Hospital Guidelines for CRPS/RSD Patients Handle With Care!

Complex Regional Pain Syndrome (CRPS), previously known as Reflex Sympathetic Dystrophy (RSD), is a "neuro-inflammatory" condition causing the nervous and immune systems to malfunction, sending constant pain signals to the brain. CRPS is characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rated CRPS higher than childbirth, amputation, and cancer pain. Those with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, and needle sticks.

Tips for Patients

- Carry a copy of the RSDSA Hospital and Emergency Guidelines, along with the "I HAVE CRPS" card, to validate and educate practitioners.
- Have your health insurance information.
- Have a list of <u>ALL</u> your allergies, medical conditions, and physicians treating you.
- Have a copy of <u>ALL</u> your medications, dosages and frequency prescribed, including vitamins, over the counter and compounded specialty medications as some may not be on hospital formulary.
- Have a list of <u>ANY</u> medical device and or implants including: spinal cord stimulators, intrathecal pain pump, implantable cardioverter defibrillators, pacemaker, cardiac stents, etc.
- Be patient when educating others about CRPS
- Consider having a letter from your doctor and or pain specialist as to conditions you are being treating for and your medical regime.
- Ask hospital staff to always **ask** before touching
- When possible, ask for a quiet, temperature/light controlled area to minimize triggers (allodynia). Dark sunglasses may help.
- When possible ask for <u>hypo-allergenic</u> items to minimize skin sensitivity (allodynia), such as; sheets, blankets, gown, cardiac monitoring EKG leads, tape, soap, cream, etc.

TJC provides accreditation to healthcare institutions to evaluate standard compliance.
TJC requires each organization to create Pain Policies to Assess, Manage and, Respect the "Patients Right" to pain management.

Tips Medical Professional:

- When possible, avoid frequent needle sticks or injections as CRPS can cause increased sensitivity to pain (Hyperalgesia).
- If PICC site is available, see if blood can be obtained from PICC instead of using vena puncture technique.
- When possible, use <u>smallest gauge</u> needle and topical numbing cream as many have thin and fragile veins. (EMLA, Synera, Lidocaine).
- When possible, obtain blood work during IV insertion to minimize additional trauma.
- Some are sensitive to <u>rate and temperature</u> of IV fluids, responding better to slower infusion.
- Hypoallergenic materials may be needed for Allodynia (things that shouldn't be painful are)
- Frequent linen changes may be needed for Hyperhidrosis (increased sweating).
- Avoid ice to CRPS limb to prevent nerve damage
- Patients may not be able to tolerate hospital socks
- Identify affected limb/s to avoid blood drawing, vital signs and or sheets/blankets from touching.
- Before moving/transporting patient, assess for possible limb atrophy (skin, muscles, and bone weakness) and for adaptive equipment and mobility aids.
- When moving/transporting patient avoid sudden movements and or bumps which can increase Dysesthesia (Creepy, crawly sensation to touch) and Dystonic movement (abnormal movements, involuntary muscle spasms) & Allodynia (things that shouldn't be painful are painful).
- A minor/major injury or surgery can require additional pain management plan, IV ketamine should be considered.
- CRPS is a REAL medical condition requiring support, education, and a plan of action.

