



A RARE DISEASE REQUIRES RARE RECORDS AND RULES

Part 4- ADDITION TO THE 3-PART SERIES

It is common for persons with IPS to forget how rare this condition is compared to more prevalent diseases such as asthma, diabetes, and hypertension. Any person with IPS also has to face the sad fact that the media, government, and the mental health professionals have now condemned and painted every person with IPS as a drug abuser who is not worthy of being trusted with an opioid, benzodiazepine, or adrenaline type stimulant. Things have gotten so out-of-hand that most doctors will be afraid to treat for fear of government penalties or condemnation by their peers, hospital, or malpractice insurance carrier.

HERE ARE RULES WE RECOMMEND TO GET CARE

1. Do not refer to yourself as a pain patient, but as a patient who has a disease that causes pain. State to medical providers: Examples "I have adhesive arachnoiditis, neuropathy, Ehlers-Danlos Syndrome, etc."
2. Put together a complete set of documented medical records and hand carry to every appointment including identification, insurance coverage, medical diagnosis, MRI's, laboratory tests, and list of past treatments.
3. Know your state's opioid prescribing guidelines and regulations. Do not ask physicians to violate these rules.
4. Research and understand your disease and carry written materials about it to your medical providers.
5. Identify a local pharmacy and health food store in your community that will fill your prescriptions and carry the supplementary agents you will need. Don't ask a doctor to find you a pharmacy.
6. Know and be able to describe the complications of your constant pain: hypertension, tachycardia, elevated cholesterol, diabetes, autoimmunity, and hormone deficiencies. Carry records that document your complications.
7. Until regular care is established, a family member-ideally a spouse-should attend all appointments with you to establish credibility and assurance to MD's, DO's, and NP's.
8. Know the name and dosage of every drug and supplement you take, and which ones are to treat the cause of your pain, suppress the pain, or treat a complication of your pain.
9. Plan on having multiple medical practitioners to treat your conditions. For example, your primary MD, DO, NP may treat your hypertension or hormone deficiencies, but a neurologist may treat the pain.
10. Due to opioid restrictions, identify non-opioid substances that will substitute or potentiate whatever opioid may be available in your community. Some examples: kratom, CBD, PEA, ketamine, oxytocin.
11. Develop a care plan of non-prescription agents to treat the cause of your pain, suppress inflammation, and boost hormone levels.

Many veterans' hospitals (VA) and private health plans now essentially ban the prescribing of opioids.

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