

CRPS INFORMATION FOR SCHOOLS



Complex Regional Pain Syndrome (CRPS) is a debilitating condition that is characterised by severe continuous pain, that may be burning, throbbing, stabbing, aching or feel like pins and needles and is considered the highest rated medical pain on the McGill University Pain Index. It rates above the pain felt in labour, cancer pain and above the pain of a traumatic amputation.

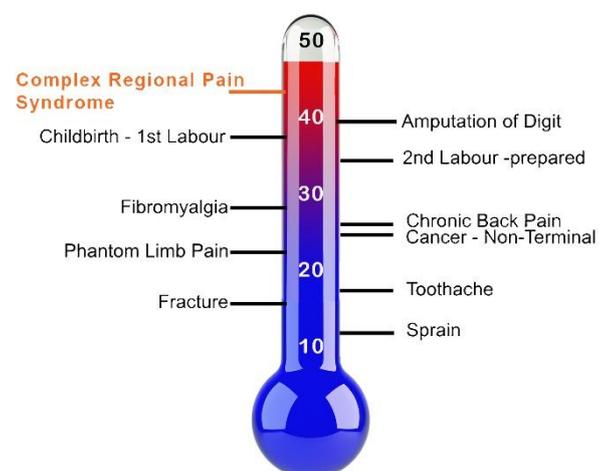
Although you may not see any signs of the pain it is very real. One of the most challenging symptoms of this condition is 'allodynia' - a painful response to non-painful stimuli. The lightest of touches on the area of pain can be excruciating, as can light breezes, wind, sound, water, clothes, air-conditioning, even sunlight.

CRPS is usually precipitated by a trauma, such as an accident, a sprain, fracture or a surgery, but CRPS can also occur after a very trivial incident or immobilisation and, on occasion, can develop spontaneously. The exact cause of CRPS is unknown, however it is believed that CRPS occurs as a result of damage to, or a malfunction of the nervous system and the immune system at the site of the injury.

Symptoms can include:

- Severe Pain
- Hyperesthesia – increased sensitivity to normal stimuli
- Allodynia – a painful response to non-painful stimuli
- Abnormal skin colour
- Abnormal swelling
- Joint stiffness
- Muscle weakness
- Dystonia and movement disorders
- Decreased limb function
- Abnormal hair or nail growth
- Insomnia
- Depression and anxiety
- Fatigue
- Memory loss
- Lack of concentration

The McGill Pain Index



NB: The McGill Pain Index is a rigorously tested scientific pain scale. Overall score is determined by compiling various numerical and cross-referenced descriptive words, allowing direct comparison across different conditions.

Students with CRPS may:

- need extra time to get between classes
- need permission to move to classes early to avoid being bumped by other students
- require help carrying their books
- require special seating arrangements to decrease pain
- need to use heat pads
- need time out of class during pain flares
- miss time at school due to appointments
- need protection from crowded situations to avoid being accidentally bumped
- have trouble concentrating in class and suffer from memory loss
- be tired in class due to sleeping problems
- require extra time for homework assignments and tests due to effects of CRPS on the limbic system in the brain plus the easy fatiguability of CRPS
- develop depression, anxiety or post-traumatic stress disorder
- be at risk of bullying

Students with CRPS may be capable of a physical activity on one day and may not be able to repeat this the next. This is normal with CRPS and should not be considered as malingering. i.e. children can be in and out of a wheelchair throughout their CRPS journey or be capable of walking 5 metres 1 day and is too sore to achieve it the next, or can write one day and the hand be too sore to hold a pen the next etc.

Physical symptoms can wax and wane and doing too much can be as detrimental as not doing enough for children recovering from CRPS. It is important that they learn to pace themselves and they work carefully with their physiotherapist to achieve a good balance.

What should Schools and Teachers Do?

Parents should be encouraged to get an **Action Plan** from their GP or Specialist outlining the child's capabilities and what special considerations may be needed for their child to continue their education at school.

i.e. avoid crowds due to allodynia
have time out as needed due to pain flares or fatigue
take medications as required
space away from wind or cold is required during lunch

Schools should discuss this with the parents and put in place an **Individual Support Plan** for the student.

You should be aware that the student may miss time due to multi-disciplinary health care appointments as these are scheduled frequently for this disorder. The student may also miss school due to extreme pain or emotional distress.

Never touch the student without asking for permission. Even the lightest of touches can cause extreme physical pain. Students with CRPS are also sensitive to loud noises, so be aware that the intercom, large crowds, and assemblies may even cause pain for students with CRPS. They may also be sensitive to changes in the weather, rain and heat and cold.

You should encourage the student to stay as involved as possible in school and extracurricular activities, especially in areas that they enjoy or are passionate about.