### INTERNATIONAL RSD FOUNDATION

## So your student has CRPS...Now what?

A resource for school administrators , nurses and teachers to understand Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy Syndrome (RSD), and how to support a student with this condition



## Welcome and thank you!

This resource has been designed for you, as a school administrator, teacher, nurse or staff support person to better understand CRPS, and how you as a school can support your student with CRPS.

This resource has been provided to you as one of your students has been diagnosed with Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy Syndrome (RSD). This resource will help to answer some of the early questions you may have about CRPS and will hopefully help foster ongoing discussions between the school, student and their guardian(s). Working together, to find proper accommodations and supports will help to ensure that this student can thrive in spite of this complex, and devastating condition.

CRPS is a debilitating, painful condition that will pose an incredible challenge to your student. It will also require a lot of effort by the student, his/her guardian(s) and the school, to find the appropriate accommodations to

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support success! This may be an overwhelming challenge for you, as a school administrator, teacher,

school nurse or support staff. However, your support, and understanding are what will make a difference in your student's life! So, thank you!

It cannot be stressed enough that the schools approach towards this student be one of an interdisciplinary team including administrators, teachers, school nurse and any other support staff. This will also require open communication with the student, and their parent(s)/guardian(s). Nurses are an essential part of the team, as at times the student may spend more time in the nurses room, than in class. The school nurse can also properly administer



any medications the student requires. This will require open communication with the student's guardians to ensure they know any added or removed medications.

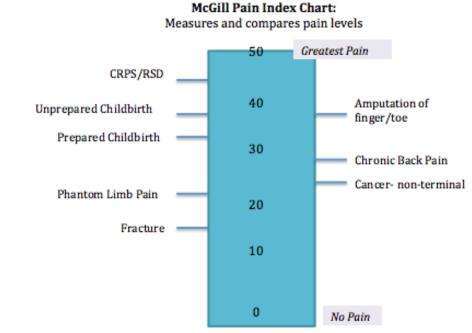
As educators, you know the value of education and ensuring supportive school environments. You know these lay the foundation to provide students with a bright start, and promote wellbeing later in life. The human brain undergoes rapid development in the early years, and continues to develop into ones late 20s. Throughout their educational years, children and youth, are building cognitive skills, gaining knowledge, and acquiring essential building blocks for the future, such as social-emotional and problem solving skills. Ensuring that your student living with CRPS thrives, in spite of this condition, is paramount.

**Thank you** for taking the time to better understand this condition, the impact it has on your student, and methods the school and staff can best use to support the student's academic and social success. Your support will help the child feel a sense of normalcy in life by attending school, being a part of regular school activities with his /her peers.



## What is CRPS?

CRPS is a poorly understood, and understudied, progressive neurological pain syndrome. It can affect anyone, at any age. CRPS is primarily a neuropathic, and partially musculoskeletal pain disorder, which also affects the autonomic system. It is a chronic disorder, which, if left untreated, can lead to disability and functional limitations.



Despite there not being one definitively known cause, there are two types of CRPS:

- CRPS I reflects the absence of a nerve injury (initially referred to as RSD); and,
- CRPS II reflects the presence of a nerve injury.

Developing this condition can be attributed to a traumatic event such as surgery, a fall, sprain, or fracture, and even in some cases, just bumping ones' toe. The pain is out of proportion to what would normally be expected of the injury. It most often affects an extremity (arm or leg), but can also move internally. You can imagine how confusing this would be to both the patient and their family!

The McGill pain scale, developed to rate various pain related traumas, found CRPS pain to be more intense than childbirth, an amputation of a finger or toe, and chronic back pain for example. CRPS affects anyone at any age. However, among school aged children and youth, CRPS is more common among pre-adolescent and adolescent girls than boys. While there is no single reliable diagnostic test, a clinical diagnosis is made based on examination meeting clinical diagnostic criteria based on their signs and symptoms, and patient history.

While pain, out of proportion to the original injury, is one of the first signs of this condition, there are ranges of other symptoms that must be met. Symptoms of this condition range depending on the person living with CRPS, and therefore not every person with CRPS will have all of these symptoms and symptoms will vary. Symptoms can also change over time as a result of treatment(s), medication(s), and stress, for example.

#### Support and empathy are essential!

CRPS can lead to severe depression. Given this condition, and its implications on one's life, it is imperative that your student be supported, and receive empathy and understanding from those around them.

Your student is likely experiencing a number of the symptoms listed below. If you want to know more about your student's experience, and their symptoms to ensure proper precautions are taken, the family is likely open to sharing more information. **Symptoms** of this condition include:

- Burning sensation (as though someone has lit their affected limb or part of their body on fire)
- Hyperalgesia (heightened sensitivity to pain. Pain is higher than expected for the initial injury)
- Allodynia (experiencing heightened pain from non-painful stimulation of the area affected such as a light human touch, touch of clothing, bedding, or water)
- Autonomic dysfunction, such as sweating, skin color changes, and changes in skin temperature (affected limb can be substantially colder than the other).
- Trophic changes. This may include reduced or no hair growth on affected area, skin changes, and brittle/cracked nails.
- Altered motor function such as weakness, reduced range of motion, muscle atrophy.
- Inflammation
- Spasms
- Insomnia and emotional disturbances-Significant changes to the limbic system, which is responsible for sleep, short-term memory problems, difficulty concentrating, word recall, confusion, etc.

#### 4 stages of CRPS:

CRPS has four stages. Depending on the originating injury, the duration of each stage can vary. In comparison to adults, the stages of CRPS in children often stagnate, reverse, or improve slowly. CRPS has confusing clinical manifestations of this condition, especially since not all signs and symptoms may be present neither at the same time nor in each patient.

<u>Stage I</u>: Pain may spread in a mirror fashion to different areas of the body (ie hand to foot, foot to hand, or right side to left side).

<u>Stage II</u>: There can be a noticeable change to both skin temperature and color; even in a matter of minutes, and can change all the time. The patient may also have hair loss, brittle and discoloured nails, and/or a skin rash, for example.

<u>Stage III</u>: Atrophy to different degrees is seen. However, this may be less noticeable due to inflammation and swelling.

In both stage II and III is not at all uncommon for CRPS to spread to other extremities. At times, it may become generalized.

<u>Stage IV</u>: Is the final stage of CRPS, and points towards the exhaustion of both the autonomic and immune systems. This includes a number of chronic, and medically concerning issues including for example: Immune system failure, intractable hypertension and edema, and a heightened risk for cancer.

# Experiences of people living with RSD:

While there is no cure, CRPS remission is possible. The prognosis for children with CRPS is much better than for adults. While remission is possible, it is important to note that the focus and goals for CRPS treatment and management is on rehabilitation, not on completely reducing pain. This means, that rehabilitation will be focused on improving function including:

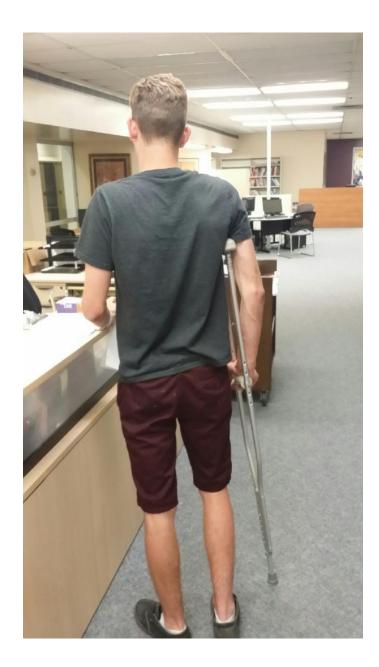
- Social functioning
- Physical functioning
- •Emotional functioning
- •Quality of life

#### So what can you do?

Most importantly, empathize and try to understand what this may be like for your student! Continue reading to learn more about this condition. And build a safe place so that your student feels open and safe to not only answer questions you may have, but also to come to you for help, as needed.

Each person living with CRPS will have varying degrees of experiences. Some people have extensive social and emotional support through their family, friends, medical practitioners and school. While others will have had a very difficult experience being recognized and believed.

People, of all ages, have experienced varying levels of support and challenges. The level of support one receives, or the challenges they are faced, can change unpredictably. Whether it be challenges in understanding what is going on with them prior to and after being diagnosed, challenges being heard and believed, to challenges of family abandonment. Each person will have their own individual story of challenges and adversity, as well as strength and perseverance.



### Student voice

The following are direct quotes from individuals living with this condition, ranging from children and youth to adults. Hearing, from their voices, may help you better understand some of the daily challenges they face. This may help you better

empathize with what your student, and their family, may be experiencing.

"[My greatest challenge is] pain! It has changed everything; my whole life. I have been disabled using a walker, crutches, and wheelchair. [I] Don't sleep. [I suffer] depression, anxietyeverything! School is awful, no one understands and no one cares. My focus is always on pain, sleep, everything. I'm not dumb but feel like it. [And] teachers have no sympathy because they have no idea. They say 'I have rheumatoid arthritis and you have to just get up and work through it'. I take pain and muscle relaxers just to exist. But, they don't [even] really help. No one understands" [High school student]

"[My greatest challenge is] having to put up with the comments from people that say 'you don't look sick' or 'you can not be in that much pain, you were able to put on make-up and nice shoes and come to school'...'how can you possibly be so ill?' It is hard having so many people not believe you"

"I'm sad that my friends don't want to be my friend anymore. I'm sad that my teachers don't help me. It is hard. I try hard. But some days I can't do school, as I can't handle. I'm in a lot of pain and it is hard" [Grade 5 student]

"[One of my greatest challenges is] adjusting to the 'new normal' life. Accepting the reality of the diagnosis while also pushing myself physically and mentally"

"My greatest challenges include:

- the ever-changing and debilitating pain
- struggling to cope and to still excel
- the side-effects of medication
- slow cognition now"

## What does this mean for the student living with CRPS?

## 1.Unpredictability

The impact of CRPS will vary between each person diagnosed with CRPS and symptoms will vary on a day-to-day basis for your student. It can also vary hour-to-hour, and minute-by-minute. Because this condition is so unpredictable, it is necessary to ensure that proper supports are in place to help the student adapt and feel supported. This also will require some flexibility and intuition on the school and teachers' parts, especially if circumstances arise that have not yet been figured out. However, it will also require dedication and communication on the student's part too.

### 2. Treatment

Due to limited knowledge and understanding about the causes of this syndrome, there are limited treatment options available. While treatment options will vary depending on the country, state/province and city one lives in, you can expect that the student will be involved with a few different treatment options. Treatment will be very individualized and is often provided through an interdisciplinary team (ie. treating physician, psychologist, physiotherapist, kinesiologist and pharmacist). Treatment options include, but are not limited to: pharmaceuticals, electrotherapy (TENS), interventionist therapy (ie. sympathetic nerve blocks), implant therapy (such as spinal cord stimulator), physical therapy (physiotherapy and occupational therapy), cognitive based therapies (i.e. breathing exercises & biofeedback) and psychological therapy (i.e. counselling & pain education).

## 3. School Attendance

Depending on the healthcare programs in your area, the student may be away from school for varying lengths of time every day, week, or month. There may also be inpatient intensive therapies that require your student to be absent from school for an extended period of time. If this is the case, be sure to work with the student and their primary caregiver(s) to determine how the student will keep up with school expectations and work. Please be prepared to provide an appropriate timeline.

It would be helpful to have a 'system' in place, for the times when your student misses school due to pain, or appointments, so that:

1. the school is aware of this absence, and

## 2. the student can get the work missed to catch up.

This may include the use of an online class site such as 'blackboard' whereby teachers can post the class lesson, and assignments, which can be accessed by the student at home. Another example may be a call-in system, where the guardian(s) or student can call into to a voicemail recording to find out the missed assignments and homework. You may also choose to have a voice recorder accessible to the teacher, so they can record the 'live' lesson, and the student can listen to it on the weekend. Find a system that reduces both stress and added work for the teacher, but is also supportive enough that the student can get caught up. This is important as it is expected a student living with CRPS will miss school days due to both elevated pain, and medical appointments necessary for recovery.

#### Things to consider:

a. Have a system in place for the guardian(s) to call in to report an absence due to elevated pain levels

b. Have a system in place for teachers to know in advance of absences due to upcoming appointments. Encourage the guardian(s) to give as much notice as possible so that the teacher can keep the student as up-to-date as possible, as well, to plan ahead for how they will prepare the student for missed work.

c. Consider setting up a blackboard, or call in system, where the student and/or guardian(s) can login or call to see what lesson was missed and any homework or assignments

d. Consider having classes recorded when the student is away. This can then help the student listen in to the lesson(s) missed and remain as up-to-date as possible. Find out if you need permission for other student's guardian(s) to record classes where student voices are heard. Get written consent

e. Ensure the student knows, pending age appropriate, that it is still their responsibility to find out missed work, and to keep up on homework and assignments. Keeping them engaged and accountable will help them stay on task. Also, depending on the age of the student, keep them accountable for letting the teachers know which classes will be missed due to appointments.

### 4. Ongoing Pain

Physical therapy, focused on restoring function and desensitization, is essential to the treatment of CRPS. Those living with CRPS will be very accustom to being told to use their affected limb(s) despite the intense pain, in order to reduce the spread of CRPS, and hopefully to gain remission. Some days this may be easier than others, so you may see him/her using mobility supports for lower limb CRPS or technological devices, such as speech to text software, for upper arm CRPS on days that pain is worse than others. Despite the possible changes in what aids they require on a day-to-day basis, do not discount whether this condition is real, or think there is something to question. Again, each day, hour, and minute will and can be different. And although the pain will be constant, their ability to cope with it will also differ as will the level of pain.

Cognitive based therapies, including breathing exercising, and other coping skills will help the student develop the strategies and skills needed to help cope with their pain. If you are noticing the student in distress, encourage them to find a quite space (or a designated quite space, see accommodations below), to practice these coping strategies.

## What factors will impact the student's ability to learn?

CRPS will have an unavoidable impact on the student's abilities in school, and their attendance. However, by working with the student and their guardian(s) everyone can work to limit the impact this condition has on their abilities. This can be achieved through varying accommodations. As well, together, you can find a way to navigate the complexities and impact of missed schooling due to pain, or appointments.

## Stress

Stress has been found to increase CRPS symptoms. Unfortunately, this may lead to the student inadvertently avoiding stressful school expectations- such as exams, and assignments. This will have to be monitored by teachers, and other support staff to ensure that the student is given appropriate accommodations and resources to help cope with and reduce these common stressors. Supports may include, oneon-one help prior to a test, breathing exercises, extended deadlines, and quiet spaces to write exams. It would also be beneficial to mention this observation to their guardian(s). If the student is receiving care through an interdisciplinary team,



their guardian(s) can mention this to the psychologist so the student can get additional skills to reduce the impact of stress.

## Other factors

In addition to stress, additional challenges include, for example:

- •Concentration and attention difficulties
- •Difficulty sleeping, and its effect on school
- •Brain fog and fatigue
- •Challenges with short term memory
- Increased frustration and hopelessness

As you can imagine, these learning challenges, in addition to the pain, will make going through school more difficult than usual. If the student was a high achieving student prior to this, it will be important to ensure that he or she has guidance counseling, and other academic supports, to cope with this change and its challenges. These challenges may result in an increased risk for depression, anxiety and hopelessness, which will need to be carefully monitored and treated. If the student had learning difficulties prior to this condition, it is essential that they continue to be supported with the proper resources and school services to ensure school success.

Further to the potential impact of the cognitive and functional challenges, absences from school, due to pain or appointments, will be a challenge for both the student, and the school. This will require dedication from all. The student, their guardian(s), and the school (administrators, teachers and support staff), will all have to work together to ensure success.

## What can you expect from, and of, your student?

Students will need to be just as determined to fulfill school requirements, as the school is in trying to meet the student where they are at, and provide the necessary accommodations (see end of resource for examples to facilitate discussions). While a number of accommodations will need to be mutually decided on, ensuring the student feels comfortable and supported at school will be essential to keeping them motivated to push through the pain to attend school, and continue to complete school assignments, tests and projects.

Having the expectation that the student continues to focus on school, and be as dedicated to it, as you are in providing accommodations and supports, is a good expectation to have. However, you will need to continually remember that this student is in immense pain, leading to cognitive challenges and changes such as concentration, focus and memory, as well as the side effects of many of the prescription medications they are likely to be on. So having realistic expectations is necessary.

As previously discussed, stress can increase CRPS pain and associated symptoms. It will be important the student knows, that while missing school due to pain flares and appointments will happen, and is accepted, it will be part of their responsibility to minimize, as much as possible, the number of classes missed. You can express expectations that the student be an active participant in vocalizing what accommodations and school systems are working and which aren't, to revisit, and address them as soon as possible.



# How to support a student with CRPS:

There are many ways you can support the student living with CRPS. Some will be easy to implement, and others may be more challenging and take more time. While this isn't an exhaustive list of how you can support the student, it includes a few key ways to support the student, and encourage towards supporting them! Your support is invaluable.

**2.Trust:** Another way to support anyone with this condition, and any other invisible condition, is to trust and believe. Trust what the student says they are going through, and believe them - their symptoms, experiences, challenges and needs. This is an essential part of supporting anyone with invisible illnesses, as too often they are not

them to continue being dedicated to their education. You may already have a good idea of the student's personality and additional ways to support them. Or, over time you will get to know the student better and how to best support and encourage them, as you interact and observe him/her. The following are some of the essential ways you can support this student:

#### 1. Be aware:

Taking time to read this resource, to better understand this condition, its impacts on the student and their

#### But what is Empathy?

According to research and thought leader Brené Browne (Ph.D, LMSW), empathy is very different from sympathy. Based on research she says sympathy and empathy are in contrast to one another. For example:

Empathy: "fuels connection".<sup>1</sup> It's ones' ability to understand and relate to someone else's story and experience, without judgement; and their ability to communicate these understandings.

Sympathy: "drives disconnection".<sup>1</sup> Staying away, trying to "silver line"<sup>1</sup> their experience with statements of "at least..."<sup>1</sup>

Check out Brené Browne's short clip on this difference! Not only is this a great resource for yourself, but also could be used with your students: https://www.youtube.com/watch? v=1Evwgu369Jw

<sup>1</sup> Browne, B. (2013).

trusted, told they are liars and making it up. This is the last thing someone dealing with this type of condition needs.

3. Empathize: When you trust your student, you can also empathize with them. Try to understand or related to their experience some how, and communicate your understanding to them. Be sure not use sympathetic statements that create disconnection such as: "at least you don't have cancer" or "at least you still have your limb".

#### 4. Prevent Bullying:

Because there is such limited awareness and understanding of this condition, compared to other medical conditions such as diabetes and cancer, any person living with CRPS is often

education, and learning ways to support them through actions and accommodations, is the first step. So thank you, for taking this essential step

questioned. Many people have been called liars, are mocked, ridiculed and even ignored. This can be an exceptionally hard reality for children and youth to deal with. One of the first things that you can do to help this child is to acknowledge that what they are going through is real, and empathize.

**5. Raise school awareness:** Not everyone in the school will be involved in understanding this condition, and what supports the student needs. However, if one, or a few people, can champion raising awareness in the school, the school and student will benefit. This may be: having this condition weaved into health class lessons; ensuring staff members understand and know that this student has this condition and how they can help them. (For example, with awareness they will know to avoid touching the student on their CRPS affected limb, stand with some distance away to avoid touching affected body part, and watch for signs of distress etc.)

6. Provide a mentor: While all school staff should be made aware of this student's condition it may be beneficial to have one person as the main point of contact. This may be, for example, an administrator, guidance counselor, or nurse. Not only would the student know who to go to if they require additional help, but will also help the guardian(s) have a point person to discuss relevant issues. This would also help the school by having a point person who liaises with the student's guardian(s) regarding any concerns or questions.

7. Educate Peers: First ask the guardian(s), and student, if they are ok with letting the other classmates know about their son or daughter's diagnosis. If the school is set up with students in one dedicated class, it may be helpful to have a brief session on what this condition is, and how students can support their fellow classmate. There will likely be a lot of questions from the students, so find out if the student living with CRPS is open to answer questions. If not, it may be necessary and beneficial to have the guardian(s) involved in this classroom discussion. Find ways to ensure there aren't unanswered questions, which would spark any type of teasing or misunderstanding. Find a way to ensure that sharing this information doesn't lead to students ridiculing and distancing themselves from the student living with CRPS.

8. Continue to be aware: Take care to watch for signs that the student is in distress, or having a bad pain day. As time goes on you will become more in tune with their signs and be better able to support them. Be patient with yourself as you learn to understand, and also be patient with the student. There are also ideas in the 'accommodations' section, for systems you can set up so you know how the student is feeling, without always asking or trying to read them through behavior.

**9. Create a peer support group:** There may be an increased risk for bullying, due to other students lack of understanding. Help build a support network around the student. If you see their group of friends disengaging over time, find ways to bring the students back together through group work and sharing.

**10. Use school resource personnel:** Ensure your school nurse is part of discussions and consults with their medical providers. The school nurse may be able to help administer medications prescribed, or help during pain flare-ups.

**11. Be encouraging:** Find small ways that you are able to show support to the student. Encourage them to continue on, despite the challenges they are faced with. School will likely pose itself as more difficult as a result of this condition, avoid any discouragement that would make the student want to stop going to school. You can continue with constructive feedback on assignments, homework, projects and tests; you will find a way to do so depending on the student's personality and needs.

## Accommodations + modifications for student success

This is by no means an exhaustive list. The needs of each student living with this condition will differ; what one student needs, another may not. Further, what a student needs can vary day to day. Continue to have open discussion, and be open to the evolving accommodations required by your student.

## Understand your student's needs

As each day can and will be different, understanding how the student is feeling on a day to day basis will be important. Consider the following as examples of the types of systems you can put into place so there is open communication and understanding of the student's daily needs:

- Set up a system that lets teachers, administrators and other students know, without asking, how the student is doing. Examples include:
  - Using a color coded sign the student places on their desk or the white board. For example:
    - Green = I'm feeling my 'normal'
    - Orange= Caution, I'm not feeling very good today.
    - Red= It's a bad day; I need to go home or find a quiet space.
    - Having a safe word that the teacher(s) knows, should a student be feeling signs

of a flare and need to excuse themselves from class to go to nurse's room, or home.

## Set up safe and supportive spaces for the student:

- Sometimes sound, light and noise can trigger different reactions. There may be different triggers that don't feel safe, and a student needs to retreat. Have a safe quite place set up that the student can retreat to if needed. Always have them tell a teacher, or administrator when they are utilizing such space, in case of fire, etc.
- Have an ergonomic assessment completed. Or allow the family to have a specialist brought in to ensure proper set up of the student's desk and work area(s). CRPS in the arm or leg, for example, will require a different set up.
- Work with the student to find out if they need additional equipment to help complete their schoolwork. For example, if the student has CPRS in their arm, consider adapting a school computer with speech to text software to help with writing assignments, and consider audio book options.
- Allow the student to have an extra set of textbooks at home so the student doesn't have to carry a heavy backpack each day.
- Ensure school accessibility. Most schools are set up with accessibility in mind. Allow students with this condition, even if not using a wheelchair or crutches, to use the school elevator, if/as necessary. One day they may be able to walk, and the other not. Be adaptable and avoid questioning why they are or are not as they were yesterday (ie. using crutches one day, no crutches another day)

- Because of allodynia (heightened sensitivity to non-painful stimulus such as touch), the slightest touch or bump to the CRPS affected area can cause an incredible amount of pain, known as a flare-up. Have the student's desk in an area of the classroom which has the least traffic and risk for bumping.
- Find a way to include school counselor. See if it would be helpful for the student to meet regularly with school counselor.

## General accommodations and modifications:

- If there is a school uniform, have discussions about modifications that can be made due to sensitivity.
- Consider what other resources the school can implement to support the student throughout the day. For example, a student aid, or a volunteer student who is in the same class who can carry their books
- While all school staff should be made aware of this student's condition, it may be beneficial to have one person as the main point of contact. This may be, for example, an administrator, guidance counselor, or nurse. This will help not only the student know who to go to if needing additional help, but will also help the guardian(s) have a point person to discuss relevant issues.

### pain levels. Talk to the student about how they are affected by different weather. If there is a recess, or mandatory outdoor time, ensure that there is open discussion about where the student can be during weather that may aggravate their pain. Trust the student is making the right decision based on their experience.

- The student may need extra time between classes. Accommodations can include extra time between classes, and class schedule flexibility. This may also include switching classes after or before the bell signalling other students to switch, to avoid bumping one's CRPS affected body part(s).
- Sometimes getting ready, or up from bed in the morning can be difficult. Consider putting a system in place that allows the student to come to school late, if needed. This will require open discussions and communication lines with their parent(s)/guardian(s).
- Ability to leave at the end of the day 5-10 minutes early to avoid the rush of students.

## Class credits, expectations and accommodations

 Discuss the possibility of extensions on projects or assignments. Living with CRPS can impact a students cognitive functioning; they may be slower at understanding, or working

> because of the pain and the impact on their brain functioning.

•Similarly, discuss extensions on exams. Also consider allowing the student to write the exam in a room alone, with supervision.

## Class and school schedule(s)

 Sometimes outdoor elements, such as cold weather, wind and rain, can affect and trigger flares in



- Sometimes the student may need some extra help understanding lessons and material due to the impact of CRPS on concentration and memory. Consider having time at the end of each day that the student can have 1 on 1 time with their teacher(s) if they need the help. Further, consider allowing the student to tape the class so they can review it at home, or as they are working on school assignments.
- If the student requires physical education for school credit, consider alternatives to this. The student will likely have many appointments, such as physical therapy. Consider allowing the student to do their physiotherapy exercises during gym time. Consider allowing them to try relaxation techniques such as yoga, meditation, Qi Gong, instead of gym class, which will pose difficulty.
- Have class lessons written down, or recorded so he/she can look them over or re-listen if they are having concentration issues.
- Exempt from physical education, and no need to go outside at recess (this may depend day to do day if the student has both good and bad days)
- Adjust curriculum if required. This will be something that needs to be negotiated between all parties.
- Reduce class load, depending on the grade the student is in. This may require the student to be in school for additional years. This will be something that needs to be discussed and mutually agreed upon.

## **Limit Stress**

To reduce stress, which is known to exacerbate the symptoms of this condition, consider the following

modifications to classroom organization, school schedule and expectations:

- Tests and exams:
  - If a student is unable to write an exam due to CRPS in arm(s) or hand(s), allow use of speech to text software, have someone transcribe to write their test answers, modify the type of tests
  - Allow for additional time to complete tests and exams
- Mobility stressors:
  - Try to confine all classes on first level of school, or provide access to elevator
  - If unable to complete physical education (P.E.) requirements, credit their physical therapy as a requirement for gym (ie. use P.E. time to do their prescribed exercises given by physiotherapist, or practice their cognitive therapies like breathing exercises, yoga, meditation)
  - If crowded hallways, allow student to leave class 5 minutes early to prepare for classroom change, or early dismissal.
  - For older students, who are able to drive, provide designated parking space close to doors.
- Homework and classroom activities:
  - Have flexible homework deadlines if they are unable to meet the deadline within reason, or give additional time to complete.

- If students unable to attend class, provide home-based instructions for how they can make up missed class time. Alternatively, record the class lecture on days they miss.
- Allow student to voice record daily 'lectures' to review at home if needed. Obtain written approval from parents of students in case of student's voices being recorded as well.
- Reduce classroom time. If the last 20 minutes are used to work on assignments, allow student to leave to go to a quite space to work, or focus on reducing pain levels

# Where to get more information:

There are quite a few resources available to better understand CRPS. For further information on this condition, or to talk to others who are well versed in CRPS, we suggest you start by looking at:

- International RSD Foundation: <u>www.rsdinfo.com</u>
- Neurological Associate Pain Management Centre:<u>www.rsdrx.com</u>
- Princess in the Tower: www.princessinthetower.org
- P.A.R.C. Promoting Awareness of RSD/ CRPS in Canada - <u>www.rsdcanada.org</u>

## **Contact Us!**

For more information, resources, and support, please feel free to contact the Foundation, at any time during regular business hours.

#### International RSD Foundation

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