



## CARETAKER PROTOCOLS

### HCA, PCA, or CNA Guidelines for CRPS/RSD Patients. Handle with Sensitivity!

Complex Regional Pain Syndrome (CRPS), previously known as Reflex Sympathetic Dystrophy (RSD), is a "neuro-inflammatory" condition that causes dysfunction in the nervous and immune systems, leading to continuous pain signals being sent 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 rates CRPS higher in intensity than childbirth, amputation, and cancer pain.

#### Tips for Patients:

- Create a clear list of your expectations that align with the healthcare aide's scope of practice.
- Use a chart to mark daily tasks and have the aide check off completed chores.
- Communicate transportation preferences regarding music volume, window position, air conditioning temperature, etc.
- Share your medication schedule with the aide to avoid pain flares.
- Inform the aide of any triggers that can worsen your pain, such as specific smells, sounds, touch, pressure, or certain foods.
- Discuss any mobility challenges you may have, including the use of canes, walkers, or wheelchairs.
- Share information about preferred positioning and any positioning aids you use, such as bolsters, pillows, soft blankets, etc.
- Communicate any skincare challenges you may face.
- Discuss any food preparation issues, including allergies, temperature considerations, and food preferences.
- Be patient while educating others about CRPS, as it can be challenging to understand even for those experiencing it firsthand.

#### Tips for Medical Professionals:

- Recognize that "brain fog" can cause short-term memory issues, and instructions may need to be repeated. Be patient and understanding.
- Recognize that CRPS is a genuine medical condition, causing 24/7, year-round, intractable pain that may fluctuate in intensity (waxing and waning).
- Understand that pain is an invisible disability, and individuals with CRPS may appear fine but are struggling.

- Be mindful that good days may be followed by days spent in bed due to extreme exhaustion, and individuals with CRPS may tire quickly.
- Always ask for permission before touching a CRPS individual, as they are extraordinarily sensitive to various stimuli such as touch, movement, vibrations, noise, light, smells, pressure, and medical procedures like vital signs and pinpricks.
- Avoid putting blankets, sheets, clothing, socks, or shoes on the person without asking first, as some individuals are highly sensitive and cannot tolerate even the slightest touch.
- Be prepared to assist individuals with CRPS in various activities of daily living, including cooking, food shopping, housework, laundry, bathing, grooming, toileting, ambulation, mobility, transfer, positioning, and transportation to medical appointments.
- Be aware that pain levels in individuals with CRPS may vary throughout the day, with some experiencing more pain in the mornings or evenings.
- Consider that individuals with CRPS may be sensitive to aromas, lighting, sunshine, wind, loud noise, and vibrations.
- Understand that CRPS can be affected by weather changes, such as hot-to-cold shifts and changes in humidity, which can trigger pain flares.
- Be mindful of potential hair, nail, teeth, mouth, and skin changes in individuals with CRPS and provide appropriate care and hygiene assistance.
- Inquire about any particular food preparation needs and be accommodating in preparing food that meets their requirements.
- During CRPS pain flares, provide a calm, quiet, and dark environment to help reduce environmental triggers.
- Be aware that CRPS can affect internal organs, such as the gastrointestinal system, urinary system, and respiratory system.
- Ensure individuals with CRPS have access to additional pillows, bolsters, soft blankets, and frequent linen changes to enhance comfort.



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