

Guide for Working With Students With Chronic Pain

The purpose of this guide is to assist you in identifying the educational needs of students with chronic pain and related functional impairments in order to design a successful school re-entry plan.

Causes of Chronic Pain

There are many situations and medical conditions that can cause students to experience chronic pain, including:

- Complex regional pain syndrome (CRPS)
- Postural orthostatic tachycardia syndrome (POTS)
- Migraines/headaches or abdominal pain
- Ehlers-Danlos syndrome
- Fibromyalgia
- Pain resulting from surgery or an injury

Impact of Chronic Pain on Academics

Chronic pain can negatively impact a student's ability to attend school on a regular basis. These students may report increased pain when presented with physical or cognitive tasks they find challenging, which allows them to 'escape' demands. This scenario can inadvertently lead to increased avoidance of stressful situations. Students with chronic pain may ask to go to the school nurse frequently or to leave school early.

It often takes many weeks of inconsistent attendance for home teaching services to be recommended, resulting in a significant amount of lost instructional time. Students with chronic pain may also have pain-related mental health conditions or symptoms such as depression and anxiety that can impact or exacerbate their experience of pain. If the student has not been attending school, the anxiety may extend to school re-entry.

In addition to the pain itself, students usually face additional challenges, including the following:

- Attention/concentration difficulties
- Sleep disruption
- Cognitive fatigue or foginess
- Anxiety or depression
- Falling behind in school
- Decreased stamina or weakness
- Decreased initiation



- Increased frustration, helplessness, or hopelessness
- Memory difficulties

Planning for School Re-entry

- **Have a Plan:** Students may benefit from a 504 plan or an individual educational plan (IEP) at the time of school reintegration.
- **Start Slowly:** A gradual re-entry for the first week may be recommended. For example, students might be in school for the entire day, but could participate in a half-day schedule of regular classes and a half-day of one-on-one instruction by a home teacher in a quiet location within the school, such as the library or guidance office. Each case will need to be considered for the best reintegration plan.
- **Meet Regularly:** It may be recommended that students meet regularly with their guidance counselor or another trusted school staff member in order to monitor and support their adjustment upon returning to school. These meetings may be informal, but should be initiated by the staff member.

Helping Students Cope with Chronic Pain

School personnel should generally try to interact with the students in the same manner they interact with other students. Students should be discouraged from going to the nurse's office if their

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complaints of usual pain can be redirected. In most cases, students should be discouraged from calling their parents or leaving school early due to usual pain, fatigue, or weakness. Instead, they should use coping strategies that they have been taught.

However, if a student exhibits what appears to be significant pain, weakness, fatigue, or behavior or medical issues unrelated to the student's medical condition (e.g., temperature, diarrhea, emesis, etc.), school personnel should assess the student's health status as they would any other student in the school, make an informed decision about the student's health needs, and notify parents as appropriate.

A few other suggestions include:

- **Refrain & Redirect:** Staff should refrain from asking students about their pain, which may serve to focus the student on it. Instead, if the student expresses pain, frustration, or other negative comments, they should be acknowledged briefly (e.g., saying, "I'm sorry you are not feeling well") and then redirected to the task at hand. It may be beneficial to redirect the student to small, concrete steps to initiate challenging tasks. If necessary, he/she may be cued to use coping strategies.
- **Structure Breaks:** In addition to the use of other coping skills, students may benefit from time-limited, structured breaks throughout the day (i.e., pre-planned times versus allowing the student to determine when he/she needs a break). The student should be discouraged from taking breaks in the nurse's office, and another location should be identified, such as the guidance office.
- **Take It Day by Day:** School personnel should be aware that students will have good days and more difficult days, during which they may require more encouragement, support, and redirection. This variability is normal and to be expected.
- **Provide Positive Reinforcement:** Frequent, labeled verbal praise (e.g., "Great job completing your homework!") for complying with demands is strongly recommended to encourage ongoing progress. Providing extra positive attention to other aspects of the student's behavior (e.g., participation in academic or extracurricular activities, using coping skills, and tolerating challenging activities) is also recommended.

Ways to Support Caregivers

- **Emotional Support:** Families who have children with chronic pain may also, understandably, experience anxiety and distress related to their child's medical condition, symptoms, and school difficulties. Parents may be encouraged to seek support for themselves.
- **Environmental Support:** Parents may benefit from environmental support in helping their child attend school. Examples are the use of a daily schedule, a reinforcement plan for participation, and consultation with an educational specialist and outpatient mental health providers.

- **Consistent Communication:** It will be important for caregivers and school staff to have consistent communication to encourage a successful school re-entry.

Pediatric Pain Rehabilitation Program at Kennedy Krieger Institute

The Pediatric Pain Rehabilitation Program at Kennedy Krieger Institute treats children and adolescents with chronic pain that has resulted in functional disability. The program is geared toward functional rehabilitation with an interdisciplinary focus. The goals of the program are:

- To help individuals develop skills and strategies to cope with their pain and related symptoms (e.g., anxiety). These strategies may include diaphragmatic breathing, relaxation, distraction, and positive self-talk.
- To help individuals participate in daily activities more fully by increasing and reinforcing their tolerance in a gradual and systematic way.
- To help individuals successfully return to school, home, and community life.

Individuals with chronic pain have complex needs, requiring an experienced, interdisciplinary team, including physicians who have experience with chronic pain, physical therapists, occupational therapists, pediatric psychologists, social workers, nurses, neuropsychologists, educators, and therapeutic recreation and child life specialists.

In a school setting, a similar team to support students with chronic pain may include:

- Administrator
- Nurse
- General or special educator
- Guidance counselor
- Psychologist
- Social worker

It may be helpful to identify a trusted staff person to be the "point person" for the student. Coordinating with the student's pediatrician and specialists from the rehabilitation team may also prove helpful.

Contact Information

Pediatric Pain Rehabilitation Program at Kennedy Krieger

For more information or to schedule an appointment, please call **443-923-9400**, or toll-free at **888-554-2080**.

TTY: **443-923-2645** or Maryland Relay **711**
kennedykrieger.org

Address:
707 North Broadway
Baltimore, MD 21205

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