

Do You Suspect You or Your Child Has CRPS? Here is How to Self-Diagnose to Know if You Need to Seek Help

The Netflix documentary Take Care of Maya has raised awareness of, and many questions about, CRPS. First among them is, "Do I have it." Here is how to self-diagnose the signs of CRPS and where to look for the right medical help.

By James Doulgeris

CRPS, or Complex Regional Pain Syndrome, is so painful it is also known as the suicide disease. It is rare, but as more pediatricians become aware of it, it may not be so rare in children as it has been rarely diagnosed. That's important because treatment within a month or two of onset can avoid long-term disability and a lifetime of misery in many cases.

The story of Maya Kowalski in the Netflix documentary *Take Care of Maya* has set off alarm bells among adults and parents with unexplained, acute chronic pain. Her forced custody by Johns Hopkins All Children's Hospital in St. Petersburg, Florida by Florida's Child Welfare Services eventually resulted in false claims of abuse by her parents and her mother's eventual suicide. While tragic, suicides connected with CRPS occur an estimated twice weekly.

How CRPS starts is usually a minor event. Here is one: Twelve-year-old Jorja suffered a seemingly minor fall during a PE class at school. She was diagnosed with a sprained ankle but despite undergoing physical therapy and wearing a cast for several weeks, Jorja's pain and symptoms continued to worsen. Eventually, the pain spread to other parts of her body, including her hands and arms. She experienced constant pain, and her mobility was severely limited. Her doctors were stumped but her family did not have the resources to get her the specialized care she needed.

Jorja's family struggled for months to gain access to a specialist who finally diagnosed her with CRPS. By then, the specialized care, support, and treatments that she needed were priced out of reach and came too late. Her disabilities will last a lifetime. Her family launched a fundraising campaign to help cover the costs of her treatment, and they became advocates for greater awareness and understanding of CRPS.

Jorja's story is a reminder of the importance of early recognition and diagnosis of CRPS. Had she been diagnosed and received proper treatment within a few months of onset, her life may have turned out very differently.

Physicians are slowly becoming more aware of this condition that affects about 1 in 1,800 people, but, as parents, we know our children best. Furthermore, as more physicians become aware, especially children, more patients are being diagnosed. ***It could be that this rare disease is less rare than it is rarely diagnosed.***

Here is what to look for, what to do, and where to find the right help in time to give your child and family the best chance to manage CRPS:

The Painful Facts

Complex Regional Pain Syndrome (CRPS), also known as Regional Sympathetic Dystrophy (RSD), is a chronic pain condition that affects one or more extremities, usually after an injury, surgery, or trauma. It may not have an identified cause at all. It can spread to affect the entire body.

It has no cure and gets worse over time. There are therapies that can slow its progression and in younger people, can even stop or reverse it into remission.

It is among the most painful conditions known to medicine and the most painful chronic condition known scoring a 42 out of 50 on the McGill Pain Scale.

Although CRPS is more commonly seen in adults, it is increasingly seen in children, typically girls ages 10 to 15 with a peak at age 12. Boys, however, get their fair share of cases and deserve their fair share of attention.

Treatment within the first two months of onset can make a lifetime of difference. And rare is a relative term. CRPS affects less than one in two thousand people.

Whether girls or boys and regardless of age, look for these telltale signs and symptoms:

If your child has ***pain that is getting worse, especially if it is more severe than one would expect*** from the original injury, trauma, or medical procedure, and that pain is:

- Described as deep, aching, cold, or burning, especially with increased skin sensitivity,
- Persistent and excessive and does not subside with healing,
- Moderate to severe caused by something that should not cause pain at all such as the touch of clothing, touching a room temperature metal or stone object, or taking a shower,
- In areas that should not be painful at all,
- Accompanied by abnormal swelling, sweating, skin color changes, hair and/or nail growth,
- Associated with abnormal skin temperature, that is, one side of the body, a foot, or a hand, warmer or colder than the other by more than 1°C or 2°F,
- Limited range of motion, weakness, or other motor disorders including paralysis or dystonia, which is involuntary, repetitive movement.

CRPS in children can be challenging to diagnose since children may not be able to describe their symptoms accurately. Therefore, a thorough evaluation by a pediatrician or a specialist in pain management is necessary.

Treatment for CRPS in children involves a multi-disciplinary approach, which will include pain management specialists and may include medication, physical therapy, occupational therapy, and psychological support. Every patient's needs are different because their experience is different. Pain medications, such as drugs used to treat neuropathy and nerve pain, ketamine, non-steroidal anti-inflammatory drugs (NSAIDs) can help relieve pain and inflammation although stronger pain medications such as opiates in severe cases may be required. Non-invasive treatments such as mirror therapy and graded motor imagery have proven to be especially effective.

In severe cases, invasive treatments such as nerve blocks or spinal cord stimulation may be recommended. However, these treatments are typically reserved for cases that have not responded to other therapies.

It is essential to seek prompt medical attention if you suspect your child has CRPS or any chronic pain condition. Early diagnosis and treatment can help prevent long-term complications that can worsen over a lifetime and improve outcomes.

Because rare diseases are rare, they are not well understood, and researched nor do they have well-established treatment, drug, or therapy protocols, called best practices. That makes the healthcare provider landscape difficult to navigate. A trained physician may be miles away.

What to do when doctors dismiss your child's symptoms or say they are at a loss?

Most doctors will see one or two CRPS cases in their lifetimes. If your doctors have not been able to diagnose the underlying cause of your child's excessive pain, it can be a frustrating and challenging situation. Here are some steps you can take:

1. Seek out a specialist in CRPS. They can perform a thorough evaluation and provide an accurate diagnosis. A pediatrician, neurologist, or pain management specialist may be a good starting point. Use Internet Search Engines, CRPS support groups and Pain Management Centers. Be tenacious and choose with care.
2. Learn as much as you can about CRPS, its symptoms, and treatment options. This information can help you become a better advocate for your child's care and treatment. An excellent resource for children with CRPS can be found on the RSDSA website by [clicking here](#).
3. Encourage your child to keep a diary of their symptoms, including when they occur, how long they last, and any triggers that seem to worsen the symptoms. Share this information with your child's doctor.
4. Take pictures of color, hair, or nail changes in the affected area, particularly when they are associated with spikes in pain.
5. Keep a diary of signs of depression such as sudden mood changes, disinterest in hygiene, eating, or socialization. Get help if they worsen.
6. Keep a healthy lifestyle and stay as active as possible: Encourage your child to adopt healthy lifestyle habits, such as getting regular exercise, eating a balanced, anti-inflammatory diet, and getting enough sleep. These habits can help improve overall health and reduce the impact of chronic pain.

Once you find the right medical team and effective treatment for your child's chronic pain, keep an open mind to alternative therapies and emotional support in consultation with your doctor.

CRPS is a lifelong passenger.

CRPS is not going to go away, even if it goes into remission, so it's important to remain diligent and to continue regular monitoring with your child's physicians. CRPS is a complex and multifaceted condition,

not only its diagnosis and treatment can be challenging but its changes over a lifetime can be as well. Remain very aware of your child's emotional and mental well-being.

The chronic pain associated with the condition can and will be a significant source of stress and anxiety over time. Suicidal ideation (obsessive thinking about suicide) among CRPS patients is as much as 75 percent in some peer-reviewed studies. It is associated with severe depression and is a real-life problem in the CRPS community.

Overall, the key to managing CRPS in children is to stay informed about the condition and treatment options and provide ongoing support and care to help your child manage their symptoms and maintain their quality of life.

Lastly, as someone who has lived with CRPS for decades, have and be that family that never lets the patient be a victim. Life will be hard enough. Live it together.

For more information on CRPS, visit the [RSDSA](#) website, and please consider a donation to this important cause.

Jim is a healthcare professional and CRPS patient with whole body involvement. He chairs the Population Health Advisory Board for RSDSA and provides content about treatments and living with CRPS. Since medically retiring after 35 years in CEO roles in hospitals, medical device companies and value-based care providers, he stays active by advising healthcare companies and systems in the AI and analytics spaces. He also works to improve care and treatments for the rare disease community including the first initiative to use clinical and claims analytics to identify, diagnose and treat rare disease beginning with CRPS/RSD. As award winning novelists for "The Dyodyne Experiment," Dougeris is hard at work on its sequel, "Sentience." He is also an active journalist writing articles and providing background and interviews on healthcare for national publications and news outlets.