Treating Complex Regional Pain Syndrome

By Kelly Mickle, Special to Lifescript
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You sprained your big left toe weeks ago, but instead of healing, the pain has grown, and now your right foot aches too. What gives? Complex regional pain syndrome is a chronic condition that often affects arms and legs and lasts weeks longer than it should. What is this elusive pain disorder? Doctors explain and share how new treatments can help...

An ankle sprain or broken wrist is uncomfortable and inconvenient, but with proper treatment you can recover completely.

But for some people, even small traumas can lead to a severe and debilitating pain disorder called complex regional pain syndrome (CRPS).

The exact cause is unclear, but research suggests it may result from nerve damage after an injury.

It feels like an intense throbbing or burning. Instead of getting better as days go by, the pain grows.

“Pain neurons [at the site of an injury] are only supposed to fire briefly to signal a problem,” says Anne Louise Oaklander, M.D., Ph.D., director of the Nerve Injury Unit at Massachusetts General Hospital in Boston. “But in CRPS, these neurons get short-circuited, causing them to fire continually – resulting in prolonged, debilitating pain.”

CRPS affects as many as 1.2 million Americans, and up to 75% are women, according to the Reflex Sympathetic Dystrophy Syndrome Association, a nonprofit that aims to help educate sufferers, insurance companies and health-care providers. (Reflex Sympathetic Dystrophy Syndrome is another name for CRPS.)

A Mysterious Condition

Because the pain often seems out of balance with the level of harm initially suffered, many patients’ concerns are dismissed.

“A doctor sees someone in agony over a sprained ankle, and it seems so exaggerated and out of proportion to the injury that they have a difficult time believing the pain is real,” explains chronic pain
specialist Robert Schwartzman, M.D., chairman of the neurology department at Drexel University College of Medicine in Philadelphia.

In 2006, Oaklander and other Massachusetts General researchers discovered key evidence of a physical abnormality linked to CRPS.

“The skin in the affected area appears to have lost some small nerve-fiber endings,” Oaklander says. “These nerve endings transmit pain messages, control skin color and temperature, and may be involved in other pain disorders – so we believe they may also be linked to CRPS.”

Other research suggests an immune response following the injury may irritate pain neurons, causing them to fire, adds Schwartzman.

That may help explain the fact that more women have the disorder.

“We aren’t exactly sure why, but women are more susceptible to autoimmune problems,” he says. Another group at risk for the pain disorder: People with broken bones.

Having your arm or leg in a cast following a fracture inhibits movement, which can further reduce blood flow and worsen damaged nerves.

So you should see a doctor immediately if swelling and inflammation worsen within the first few days of getting the cast, advises Oaklander.

In rare cases, even donating blood can put you at risk for CRPS.

“There are two sensory nerves that wrap around the vein where blood is drawn,” says Oaklander. “If this nerve is accidentally pricked or injured during blood donation, you can wind up with symptoms of CRPS.”

Fortunately, these cases are very mild and can be easily treated, so consult your doctor if you notice discomfort following blood donation.

**Decoding the Symptoms**

Besides an intense throbbing pain that gets worse instead of better, the affected area in CRPS may also be extremely sensitive to touch and subject to drastic changes in temperature and color. “Overstimulated pain nerves change how blood vessels react,” Schwartzman says. “As they dilate, it causes the area to turn hot, red and swollen. And then they constrict, leaving the area cold and blue.”

These damaged nerves are also connected to your sweat glands, bones and muscles, so their misfiring results in excessive sweating, muscle spasms, joint stiffness and decreased mobility, Schwartzman says.

While pain may begin at the point of injury, in some cases it spreads.
“Some people find the pain that started in their right foot will suddenly appear in their left foot,” Schwartzman says. “We believe this may be caused by a reorganization of nerves and neurotransmitters caused by the trauma.”

“Left untreated, complex regional pain syndrome will continue to get worse, and joints and muscles may begin to weaken and atrophy,” says pain-management specialist Charles Argoff, M.D., a neurologist at the Albany Medical Center in New York.

Changing the way you stand, walk or hold yourself in an attempt to alleviate pain in the affected limb can also lead to back, neck and shoulder problems, Argoff says.

“Symptoms vary from person to person, but the sooner you receive treatment, the more effective it will be,” he says. Getting a Diagnosis
Identifying the problem can be extremely difficult if your doctor doesn’t know what to look for.

That’s especially true of what’s called type 2 CRPS.

While type 1 is caused by an injury you can see, type 2 results from nerve damage whose origins may be unclear.

“Women are often misdiagnosed with fibromyalgia, another chronic syndrome characterized by bodywide pain,” Schwartzman says. “And doctors unfamiliar with complex regional pain syndrome still assume patients are embellishing their symptoms, so it’s important to be persistent until you get the care you need.”

Unfortunately, there’s no single test to determine whether you have CRPS.

Neurologists and peripheral nerve specialists are best trained to make the diagnosis.

“They’ll conduct a clinical exam to measure skin temperature, sweat, skin sensitivity and circulation in affected limbs, which can all [show] signs of the condition,” Oaklander explains.

“Bone scans and X-rays may also be used, as CRPS can reduce blood flow and cause loss of bone minerals and other changes in bone cartilage,” Schwartzman says. “And an MRI can also reveal tissue damage that signals CRPS.” Getting Treatment
While there’s no cure for complex regional pain syndrome, early treatment can slow progression of the condition and, for many people, lead to a state of remission.

The first rule is to stay active, even if your natural instinct is to give your body a break.

“If you don’t use it, you lose it,” Argoff says. “Early movement and physical therapy are crucial to restoring circulation and mobility in the affected area. If you remain stationary and don’t get your blood pumping, the swelling may worsen and muscles may begin to deteriorate.”

What’s more, brain-imaging tests suggest that if you stop using the limb, the synapses that send its
messages to the brain will wither from lack of use and be taken over by signals from more active parts of your body – making it even more difficult to recover normal movement, says Oaklander.

Pain medications are often prescribed to help patients get the exercise needed for rehabilitation.

Corticosteroids are used to ease inflammation, blood pressure medications may be used to improve circulation, and medications such as Fosamax and Miacalcin can help stave off bone loss.

Unfortunately, the condition can have profound psychological effects, and depression and anxiety can heighten the perception of pain.

As a result, antidepressants are sometimes used with other remedies to improve quality of life, says Schwartzman. Injecting Botox into the affected area can reduce pain by almost a third, according to a 2011 study by Schwartzman and colleagues at Drexel University.

The toxin helps paralyze pain nerves, preventing them from firing and helping muscles relax.

Research also suggests that spinal cord stimulation may be successful at treating complex regional pain syndrome.

“Electrodes give off a tingling sensation in the painful area [that replaces the feeling of pain],” Argoff says. “They’ve improved pain control for many patients.”

Another promising treatment are sympathetic nerve blocks – anesthetics administered intravenously to turn off pain receptors, or placed next to the spine to block sympathetic nerves (which mobilize the body’s stress response).

“Within two days of treatment, patients should expect to feel an improvement,” Schwartzman says. “The response is variable, but if it’s successful, it usually lasts for three months. And occasionally, if the patient is treated early, they won’t need any additional rounds of treatment.”

For some patients with an unknown trauma, surgery may be the best option.

“You may have tiny tumors, vascular malformations or entrapment of a nerve, which can be corrected during nerve surgery,” Oaklander says.

“Unfortunately, there’s no one-size-fits-all remedy,” Argoff says. “A combination that works for one patient may not work for another.” Identifying the problem can be extremely difficult if your doctor doesn’t know what to look for.

That’s especially true of what’s called type 2 CRPS.

While type 1 is caused by an injury you can see, type 2 results from nerve damage whose origins may be unclear.
Some simple lifestyle changes appear to also increase your chances of recovery.

“One of the most common barriers I see in healing is smoking,” Oaklander says. “Cigarettes constrict your blood vessels, which means the affected area isn’t getting the oxygen it needs to repair the damage. I’ve seen smoking cessation alone help cure people with complex regional pain syndrome.”

Diabetes can also impair blood flow and prevent damaged nerves from healing, so monitoring your diabetes with help from your doctor, and maintaining a healthy weight through diet and exercise, may also speed recovery, suggests Oaklander.

Whatever your recommended treatment, the first step toward healing is speaking up, Oaklander says.

“This pain is real and you don’t have to live with it,” he insists. “Patients should expect to recover, but you can’t get better if you don’t get help.”

For more expert advice and information, visit our Pain Health Center. How Bad Is Your Back Pain?
So your back hurts? Take our back pain quiz to see how severe it really is. You may need to see a doctor but have just been avoiding it, thinking it will get better. On the other hand, your back pain may be more normal than you suspect. Find out where your back pain ranks in this back pain quiz.