Hospital, Emergency Room, and Urgent Care Guidelines for CRPS 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 rates 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 RSDSA's Hospital/Emergency Room and Dental Guidelines, along with the "I Have CRPS" card, to educate practitioners.

- Have your health insurance information handy
- Have a list of ALL allergies, medical history, and physicians treating you
- Have a copy of ALL medications, including dosage and frequency prescribed, vitamins, over the counter medications, and/or compounded specialty medications as some may not be on hospital formulary. Bring your medications with you as well
- Have a list of ANY active implantable medical device (AIMD): spinal cord stimulators, pain pump, cardiac pacemaker, defibrillators, stents, monitoring devices, etc.
- Have a list of ANY implants: breast, cochlear, intra-ocular lens, heart valves, contraceptive, hip, heart, valves, etc.
- Have a list of ANY organ transplants and or prosthesis devices
- Consider having a letter from your primary care provider and/or pain physician with conditions you are being treated for and your medical routine
- When possible, bring someone with you and keep a journal of the appointment
- Request that staff 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 minimize triggers (allodynia), especially if staying overnight in the emergency department. Dark sunglasses may help with bright lights.
- To minimize allodynia (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, bandaids, etc.)



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Tips for Medical Professionals

CRPS has both a sensory and autonomic dysfunction resulting in central sensitization of pain, causing:

<u>Hyperalgesia</u> (increased sensitivity to pain)

- Avoid frequent needle sticks and injections
- Assess if patient has PICC line access for bloodwork, medications, and infusions
- Use the **smallest gauge** needle (butterfly) when possible
- Numbing cream prior to needle sticks can be helpful as many have thin and fragile veins (EMLA, Synera, and Lidocaine)
- Obtain blood work <u>during IV insertion</u> to minimize 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
- Identify CRPS limb(s) to avoid blood drawing, vital signs, and or sheets/blankets from touching
- Avoid ice to CRPS limb to prevent further nerve damage
- Use NON-CRPS limb for vital signs when possible
- 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)

Dvsesthesia (creepy, crawly, sensation to touch)

Avoid using CRPS limb for treatment

Overview:

An injury or surgery may require an 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