

For Patients

MANAGING PAIN

How Do I Live with This Pain

Pradeep Chopra, MD

For therapy and medications, start low and go slow.

Chronic pain in patients with dysautonomia is usually due to an underlying cause. For example, a patient with neuropathy (pain due to nerve damage) may develop dysautonomia. The pain in this case is because of the neuropathy and not the dysautonomia. Dysautonomia may make it more challenging for the patient to function. Patients with certain coexisting conditions are more prone to chronic pain in dysautonomia, such as those with Ehlers Danlos syndrome, complex regional pain syndrome, fibromyalgia, and other chronic neuropathic pain conditions. The main symptoms of dysautonomia are feeling lightheaded, fainting or almost fainting, headaches, blurry vision, fatigue, poor concentration, palpitations, nausea and vomiting, unable to do low impact exercises, shortness of breath and air hunger.

Patients who are disabled for several months from chronic pain are more prone to developing symptoms of orthostatic intolerance (a form of dysautonomia)². In a study done at the Mayo Clinic in patients with dysautonomia, 74% had fatigue, and 88% had chronic pain (chronic headache in 69% and chronic abdominal pain in 39%).¹

Fatigue is much more common in adolescents. When patients have a difficult time functioning because of their pain, their symptoms of dysautonomia also worsen and make them even more disabled. Both conditions should be treated at the same time. Neuropathic pain (pain due to damaged nerves) is common in chronic pain. Neuropathy may happen in peripheral nerves, but it can also affect autonomic nerves (nerves that control automatic functions in the body, such as heart beating, blood pressure, movement of intestines). Once it affects the autonomic nervous system, it presents with symptoms of dysautonomia.

Common Patient Complaints

- *I get pain in the back of my neck and head. You know, it's an ache that comes and goes, usually with stress, in that region around my neck and shoulders.*
- *When my symptoms flare up I can't get out of bed and my body hurts all over. It is hard to explain.*
- *I have pain all over. I can't think of a place in my body where I'm not experiencing pain. Ok, maybe my earlobes."*
- *My right leg always hurts. It's a dull ache. Some days it is worse than others.*

- *I have horrible migraine headaches almost every day. Usually on a scale of 6-9 out of 10.*
- *I have these very sharp pains in my chest. Sometimes they are like a stabbing pain. Sometimes they are a burning pain. No one can tell me why I get them.*

Most patients do not relate their symptoms of pain to their symptoms of dysautonomia. They do not mention their pain to their cardiologist or neurologist who is treating their dysautonomia. On the other hand, patients do not mention their symptoms of dizziness and palpitations to their pain medicine specialist.

Tips for Managing Pain in Dysautonomia:

1. Hydrate well. Drink plenty of fluids with electrolytes. Sports drinks are good for hydrating. Hydrating improves symptoms of dysautonomia and muscle spasms.

2. Exercise releases natural pain-relieving chemicals in the system. Exercise in some form every day should be a part of every patient's treatment plan. Exercise helps improve function and helps blood flow, which prevents stiffness.
3. Use Narcotics sparingly: Narcotics in high doses, or taken for prolonged periods of time, may sensitize you to pain, forcing you to take more which, in turn, sensitizes you to pain even more, especially in neuropathic pain. Short courses of small dose narcotics may be helpful, if they help you exercise more, which is far more beneficial in the long run.
4. Discuss your pain with your doctor. If appropriate, seek the advice of pain experts who consult with your primary care physician and specialists who treat your dysautonomia.
5. Consider pain when you sleep. Pain may prevent you from sleeping. If you take a sedative, then the pain keeps you awake and the sedative makes you groggy, making things worse. If the pain keeps you awake, then consider measures to treat pain rather than taking a sedative. Follow the rules of good sleep hygiene. Discuss this with your doctor.
6. Develop an arsenal of "pain-helpers." Ideas include, cool compresses, stretching techniques, vitamin C, loose, comfortable clothes, well-fitting shoes, good sleep hygiene.

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1. 1 Fischer PR, Brands CK, Porter CJ, et al: High prevalence of orthostatic intolerance in adolescents in a General Pediatric Referral Clinic. Clin Auton Res 15:340, 2005
 2. 2 Mack KJ, Johnson JN, Rowe P: Orthostatic Intolerance and the headache patient. Semin Pediatr Neurol 17:109-116. 2010. Elsevier.
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For Physicians

MANAGING PAIN

Pradeep Chopra, MD

Managing pain should be directed towards restoring function.

Pain may be nociceptive (structural) pain or neuropathic pain. Chronic pain has an element of both nociceptive pain and neuro- pathic pain. Some conditions may have one more than the other. For example, in osteoarthritis the pain is predominantly nociceptive, but there is also some pain that is neuropathic. Diabetic neuropathy has some nociceptive pain.

Dysautonomia is much more common in neuropathic pain conditions such as complex regional pain syndrome (also known as reflex sympathetic dystrophy). Conditions that are commonly associated with dysautonomia are Ehlers Danlos syndrome (EDS), complex regional pain syndrome (CRPS), fibromyalgia, migraines and chronic daily headaches.

Patients with chronic pain and dysautonomia have a dual set of issues. Patients may be non-functional because of their chronic pain and orthostatic intolerance. Ideally both of these problems should be managed at the same time. Fatigue is a symptom of orthostatic intolerance. Fatigue is also associated with chronic pain. Managing fatigue will depend on optimal pain control and managing the patient's symptoms of orthostatic intolerance. Treating one without the other will be challenging.

Central Sensitization is the key to explaining chronic pain. Treatment goals must include decreasing central sensitization and restoring function.

One of the challenges in treating this population of patients is the perceived behavioral aspect. Conditions such as EDS, CRPS and fibromyalgia are common in adolescent to young females. A classical presentation is severe disabling pain, syncope, pre-syncope, fatigue, headaches, and nausea. Physicians who are not aware of the connection between chronic pain and dysautonomia often brand these patients with a behavioral diagnosis. This in turn is devastating for the patient because all avenues of treating the real condition are closed. Understandably, these young patients with a severe condition may have an element of depression, but the correct management lies in treating the underlying organic condition.

Treatment options are directed toward restoring function rather than focused on lowering pain. It is very important that a multidisciplinary approach be taken that included a pain medicine specialist, cardiologist, physical therapist, and an occupational therapist. Treatment should start with eliciting a good history and performing a physical examination rather than relying purely on imaging studies or laboratory tests. Once the underlying issues are identified, they should be approached by specialists working together with the goal of restoring function.

Pradeep Chopra, MD, MHCM is a Pain Medicine specialist with a special interest in complex pain conditions such as Ehlers Danlos Syndrome and Complex Regional Pain Syndrome in adults and children. Dr. Chopra completed his residency in Anesthesia and Critical Care from Harvard Medical School. He completed his Fellowship in Pain Medicine from Harvard Medical School. He is now an Assistant Professor (Clinical) at Brown Medical School, Rhode Island, USA, and the Director, Multidisciplinary Pain Management Center. He is the recipient of many awards, including The Schwartz Center Compassionate Caregiver Award 2013.

