

- 6 Arrange special transportation if traveling on a crowded, bumpy school bus is too difficult.
- 7 For older students, provide a designated handicapped parking space.
- 8 Arrange for the student to meet with the school counselor on a regular basis.²

Special Services for Those Who Can't Go to School

Students with CRPS may qualify for special services, such as a 504 plan or an Individual Education Plan (IEP).

Section 504

Section 504 of the Rehabilitation Act of 1973 is a civil rights law that prevents discrimination against individuals with disabilities from any institution that receives federal funds from the U.S. Department of Education. Some private schools that do not receive federal funding may be exempt from Section 504. According to the United States Department of Education, a student qualifies for Section 504 protection if he or she has "has a physical or mental impairment that substantially limits one or more major life activities."³

"I hate CRPS. I hate the pain I get from it. But, I am done letting it run my life. From now on it is not in charge, I am. Life is to be lived."

—Karen Richards, age 11

Individual Education Plan

An Individualized Education Plan (IEP) is developed in accordance with the Individuals with Disabilities Education Act (IDEA), which governs special education. IDEA has a number of eligible categories, including Otherwise Health Impaired (OHI). The criteria for an OHI designation is "limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (a) is due to chronic or acute health problems...and (b) adversely affects a child's educational performance."⁴

More Information

US Department of Education, Office of Civil Rights

Protecting Students With Disabilities:

<http://www.ed.gov/about/offices/list/ocr/504faq.html>

National Dissemination Center for Children with Disabilities (NICHCY)

Individuals with Disabilities Education Act (IDEA):

<http://www.nichcy.org/Laws/IDEA/>

Disabilities: <http://www.nichcy.org/Disabilities/>

Laws: <http://www.nichcy.org/Laws/>

¹ Sherry D Short and long-term outcomes of children with complex regional pain syndrome type 1 treated with exercise therapy. *Clin J Pain*. 1999;15:218-23.

² Switalski D. Does Your Child's School Have a "Faker's Club"? The CRPS Student's Rights. *RSDSA Review*. 2008; 21:6,7,10.

³ <http://www2.ed.gov/about/offices/list/ocr/504faq.html#protected>

⁴ 34 Code of Federal Regulations § 300.7(c)(9) (hereinafter C.F.R.). [<http://www2.ed.gov/legislation/FedRegister/finrule/1999-1/031299a.pdf>]

Reflex Sympathetic Dystrophy Syndrome Association, 99

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Helping Youth with CRPS Succeed School



"At the evaluation meeting, one of your questions should be 'What are WE going to do to help my child?'"

—Dorothy Switalski

Children and adolescents suffering from complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy (RSD), need understanding and support to maintain a sense of normalcy. A student's condition may vary from day to day, and the persistent pain associated with CRPS is invisible, so many health care professionals and school personnel may assume the child is faking and may doubt his or her pain.

If you visit the RSDSA website, there are several stories from young women who, in spite of the terrible pain caused by CRPS, are achieving their goals and living fulfilling lives. Yvonne writes, "My life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life."

We want to help you understand how you can help children who have CRPS, either by simply being supportive or helping make accommodations and modifications in the school environment. Your support and understanding can determine whether our children succeed or fail.



What is CRPS?

CRPS is a neuroinflammatory syndrome characterized by pain in one or more limbs and/or ankles, feet, abdomen, or hands though virtually any part of the body can be affected. The pain, described as burning or sharp, typically appears after a traumatic event, such as a broken bone, sprain, sports injury,

automobile accident, or bad fall. There is often coldness and swelling in the affected limb(s) as well as allodynia (a painful response to a normally innocuous stimulus). The pain is disproportionate to the original injury and is present long after the original trauma has healed. CRPS is more common among pre- and adolescent girls than boys by about 5 to 1. It is usually seen in girls who engage in sports, dancing, or gymnastics.

Although the cause of CRPS is unknown, overuse injuries, trauma, psychological stress, nutritional factors, and hormones are possible contributors. CRPS is thought to reflect overreaction of the autonomic nervous system, leading to transmission of pain signals after the initial injury. As there is no single test for CRPS, the diagnosis is made clinically by patient history, thorough examination, and the results of numerous tests to rule out other serious conditions.

CRPS is not life-threatening, but it can become chronic and even spread to other parts of the body. It can be highly disruptive and interfere with daily activity, leading to as many as 25% of school days missed. Early diagnosis and treatment, with an emphasis on movement, behavioral approaches, and rehabilitation, offer the highest probability of remission, which may be achieved in almost 92% of those treated.

Treatment options

Physical/exercise therapy of the affected body part is the most effective treatment for pediatric CRPS. This therapy

desensitizes and restores function—strength, endurance, and range of motion. Mind-body techniques, such as relaxation, biofeedback, and self-hypnosis, are helpful for pain management and can alleviate the fear of movement often seen in people with CRPS. Psychological interventions to help with coping and emotional responses, and family therapy, to promote adaptive parental/familial responses, can also be valuable. Medications, nerve blocks, and interventional measures, such as a tunneled epidural catheter or spinal cord stimulator, can also be used to facilitate and accelerate progress in physical therapy. A comprehensive coordinated interdisciplinary approach for CRPS management will provide the best results in the majority of children.

Students with CRPS and School

For those students who are able, we recommend the following:

- ✓ Attend school daily whenever possible
- ✓ Permit the student to go to the nurse when needed (may be experiencing a pain flare-up)
- ✓ Limit the use of over-the-counter medications
- ✓ Be allowed to walk in the back of the classroom or in the hallway periodically without disruption to others to stretch and move for pain reduction
- ✓ Establish routines and schedules for learning and extracurricular activities
- ✓ Be as independent as possible in completing assignments
- ✓ Be encouraged to practice normal activities

Other interventions that can be practiced as needed include:

- ✓ Psychological intervention for child and family to assist with adjustment to home and community, behavioral interventions, and emotional support
- ✓ Relaxation techniques and cognitive-behavioral exercises/strategies
- ✓ Monitoring for “overachiever” behaviors, over-scheduling, apathy and reduced motivation and/or initiation, and anxiety, depressed mood, and/or inflexibility.¹

When Students Require Special Accommodations

Some students may not be able to resume activities as normal. Some accommodations that have helped students with CRPS are listed below.

- 1 Because the slightest bump can cause lasting flare-ups of this very painful syndrome, every effort should be made to see that the child is not exposed to the bumping and jostling of school hallways. The student’s desk in each classroom should be positioned away from traffic patterns to avoid inadvertent bumping.
- 2 Determine whether the student needs ergonomic seating/adjustable desk.
- 3 Designate another student as a helper who can carry the student’s books/belongings during the day, help at lunch, and during the changing of classes.
- 4 Because students with CRPS in their upper extremity may have difficulty writing, allow the student to record lectures, use a keyboard with a portable word processor, or use another student’s notes.
- 5 Given that CRPS symptoms can be exacerbated by the cold, allow the student to bring a heating pad. Also, guidelines should be developed regarding whether the child should go outside for recess when it is excessively cold; care must be taken to see that the patient has adequate warm clothing, and is kept out of drafts.
- 6 Allow students to have an extra set of books at home in addition to school.
- 7 Permit the student to leave 5 minutes prior to the end of class to avoid the congested hallways.
- 8 Confer with parents as to whether they wish the child’s classmates to be aware of the syndrome.
- 9 If there is a dress code, the child may need to adapt clothing due to sensitivity to clothing and increased sweating.
- 10 Special accommodations may be necessary for school field trips, including transportation, medication disbursement, and lodging (if an overnight trip).

- 11 Ask before touching the student—a simple pat on the back can cause increased pain.
- 12 Allow a student with CRPS to sit in a quieter area of the cafeteria if the noise is bothersome; however, do not isolate the student from others.
- 13 Students with CRPS are also sensitive to noise and vibrations. Please take this into consideration when fire drills, assemblies, and pep rallies are planned. Allow students to position themselves away from loudspeakers/intercoms—even the classroom bell for beginning and end of class may affect a student with CRPS.

Limiting Stress

Because stress is a known cause of exacerbation of this syndrome, academic schedules and curricula may have to be modified, including:

- 1 Schedule all classes on one level or provide student with key to the elevator.
- 2 Implement flexible homework and make-up policies (homework and tests are a major cause of additional stress).
- 3 If a student is unable to write, modify normal test taking, and allow additional time for tests.
- 4 Reduce school time if necessary (students may be late due to pain flare-ups) and supplement with home-based instruction and tutoring.
- 5 If mobility is impaired, credit the student’s physical/occupational therapy as the requirement for gym (if the school has a pool, allow the student to use the pool during gym).

“My life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life.”

—Yvonne