Emergency Department and Urgent Care 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 ALL your allergies, medical history, and physicians treating you.
- Have a copy of ALL your medications, including: dosage and frequency prescribed, vitamins over the counter medications (OTC), and or compounded specialty medications as some may not be on hospital formulary. *Bring your own medication.
- Have a list of ANY active implantable medical device (AIMD): spinal cord stimulators, pain pump, cardiac pacemaker, defibrillators, stents and monitoring devices, etc.
- Have a list of ANY implants: breast, cochlear (ear). Intraocular lens (eye), heart valves, contraceptive, hip, heart, valves, etc.
- Have a list of ANY organ transplants and or prosthesis devices.
- Consider having a letter from your doctor and or pain doctor with conditions you are being treated for and your medical routine.
- When possible, bring someone with you, keep a journal.
- Ask hospital staff to always ask before touching, share where you can be touched and or positioned.
- When possible, ask for a quiet, temperature and light controlled area to minimized triggers (alldynia) especially if staying overnight in the Emergency Department. Dark sun glasses may help with bright lights.
- To minimize alldynia (things that shouldn’t be painful but are painful) bring items that are helpful with you.
- Ask the staff to use hypoallergenic items when possible (sheets, blankets, gown, cardiac monitoring EKG leads, paper tape, soap, cream, band aids, etc.)

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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:
- CRPS has both a sensory and autonomic dysfunction resulting in Central Sensitization of pain, causing:
  - Hyperalgesia (increased sensitivity to pain)
- Avoid frequent needle sticks and injections
- Assess if patient has PICC line access for bloodwork, medications, and infusions
- Use smallest gauge needle (butterfly) when possible.
- Numbing cream prior to needle sticks can be helpful as many have thing and fragile veins (EMLA, Synera, and Lidocaine).
- Obtain blood work during IV insertion minimizes trauma.
- Adjust rate and temperature of IV fluids if possible, as some respond better to slower and warmer infusions
- Illness, injury, trauma can exacerbate CRPS symptoms.
- Allodynia (pain induced from non-painful stimulus such as touch, clothing, sheets, temperature, exam, diagnostics).
- Hypoallergenic materials may be helpful.
- Patients may not be able to tolerate hospital socks.
- Bright lights and temperature variations can be painful.
- Avoid ice to CRPS limb, prevent further nerve damage
- Use NON-CRPS limb for vital signs when possible
- Identify CRPS limb(s) to avoid blood drawing, v/s, and or sheets/blankets from touching.
- Moving and transporting patient: avoid bumps, sudden movements, vibrations and touch of affected area.
- Noise from monitors, pumps, diagnostics, voices, phones, TV, intercom, can elevate pain.
- Atrophy (skin, muscles and bone weakness)
- Assess for limited ROM, weakness and need for adaptive equipment and or mobility aids.
- Hyperhidrosis (abnormal sweating pattern)
- Frequent linen changes may be needed.
- Abnormal Skin Changes
  - Color changes (mottle, cyanotic, red, purple).
  - Skin temperature difference.
  - Hair/nail changes and swelling
- Movement Disorders
  - Assess for motor disorders, involuntary muscle spasms and movements (bradykinesia, dystonia, myoclonus, excessive startle, and tremor).
- Dysesthesia (creepy, crawly, sensation to touch)
  - Avoid using CRPS limb for treatment

Overview:
A minor/major injury or surgery may require additional pain management plan, including IV Ketamine.
- Many have secondary conditions (POTS, MCAS, EDS)
- CRPS is a REAL medical condition requiring support, education, and a plan of action.

Accredited Courses on CRPS for Practitioners:
- https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/