

COMPLEX REGIONAL PAIN SYNDROME

Background

Complex regional pain syndrome (CRPS) is a severely disabling, progressive neurological disorder. The pain is disproportionate to the severity of the actual injury or stimulus and cannot be explained by the initial trauma. CRPS most often affects the arms, legs, hands, or feet. CRPS is often difficult to diagnosis because it may or may not be associated with a precipitating injury. Most pediatric cases are diagnosed are girls between the ages of 8-16 years old.

The cause of CRPS is not fully understood but research supports a dysfunctional interaction between the central and peripheral nervous systems and/or an inappropriate inflammatory response.

CRPS can be triggered by an initial injury including sprain, twist, dislocation, fracture, soft tissue injury (e.g., burn, bruise), or surgical procedure. Even minor medical procedures may be a trigger. In other cases, no actual injury is identified. Pain may start in a small area like a finger or toe before spreading to affect an entire limb.

The main feature of CRPS is amplified, unrelenting and excessive sensitivity to pain from a stimulus or touch that is not normally painful (e.g., touch of a shirt, wind on face). Pain can be continuous, aching, burning, shooting, stabbing or stinging. Pain often intensifies over time and can spread throughout the affected region. In rare cases, pain can spread to the opposite extremity. Other signs and symptoms of CRPS include changes in skin temperature and color, swelling, joint stiffness and muscle weakness. Pain is associated in lower extremities for children, compared to the upper extremities of adults. Pediatric cases are also less likely to have a history of a precipitating injury prior to onset of CRPS.

There is no cure for CRPS but remission is possible. Early recognition promotes a favorable prognosis and restoration of function. Treatment is directed at the contributing factors and a multidisciplinary approach can include a combination of pharmacotherapy, physical therapy, and psychotherapy aimed at improving quality of life.



Top Takeaways for School Considerations

CRPS is a developmental health concern that can interfere with a student's functional ability. Students are at increased risk for school absenteeism.

Psychological comorbid disorders are more prominent in pediatric cases including stress, anxiety, disordered eating and self-injury.

Children with CRPS are often described as high achievers.

Children with CRPS often have an incongruent affect meaning their appearance and demeanor is not always consistent with reports of severe pain.

It is important to understand the school staff's perception and reaction to pain. Negative interactions and perceived lack of support could potentially influence the student's ability and motivation in the classroom.

Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of pain (acute/chronic), impaired physical mobility and risk for injury
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Student-specific triggers, avoidance, or intervention strategies
- Use of specialized equipment, adaptive equipment, and orthotics
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Equipment troubleshooting (consider equipment/device user manual, battery, charger)
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

Discussion Starters for Educational Team

1. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
2. Can rest breaks, safe spaces or reduced stimulation times be built into the student's schedule?
3. Does the student need support with gross or fine motor skills in the classroom?
4. Does the student require activity precautions to prevent injury?
5. Is the physical school environment safely accessible for the student's mobility needs (e.g., entry and exit, ramps, location of classes, access to elevator, doorways)?
6. Does the classroom environment support the student's needs and/or equipment (e.g., desk/seating options, maneuverability space, electrical outlets, flash pass for bathroom or nurse)?

Resources

Kennedy Krieger Institute: Pediatric Pain Rehabilitation Program
kennedykrieger.org

Meg Foundation
megfoundationforpain.org

Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)
rds.org



Scan QR code or visit **KennedyKrieger.org/Redirect** for more information.