

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, changes in bone, skin, hair and teeth, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rated CRPS higher than childbirth, amputation, and cancer pain.

### **Tips for HCAs, PCAs, or CNAs**

- CRPS, is a REAL medical condition, experienced 24/7, 365 days a year as intractable, unrelenting pain, that “waxes and wanes.”
- Pain is an invisible disability. Individuals may look fine but are struggling.
- Good days are often followed by days spent in bed, with extreme exhaustion. Many tire easily.
- Please always ask first before touching a CRPS individual.
- Individuals with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, smells, pressure, material, and basic medical care such as vital signs, pin pricks, etc.
- Please, do not put blankets, sheets, clothing, socks, or shoes on the person without first asking. Some individuals are super-sensitive and cannot tolerate the slightest touch.
- Individuals with CRPS may need help cooking, food shopping, help with housework, laundry, or bathing, grooming, toileting, ambulation, mobility, transfer, positioning, and transportation to the doctor’s office.
- Pain levels may depend on the time of day. For some, mornings are best and evenings become brutal. Or vice versa.
- Individuals with CRPS may be sensitive to aromas (perfume, fragrances, cigarette smoke) lighting, sunshine, wind, lights, loud noise, and vibrations.
- Individuals with CRPS can feel approaching weather fronts. Changes in weather (hot to cold, vice versa), and humidity can cause CRPS pain flares, even on sunny days.
- CRPS can cause hair, nails to become thicker, fragile and or brittle.
- CRPS can affect teeth & mouth changes (dry, thin, brittle, sores) Gentle oral hygiene can be helpful. (i.e., biotin, soft toothbrush, warm water rinses, etc.)
- CRPS can affect skin color and temperature changes. Many have itchy, dry, thin skin, which requires attention to skin care to avoid breakdown. May see skin lesions, and or rashes, etc.
- Ask if there are special food preparation needs (i.e., soft, pulverized, room temperature, etc.)
- During CRPS pain flares, individuals may need to rest in a calm, quiet, dark room to decrease environmental triggers.
- CRPS can affect any internal organs such as the GI system (i.e.: bloating, diarrhea, constipation, pain), urinary, respiratory, etc.
- Individuals with CRPS, may need additional pillows, bolsters, soft blankets, frequent linen changes to help with comfort.
- CRPS can cause “brain fog”, which may cause short-term memory issues and instructions may need to be repeated. Be patient.

## **Tips For Individuals with CRPS**

- Develop a clear list of your expectations that correspond to the healthcare aide's scope of practice.
- Use a chart, marking each day what needs to be done and require that the aide mark off the chore when he/she completes it.
- If transportation is needed, develop beforehand your expectations regarding volume of music, windows open or closed, air conditioning temperature etc.
- Acquaint your aide with your medication schedule to help avoid pain flareups.
- Inform what may cause your pain to increase. What smells? What sounds? What touch, pressure? Where on your body? What foods hurt/help?
- Discuss your mobility challenges (cane, walker, wheelchair).
- Discuss positioning, and or positioning aides utilized. (bolsters, pillows, soft blankets, linens, etc.)
- Discuss any skin care challenges.
- Discuss any food preparation issues (allergies, temperature considerations, types of food).
- Remember CRPS is hard to understand ourselves, be patient while educating others.