016)
- I suffer from a spinal cord injury. The PROP/CDC argument that cancer pain is different from non-cancer pain was shot down by FDA scientists after careful review FDA-2012-O-0818. (893)
- How many hours do you guys sleep? I cannot sleep at night and usually sleep during the day. I'm literally bed ridden. I think I've been up now for 60 hours, because of the current flare I'm in. I hate that my family sees me this way. This is torture we didn't ask for. We did not ask for this pain. (891)
- What's it going to take for the FDA and etc. to stop this madness? I was cut off 10 months ago. I was a responsible patient and never diverted, for the last 10 years. I was on the same milligram and the same quantity of medications for that period. I finally asked for an increase, and was suddenly cut off of all my medications, without a discussion. I'm planning the end of my life. I cannot live in this bed much longer. Horrible. (890)
- I was told by palliative care: "You don't have cancer, so I can't take your case, until all your doctors have given up". On their website it states "they are to manage complex symptoms, to improve quality of life, while still getting treatment." (889)
- It's a shame. The fine men and women that went to war for our freedom, but US veterans can't get relief from the trauma and permanent injuries afterwards. How sick and sad. (898)
- I have medical trauma from the years of gas lighting, I suffered in the conventional medical system, as a nurse and as a chronic pain patient. It's no wonder people can't get better. Such a scam. (897)
- This prescribing "2 Tylenol and call me in the morning" for chronic pain isn't working. When every minute, every breath, every move you make hurts you and you need more than a Tylenol. We're not addicts. Quality of life matters. (1017)
- 61% of pain patients have debilitating anxiety (PTSD) before going to the pharmacy or doctor's office. (895)
- Doctors get kickbacks for monthly urine tests. My pain story went bad, since the 2016 CDC Guidelines came out. I've been a chronic pain patient for 15 years, at over 1300 MME and zero problems. The past 5 years have been one long problem, and nothing makes sense. (894)
- Being a CPP and living in chronic intractable pain is so difficult, more difficult than you'd assume or think. It makes you crazy. Also being in pain like I am, almost all my life (since I've been 7 years old) is even harder. So don't tell me how to act. I'm just trying to live.... seriously. (893)

- I used to be able to live, go to school, have a career, go out, clean, etc. I was going to have kids and a life. Now I'm living day to day. I hate that my pain doctor thinks force tapering is working, because I never run out of pills or pain patches. I don't because I can't. Don't they get that? (892)
- I want my therapeutic dose back. I'm not even close and still weaning, even though I'm always in chronic pain. I also keep having massive painful surgeries and infections. Why do I have to wean? It's going to kill me eventually either by me having a heart attack or stress. (891)
- They think if you're on too many pain meds, you are an addict. How do I look better? Can you feel what I feel? I'm getting used to suffering more and more. I've been a CCP for almost all my life and I handle it well. Also, you can't act like you feel all the time. I want to be taken seriously. (890)
- It's horrible. It's not right. My father is in severe pain. He was prescribed oxycodone since 1995, but had it taken away in 2019. He now goes to a methadone clinic, because it's his only option. He hates how methadone makes him feel. He feels dead inside. He was a completely different person on his old pain meds. (889)
- As many know, it is extremely hard to get doctors to take new patients. I travel 6 hours round trip to get to my doctor. I got into palliative care in NY 2 months prior to the pandemic. My doctor had to join a larger hospital. She's now going into research. The 7th doctor in 7 years is gone. I fear there will be no more doctors to take on the patients needing pain doctors. (888)
- I'm trying to live as normal of a life as possible, and take care of my family, like everyone else. I don't get high from opiates, and want the option because they work. NSAIDs destroyed my mom's heart and stomach. I won't take them, and acetaminophen does nothing for me. (901)
- I have 30 years of documented back injuries, 3 slipped discs, 4 facet joints degenerative, 3 compressed discs in my neck, arthritis and bone spurs in my entire spine. I was told to only take aspirin, because of my hypertension. Every 2 months I have cancer biopsies now. (902)
- I was on Vicodin, quantity 240 / 5 mg a month, with 5 refills (never took that amount). I owned a business, worked 60 hours a week, a single mom and church on Sundays. Obviously I wasn't addicted/abusing my medication. Now I'm disabled on SSD since 2012, the year my meds stopped. I live in pain and stay home. (900)
- The addiction problems are all a bunch of B.S that the FDA and the CDC are spreading. It's despicable. (899)
- I went in for a surgery consultation a couple weeks ago for an infected abdominal mass. After one attempt at surgery its growing endometriosis outside of my naval. My doctor said if he cuts through the muscle and fascia, he would not prescribe any pain meds. That sounds awfully painful. He said to me, "Pain, that's life." (898)
- This mess is ridiculous. The government needs to get out of the doctor's office and stop ruining the doctor / patient relationship. People are to blind up see this akin to Nazi-ism. (897)
- Most people don't have a clue just how soul crushing it is to only have the ability to do minor tasks, only a couple days out of each month. Most of the time we, as chronic pain patients, feel useless. I expected to feel useless at some point, I just thought I'd be 90 not 55. (1018)
- I can put on my own bra. When my wrists are bad, it can take half an hour before my hands recover enough to use them again. Only then can I do snaps, buttons and laces. (895)
- The people who are making the decisions for chronic pain patients are not the ones dealing with chronic pain, which will rob you of your ability to function and quality of life. As they say, "You don't get it, until you get it." (894)

- I was on pain meds for 14 years, when I suddenly had them stripped away, right after my C-ADR surgery. It was hell. Uncontrolled post op pain and with d's at the same time. I literally shattered 3 teeth because of the suffering. (893)
- I made an appointment with a pain management doctor today. My family thinks I should be excited at the prospect of some kind of relief, but it just feels like impending doom. Which of the thousands of torturous ways will they hurt me this time? (892)
- I have been on pain meds for almost 16 years and never had a problem. One doctor decreased my meds from 3x per day to 1x per day, because I refused to keep having spinal injections. Now I am starting to see a trend with the new doctor I have. If you don't subject to the injections, you won't get pain meds. (891)
- I went to see a new rheumatologist. The first words out of her mouth was "You know we don't prescribe narcotics?" I said that I was over that b.s, because I know they are not concerned about pain, my quality of life or wellbeing. (877)
- Makes you wonder how doctors can continue to watch their patients deteriorate so much and so badly. Yet they still don't get together and fight for us or their careers in unison. They are gradually giving up their power out of fear, much the same as we as US citizens are doing, in increments. (976)
- I get yelled at and treated like I'm a drug seeker. It's like they put their fingers in their ears and not listen or a straight up "I know you have chronic pain and won't prescribe any controlled substances." It doesn't matter if you try to have a normal conversation with your doctor, they no longer are our doctor, and the government is. (975)
- When insurance forced me to switch PCP's, the new one refused to continue Prozac and Xanax, after years of my previous primary treatment for my panic disorder/anxiety.. The doctor did not try to replace my medications. Instead she guilted me into buying \$350 of vitamins from her office. (974)
- Try 30 years of pain control. Now they've robbed me of living a somewhat normal existence. Not only did they cut pain medicine, but they stopped prescribing all my other medications. The DEA knows this. They've tracked me for decades. Most doctors know this and buckle under the threats of losing a license from the DEA or state medical boards. WOW! (972)
- When you get down to it, patients who've done well on opioids for years and are now forced into procedures, are also a product of board of medicine, state laws and the DEA. I was also given the option to take 50mme or Suboxone, even though state law is 90mme. Legacy patients were to be exempt from the 2016 CDC Guidelines, but my meds were slashed. (970)
- A Kaiser MD told me I didn't really want to help myself when I declined surgery vs. taking pain medicine, which was working fine concerning my pain. Also, after a drug screen showed I wasn't using other drugs, which I told her I wasn't taking other medications or illicit drugs, the same MD replied "People lie." (961)
- My first pain specialist told me I was rude, passive aggressive, manipulative and I tried to bargain. I asked my family, who came with me, what was said. They said "you weren't bargaining, you were begging him," after 2 weeks of stripped medication. I need help so badly. (962)
- I look sick but not too sick. I am currently off Rx opioids, getting painful DMSO treatments, allergic to steroids/nsaids/aleve/etc., and the induced hyperemesis. 36 pounds down in 6 weeks without trying. I go to the Mayo Clinic in June for 7-10 days, without any medications. These doctors aren't providing any options that work to relieve my pain. (963)
- I was on 270mme of morphine a day. I was doing fine for 9 years. Then I was told that it is too high of pain medications. Not for me. It was my maintenance dose, and constipation was the only problem or side effect. (964)

- Multidiscipline TX plans and having a team when you live with pain is best practice. Forcing patients who are desperate to agree to ineffective TX, at great personal cost, so the HCP can avoid RXing opioids, which are safe and effective for tens of millions. What's wrong with all of this? (966)
- What happened to my poor sick mother, half dead with 3 kinds of cancer, driving monthly to take a urine test at 74 years old and 89 pounds? How is that doctoring? She is one of many millions suffering this fate. (968)
- Why don't they teach the benefit, rather necessity of pain medicine in post op recovery, especially with back surgery? Pain meds prevent nerve and muscle irritation and aid healing and blood flow. I've been a chronic pain patient since the 90's and I understand the need for pain relief. (969)
- My first GP in CA, on seeing I had been prescribed low dose Hydrocodone for 2 years was responsible for managing my pain, when nothing else worked. They wrote in my chart that I was likely an "addict" and shared with me two books about the horrors of opioid addiction. I fired her. (951)
- My last neurosurgeon told me I had Arachnoiditis and there was nothing he could do for my pain. He told me "I should just think about something else". He shared with me that he used to do brain surgery on kids and ONLY gave them Tylenol and that they were "just fine." (952)
- I am a 67 year old woman who has a history of congenital spinal deformities, total body CRPS and a history -- dating back to my early 20's -- of Adhesive Arachnoiditis. I've lived in a nursing facility for 28 years. My pain specialist told me that the law states that they can't prescribe no more than an oral equivalent of 90mme of morphine at one dispensing. Is there really such a law stating this state or federally? (953)
- Some doctors swear taking your daily dose of morphine can cause you to OD. Where they get this information is a mystery, but I have had VA doctors tell me that this can happen and it's a true statement. After 9 years, being on pain medications daily, I have serious doubts about this claim. (954)
- I was never treated with one ounce of compassion. I've always been treated with extreme indifference and downright disdain. Why are they pain management doctors if they hate us? It's astounding what they get away with. I'm a responsible adult, I'm not lying, and I'm dying. (955)
- I had decent relief for 20 years with LTOT. I was a wife, mother, housekeeper and gardener, a friend and a lover. I was force tapered off my pain medications 5 years ago. Now I'm none of those anymore, and now have high blood pressure and high cholesterol. (956)
- I was called an addict straight to my face by a pain clinic doctor after losing my PCP for nearly ten years. He had abandoned his pain patients because of DEA harassment. (957)
- I was told I'm a nurse, therefore I know too much. No, I educated myself on my illness and I was correct. My new doctor told me she'd only take me if I weaned off my opiates. I told her I had SCS inserted and was willing to try. She said you will wean and you won't go back up. I dropped Ms04 60 mg x po bid to Ms04 15 mg po bid. Told her I can't go any lower. So far I've been left alone. Norco 10/325 po bid breakthrough pain taken as daily not prn now. (958)
- Just tell me where I can live, where people have a heart. That will treat veterans that were blown up with compassion. The VA is useless. Medicare is just as bad. What the f***k did I serve for? Why the f***k was I tortured to be accepted into special forces, then to only to be screwed over by the America I fought for? This is not freedom! This is not the America I fought for! (959)
- I feel so guilty about making my fiancé live through this with me. He met me before my accident. I used to have so much fun. I had so much energy, I loved going out. Then I got run over by a truck. Everything changed. I feel like I catfished him. (950)

- My ex neurologist told me that he made no money off patients like me. Also, a student at the psychology office that did my spinal cord stem evaluation said I had a personality disorder. My regular psychologist disputed that, but the neurologist put it in the chart anyway. (940)
- I was referred to the University Pain Clinic, because I have CRPS. I wanted ketamine infusions. They didn't examine me and basically said there was nothing wrong with me. When I went to another pain clinic, the MD said I would have to be a great actress to fake having CRPS. (941)
- I fired a pain doctor from my care who tried to deny me a prescription for Valium in order to get an MRI of my spine. I'm claustrophobic. It showed up in the following month's urine test. The doctor was a royal bitch. (942)
- After being denied proper pain medications, my best friend was told by his doctor, "If the pain is really that bad, you could always just kill yourself." Likely the doctor was being sarcastic and it was a bit of dark humor. I will never know. Because my best friend is now dead. He killed himself because the pain was really that bad. (943)
- What my neurosurgeon said to me: "That doesn't happen to real people. I can be your cheerleader, but not an active member of your healthcare team. We don't treat pain, we're just spine doctors. Pain management is a misnomer." I prescribe a lot of opioids, and whatever you have, isn't what real pain looks like. (944)
- What a doctor said to me: Sorry you were referred to us, but stop coming here. We can't help you and I don't know who can." Then my doctor was talking about me to students saying, "This is a case where we won't intervene since he's been in pain for so long without an answer. Opioids cause more pain than they alleviate pain." (945)
- I told my doctor I was suffering, even suicidal at 8 days with no pain meds. He ignored my calls for 6 days. Finally he called and I told him that I've resorted to Brandy to relieve my pain. He lectured me, called me reckless, and threatened to discharge me. He then put me on a daily dispensing of pain medications with pee tests. He didn't trust me. (946)
- I was always the first one to jump up and to help anyone. After being taken off my proper pain medication therapy, I have a hard time helping myself. I guess it's hard for doctors to believe that medication can make that much of a difference. Unfortunately it does. (948)
- I was given a refill for a 5 day supply of pain medication, because I had some left after 14 days. I absolutely insisted my doctor do something, since he said injections were a poor option, SSRI caused massive GI upset and NSAIDS caused bleeding. What else was there? He agreed, on the one condition, that I never ask for a refill of pain medications again. (949)
- A doctor told me "everyone who takes opioids gets addicted." Then he recommended another doctor in the clinic who was willing to prescribe, but only about 1/3 of what I need. She left the clinic, and now I have no pain meds. I can't even walk a block anymore. (939)
- After my doctor of 25 years died, the first doctor I tried calling, they called me a liar when I said I was never drug tested for Xanax. She then said I probably had dementia from Xanax, which I don't have. I told them my prior doctor knew I wasn't a drug addict. She said "no one can tell if a person is a drug addict." (931)
- One pain doctor said my MRI was "not bad...not bad at all" and that he had chronic shoulder pain that he dealt with, therefore I could deal with my pain. He also diagnosed me with hyperalgesia after a 10 minute consult. (932)
- "Taking pain medicine interferes with your body's own natural pain killers." My orthopedic surgeon who did a total knee replacement, to his credit, prescribed me pain medication, but the pharmacy (Walmart) refused to fill it. I had to take an old medicine that was too weak and I suffered a lot. (933)

- No one pays attention to rank and file. A group of scientists called “Spider“ wrote a letter about Dr. Andrew Kolodny. They said that he was running around in the CDC, like he was in charge. Then the 2016 CDC Guideline drafting occurred at the same time as Zika virus. Both were epic failures. (935)
- “You seem like a smart educated person, don’t you understand you’re addicted?” That’s how my last appointment with my new pain management specialist started. I was referred to an addiction specialist, not a pain management provider. (936)
- It’s been a little over two years since my forced tapering began. The pain has only gotten worse. I think this is a case of gas lighting. Just keep lying; they’ll eventually believe it’s true. (937)
- We all share some common traits: fatigue, isolating ourselves, mood swings, anger, often lying in bed or sitting in the recliner all day. I’m unable to complete tasks. When my pain is treated, I could accomplish so much. I could shower, clean the house, cook meals and mow the lawn. (938)
- The nurse stated, “Since we won’t be seeing you again,” they literally escorted me out the backdoor like trash. What were they afraid of? That I’d make a scene in the waiting room area? This is the treatment I received after I admitted that they were not treating my pain and that was causing my health issues, and this was my reason for being there. They don’t treat pain. Having pain obviously isn’t a reason to go to the doctor. (930)
- I was taken by ambulance to the emergency room and I spent 9 hours screaming in pain. My husband gave the nurses my med list. When they saw I was prescribed opioids, suddenly all my care stopped. The nurse told me to stop screaming, that I was upsetting the other patients. They told me that I couldn’t possibly hurt that bad. The ultrasound showed an ovarian torsion; I lost the ovary. (921)
- I overheard the PA at my pain management doctor’s office laughing out loud, “She wants more! Hahahaha!” She was referring to another elderly patient. I felt sick to my stomach. They hurt me, and I knew they were hurting others. I found one patient on the ground outside their office crying. She could barely walk. (922)
- I was told, “Leave the ER now, while I was projectile vomiting and in a diaphoretic sweat, or I’ll have you arrested.” (923)
- I’ve been told to get more surgeries, instead of taking opioids. I can’t get any more surgeries, not yet anyway. How am I supposed to make a surgeon perform surgery, if it is not needed yet? (924)
- After getting my meds at Walgreens for 17 years, I had a young girl pharmacist literally come from behind the counter and screech, “You can’t get that here anymore.” (925)
- I was in severe abdominal pain (hx of endo) and went to the hospital for immediate relief, since I could hardly move. I was asked four times, if I could be pregnant, despite explaining that I’m a lesbian and there was no chance. Each and every time. I still did not receive pain meds or an apology. (926)
- The doctor said to “open up and say ah.” Then she said “Oh, you can’t take pain meds because your throat is too tiny and you will die in your sleep.” Then she walked out in the middle of the appointment, refusing to explain herself. (928)
- I have CRPS from a workplace assault and when my acute pain isn’t managed, my CRPS flares. I was told the surgeon would prescribe the quantity of pain medication for two (2) pills total. The explanation that was given to me, was the surgeon would be in trouble with the DEA if he prescribed more pain meds. (929)
- When I first went to pain management, it was scary and sad to sit and listen to so many stories. I always come out of the appointment thinking two things: maybe my situation isn’t so bad, and please let me leave this God awful depressing place. (920)

- Being cut off pain med makes you a not so nice person sometimes. I'm lucky my husband of 25 years still loves me. (916)
- I had a manager spread a rumor that I was addicted to painkillers, even after knowing I was in a car accident and had emergency surgery. Two other coworkers tried to give me an intervention. It was disgusting. (917)
- So now I am back to taking my usual medications without any problems whatsoever. Just as I was before. Why the heck did I have to suffer like that? It was this one bad pain management doctor. I have all new doctors willing to prescribe the proper medications that I need, and I am getting stronger every day. But I'm afraid I will never be the same. Being force tapered has caused new health issues that haven't gone away, even though I'm back on my medications. It's caused me to have a constant fear that I will lose my new doctors. (918)
- I had a pain doctor say he only prescribes opioids to cancer patients, because they are going to die anyway. My mom and I sat there in shock for a minute. (919)
- I'm thankful that I get "some medicine" every month. But like most patients, it was reduced drastically. I've been on opiates for chronic posttraumatic pain for many years without a problem, until PROP, CDC issues. (915)
- My mommy who had MS passed away from secondary health conditions, due to not getting adequate treatment for the last 11 years of her life. She suffered terribly and unnecessarily for so many years, after getting adequate treatment for the first part of her illness. (914)
- Here in California you can go outside, water your pot plants naked while smoking a joint, drinking your 4th glass of Tequila, tripping balls on magic mushrooms, after getting clean needles downtown. But you can't get legal, controlled pain meds from your doctor for a devastating illness/injury. (913)
- My doctor has cut down my pain medication, until I'm bedridden and suicidal. He's still not satisfied with that and he now wants to cut my medications down until I actually commit suicide, because the stress of the last forced tapers caused me to develop interstitial cystitis, psoriasis and psoriatic arthritis. It also flared up my other autoimmune diseases to the point that 2xs the dose of Humira, isn't able to get them back into remission. I don't drive now because I have uncontrolled pain and muscle spasms. I never know when my arms and legs will become so painful that I can't use them. If I want to go out of the house, a family member drives me. So because this war on intelligence and sanity took away my human rights to not be tortured, that's a red flag. (916)
- If I were ever able to find a doctor to treat me, I would definitely be red flagged, as I cannot afford health insurance and I would have to pay cash. Nobody seems to want to help the uninsured. (912)
- My pharmacist has actually called my doctor, questioning him on the dose and mg's he prescribed to me, causing my doctor to rethink or change my scripts out of fear. They have also refused to order in a med my doctor requested for me. (911)
- The assumption is, anyone that takes pain medication, has OUD and is implied by this statement and "when clinically indicated" still leaves patient wide open to being denied pain care because all a doctor has to do is say it is not clinically indicated (910)
- Last week my pharmacist told me my script would be ready in 2 hours. When I showed up, they said my insurance company refused the script for a PA. I called Cigna and they said, "No that's not what we said." They only needed to call them to confirm the dose. Strange. (909)
- I can't even get my doctors to prescribe Tramadol or Ultracet anymore. Back in 2012-2015 I would be prescribed it whenever I needed it. Back in the day, I was prescribed enough painkillers to get me through horrific monthly cramps. Without them, it was hard to endure 4-5 days of hell. (906)

- I was forced off my pain meds and put on the Suboxone strips. I hate it. They don't work at all on my pain. All I do now is mostly sleep. (905)
- The last surgical consult presented pharmacogenetics testing, showing I do not metabolize codeine or derivatives. I was not going to be prescribed any postoperative pain medication until I explained, acute pain is different from chronic pain, and I must have post-operative pain relief. (904)
- Three years I've been on medicines that I don't metabolize. They finally stopped prescribing them, but have given me nothing to replace them. They just took me off the medications, and didn't bother to find another medication that works. I keep being refused the medications I know that work, for a variety of reasons. The doctors state they can't prescribe them because of the CDC guidelines. This is B.S. (903)
- Down from two years ago, to only 10% of my regular dose of pain medications. I can't work any longer. I was a landscaper. I used power tools, chainsaws and everything in between. This shows that prescribing opioids long term is beneficial for a lot of folks. It helped me for around 20 years. I was on a steady dose for around 19 years. I wish I could be prescribed the level of pain medications I used to be on. (902)
- Last week I visited my primary care doctor and they were switching to a new system. My nurse, whom I've known for over a decade, was asking me some rather intrusive questions that had nothing to do with my health or reason for seeing the doctor. I immediately caught on, and told her flat out, that I will not answer those questions (what kind of house do I have? Do I own guns? Do I have pets? Do I smoke? Do I drink alcohol? Do I use drugs?) This is nobody's business but my own. Doctor/patient confidentiality is a thing of the past. It's all on the computer now. Be very careful what you share about yourself. (901)
- I am scared to death that everyday my pain medicine will be taken from me. I wouldn't want to live without my pain meds. I can't face the fact of living the next 20-30 years and having no quality of life, without my medications. (900)
- The US prescribes twice the opiate pain medicine as in the UK, so our addiction rate is twice as high. Nope, it's the same. Because US doctors don't allow refills, they have to write more prescriptions. (899)
- I'm thinking of calling an independent neurologist and pain specialist. I'm going to call their office tomorrow to see if they can help. I'm serious, I'm having a really rough time. I spent two hours on a crisis line today. My therapist is on maternity leave. (898)
- I feel suicidal every day, multiple times. I'm 60 and a widower of a veteran. Seven months ago I was cut off my Oxycodone, after 10 years of responsibly taking my meds. This is ridiculous. Northeastern, Ohio is the land of Opioid Phobia! (897)
- I have been with the same pain clinic for 15 years and was discharged due to a medication not being in my system. This was after reducing my meds over 70%. I never asked for early refills. I never took more than I was originally prescribed, and knew that if I ran out, I would pay for it. I knew that they wanted me out of the clinic. The new doctor didn't like the fact that I was honest with her every visit. She wanted me to just go along with what they were doing. Life is hell now. (896)
- As a chronic pain patient, the reason so many of us are killing ourselves is because physicians, PA's, nurses and pharmacists do not believe that we are in as much pain as we say we are. They also say that we are drug seeking. I have CRPS. When I shattered my leg 12 years ago and had surgery, a nurse told me I needed so much more medication, because I must have been a drug abuser in my younger days. I was not. I have had a doctor refuse to examine me, saying that I was drug seeking, only to find out I had 5 broken bones in my foot. My own pain management doctor hasn't increased my medication in over 5 years. I am bed ridden and in terrible pain. He is afraid of losing his license. I am only alive for my daughter. And you ask us why we are suicidal? We are under medicated now. The CDC guidelines are killing those of us who wouldn't dream of misusing our meds. (854)

- I'd like to post my daughter's comments. She suffers from Trigeminal Neuralgia Type 2, which means is on both sides of her head and inoperable. It is considered to be the worst pain known to man. Up to 20 percent of those who suffer from it, that and are not treated properly, will commit suicide. She's been treated by a good neurologist, but has side effects from the meds. (1010)
- RSD; intractable pain; living in hell; no quality of life. No treatments for my pain; none of my treating physicians are addressing it at all. So many trauma surgeries to my afflicted limb, bone infarction and my surgeon won't even prescribe something to relieve my pain. I'm laying here without a knee in my limb. Not looking forward to the next surgery. I am scared. (1011)
- Ehlers-Danlos Syndrome. I had been functional on a minimum dose of Norco for years, then the "opioid crisis" occurred and I was taken off the Norco and put on Topamax, which doesn't help and leaves me bedridden a lot of the time. I am now applying for disability, because of being in pain constantly. (977)
- I am 27 years old, will turn 28 years old this September, and I have Complex Regional Pain Syndrome and Fibromyalgia. I can't lift what I once did. I require extra help at home. I'm getting adequate pain treatment right now. I worry daily that I will lose my pain treatment, which means I will have no life. (978)
- I have EDS. Imagine popping popcorn, that's what it sounds like every day to me... Never knowing when I will have a subluxation or full on dislocation. I have to be careful about what I do. Duke Orthopedics is doing great at keeping me walking and in the least restrictive braces as possible. Duke Pain Clinic is also doing great keeping the pain under control. I have had RSDS (CRPS) for 20 years due to a complication of a knee surgery, which spread to both legs and back quickly. In addition, I have a very severe hyper-inflammatory response to any invasive procedures (even dental) anywhere on the body, so I guess you could say that the RSDS is in my entire body. I am in bed all the time normally, but when I am up, my legs start swelling and my pain gradually increases to the point that 3 hours of sitting is extremely painful (I have pain while sitting in bed too, but it's much less than sitting in the W/Cc, until early evening, then it becomes more severe). I have an intense burning with a deep aching -- to the bone in my legs, feet and back, plus neuropathy in both legs/feet. Too many associated symptoms to list. I have been on a w/c for 19 years, due to injuries to the spinal cord. I then had 2 spinal nerve roots, after complications during 2 procedures. My first trial, SCS, resulted in a lead going into my spinal cord, then radio-frequency lesioning one month later. Both were done by the same MD that had no experience with this procedure. He destroyed 2 nerve roots at L4 and L5. Plus, I have arthritis in the spine, hips, knee, wrists and elbows. (979)
- I have Arnold Chiari Malformation I and pinhole. It is an incurable, painful, progressive disease. It is extremely fickle, and the pain depends on the day. There are about 25 symptoms that can go with it. Currently, I'm not being treated sufficiently, despite being treated successfully for 16 years prior. Thanks 2016 CDC Guidelines on Opiates! (981)
- Ankylosing Spondylitis, DDD, DJD, Severe Osteoarthritis, Phantom Limb Pain, Peripheral Neuropathy, IBS-D, Fibromyalgia. I was cut off cold turkey after 6 years of effective opioid therapy, due to the release of the 2016 CDC guidelines. I'm living in a rural area in Wyoming. I have no access to a doctor. (983)
- Trigeminal Neuralgia. It's like hot lightning bolts shooting through my face. I had surgery, but it got worse. Nothing stops the intense, drop to my knees pain. Nothing, except pain medication. Pain meds take the edge off just enough to deal with it. (984)
- I have late stage Lyme disease that causes painful migraines, debilitating pain, organ damage and there's no medications to cure it. Pain medication is the only thing that makes life bearable. (985)
- I got CRPS following an accident that damaged the structure of both my feet and one ankle. I will never be pain free again despite multiple surgeries, injections, pt (very difficult to accept). BP did drop 20 points when pain medication stabilized the pain at an average of 5 instead of 7 out of 10. (987)

- I have Ehlers Danlos Syndrome Type 3; the main symptom is chronic pain. All movement causes pain in my legs, arms, feet, hands and neck. Burning pain in my back is a constant problem. Narcotic therapy changed my life. Now my medications are reduced by 75%. I'm in so much pain every day. (988)
- Sarcoidosis with Hashimoto's. It's tiring always staying one step ahead of complications. Painful during flare ups or weather related changes. Balancing out the replacement medication levels can be difficult. For the most part treated sufficiently, except during complications. (989)
- I have stiff person's disease. The pain caused by muscle cramping is so bad that it breaks my bones. It is terrifying and nauseating. The startle reflex I have causes horrific pain, because it also causes cramps. The severe anxiety I have with it causes cramps and pain. My health issues are currently not treated correctly because I need pain medication during flares, which I'm not always prescribed during flares.
- Onycho Osteodysplasia. A hereditary syndrome that affected my joint development. It affects my kidneys, eyes, spine and connective tissue with chronic subluxations. AKA Nail-Patella Syndrome. Painful and exhausting. I'm not being treated sufficiently to live independently, due to lack of pain medication. Help. (991)
- Neuropathy runs in my family. I'm disabled from an on sight accident while at my job, that caused 2 herniated discs and one bulging disc. I've been treated with pain meds, and have spent many nights and weeks in hospital, due to pain. Thank God for meds. It's been my lifeline. (992)
- Degenerative Spine Disorder. I don't know if it's rare, but it is painful. The last 6 years I've had surgery to repair the surgery from the year before. My spine won't heal properly. I have crippling pain in my back, hips, legs and feet. I was treated well until 2016, when the CDC Guidelines came out. I had my 5th back operation on August 27th. I pray I'll get continued pain medications so I can heal correctly and have a quality of life. (994)
- RA equals no life of my own anymore. This disease owns me. My insurance company does too, and most of the doctors who decide my treatments care mostly about themselves, their DEA licenses and their convenience. My health does not matter to them. (995)
- I have Myalgia Encephalomyelitis, POTS, CVID and Inflammatory Arthritis. I have constant pain in my bones, muscles, nerves along with 20+ symptoms that worsens with little physical/mental exertion. When I have access to pain medication, life is manageable. When I don't, I often wish God would take me to heaven. (996)
- I have Degenerative Discs Disease and had 5 spinal surgeries. I live in pain every day. It has ruined my life. My doctor is wonderful and I am treated well. Nerve pain is difficult to treat. I know it's rare for patients like myself to have access to pain medication. I have done so far and I'm thankful. (997)
- I have Lyme disease, Degenerative Disc Disease, Chiari Malformation and Hashimotos. These are just a few of my diseases, which make me live in pain 24 hours a day. I have stopped going to doctors, because they treat me like a crazy person and don't care to help. (999)
- I have Crohn's disease, DDD, Severe Osteoarthritis, Fibromyalgia, Lymphedema, and Neuropathy in my legs and had a partial traumatic amputation of my left foot at age 4. It's very painful to walk and I must use a walker or wheelchair. It feels like my bones will pierce through my skin and I have a hot poker pain in my back. It feels like I am invisible and no one wants to address my pain. It seems uncomfortable for them. I have not been effectively treated since forced tapers started in 2016. (1000)
- I have Gastroparesis and Gastric Paralysis. I am being sufficiently treated. I'm currently stuck on a feeding tube and have abdominal pain every day. I also have Crohn's Disease. Life is hell when I don't have access to pain medications. (1002)

- I have intractable low back pain from an ALIF 360 done 5 years ago. There's scar tissue on nerve roots at two levels. I have DX of AA, Anxiety, Anticholinergic Syndrome, Lumbar Spondylosis, Post Laminectomy Syndrome and Primary Arthritis of the left hip (right already replaced). I have Spinal Stenosis at two levels. Pain is adequately treated after going through Emory neurosurgeon and getting a referral to Atlanta's best pain clinic. I have around the clock trans-dermal patch. I cannot take SSRI, SRI or TCA drugs so I get prescribed stronger pain medications. I know I'm very lucky. (1003)
- Gastroparesis (for my 11 month old daughter); lots of vomiting, abdominal pain, constipation. Yes, being treated sufficiently. (1004)
- Adiposis Dolorosa/Dercum's Disease. This is a rare, extremely, painful disease that most doctors have never even heard of. This disease causes lumps or lipomas to grow all over my body. Some grow just under the skin which feels like you are laying on a bed of marbles. Some are very firm and grow deeper into the muscle pushing on nerves, tendons and ligaments. This disease also causes tissue to swell, it causes bouts of cellulitis, due to the severe swelling. Some of this swollen tissue becomes mounds of hard painful tissue. Again, it is very painful and there is no cure. Right now I am being treated for my pain, but I have already been asked to take a pain cut, so who knows how long that will last. (1005)
- Pancreatitis. Had a major acute attack that nearly killed me. 87 days in the ICU. Feeding tube at home and antibiotics for nearly 6 month after discharge. Many surgeries; loads of scar tissue in abdomen. Have had 1-2 attacks per year and 3-5 hospital stays a year. Average 5 days. With daily pain meds, I've been able to go back to work full time. I've had to change doctors 3 times, to keep pain meds since the 2016 CDC Guideline deal. This doctor is my last hope. They are the last pain doctor in my area. (1006)
- Thoracic Intramedullary Cystic Neoplasm of the spinal cord, T5-9. Intramedullary spinal cord neoplasms are rare. Accounting for about 2-4% of all Central Nervous System tumors. Surgery was successful enough to let me walk again with a cane, instead of being confined to a wheelchair, but they were unable to remove all of the tumor. This caused a compression of the spinal cord, spinal stenosis and arachnoid cysts. I am under medicated, but afraid to ask for a higher dose, because of the current opioid hysteria. I have muscle spasms, but have not been able to find a successful treatment for this. Protein C deficiency and Lupus Ana controlled by Warfarin, rules out many types of anti-inflammatories. (1007)
- Sarcoidosis, pain 24/7. No help from doctors. (1008)
- My doctor is ruining my quality of life by withholding needed pain medications. The end result is that I'll be bed bound, for the rest of my life. (Wife, mother, grandmother with Fibromyalgia) (1012)
- It's not just the pain, it's also the agony and hopelessness of being dismissed, humiliated and ignored by medical personnel. (Stress management coach and mediation teacher with chronic pain) (1013)
- It would be great if we had the right amount of pain meds, so we could thrive instead of survive. (Woman with chronic pain for 15 years after injury) (1019)
- The medical community is holding us hostage because they have all the control. Time to take back the control. Let our voices be heard. (Fibromyalgia sufferer) (1020)
- There's so much corruption behind the fictitious opioid epidemic. It's costing legit pain patients their lives. Denying us lifesaving pain meds. (New Jersey woman) (1021)
- The way the last pain doctor treated me keeps me away from all doctors. He didn't help my pain, but wounded my spirit. (Retired female Marine master sergeant) (1022)

- I just had a gallbladder surgeon tell me 2 weeks ago that she wouldn't be able to give me pain meds after surgery to control the pain. It seems we are back in the Dark Ages. (Wife, mother with chronic pain) (1023)
- I'm the patient who sees you. You get paid for a service. If I'm in pain your job is clear. Medicine is a service job. (Male biochemical engineer) (1024)
- When there is no cure for a Degenerative Disease, not treating pain is inhumane. Isn't it? (Wife and mother) (1025)
- I had a pharmacist straight up refuse to fill my Rx, even after talking to my doctor, who Okayed it. Luckily another pharmacist filled my prescription. (Male with EDS and POTS) (1026)

This occurred in seven million pain patients in the United States since the original publication of the CDC Guideline for Opioid Prescribing and Chronic Pain.

See [NPC Publication #051 "Seven Million Harmed"](#).

National Pain Council, LLC
Executive Director
Jonelle Elgaway

Comments welcomed. Email us at Nationalpaincouncil@gmail.com

Additional NPC Publications can be viewed at: <http://www.nationalpaincouncil.org/publications>