Confronting Complex Regional Pain Syndrome

Knowledge, healthy habits, and early intervention help

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A clinical team approach helps when tackling this baffling, rare syndrome

Complex Regional Pain Syndrome (CRPS) is a perplexing, debilitating, rare syndrome that typically occurs after surgery, and causes pain out of proportion to the original cause. It used to be called RSD – Reflex Sympathetic Dystrophy – but, since that actually doesn't describe anything correctly about the condition, that name was abandoned quite a few years ago.

The pain mostly occurs at the ends of people's limbs, such as the hand and elbow, or foot and knee. The limb may feel weird or different; it may feel hot or cold, seem swollen or turn a funny color. The skin may seem super-sensitive and painful to even light touch that obviously isn't doing any harm.

Probably not more than 1% of injuries or surgeries lead to this condition, in which the person has more pain than a doctor would imagine they should have for what has happened. It perplexes the person as much as their health care providers, as both are trying to relate it all back to the original injury or surgery and it's not making any sense.

Diagnosis

Diagnosis is done through a process of elimination rather than particular identifying tests. Doctors and researchers are still coming to terms with exactly what may cause it. There are some theories, however, that may turn out to be true.

One is that some forms of inflammation start in the limb after injury or surgery (as is typical) but, for one reason or another, the inflammation spreads from the affected tissues to the peripheral nerves, which become inflamed, causing a lot of nerve pain. Subsequently, changes in the spinal cord and brain occur that influence how the nervous system interprets pain signals and these structures may amplify the pain signals coming from the peripheral nerves. This is a very complex process that is not really well understood.

What we do know is that the longer one has CRPS without specific treatment aimed at the condition, the more difficult it is to treat and the less impressive the results of treatment. So there is a real push on to have people diagnosed early and treated by doctors familiar with the condition, such as pain specialists, rehabilitation specialists, neurologists, etc., in conjunction with physical therapists such as physiotherapists, hand therapists, and occupational therapists.

Changing treatments

Treatments have changed over the past 10 years and probably will continue to change, as more is learned about the condition. There are some things that doctors agree upon:

- One feature of CRPS is that the brain tends to focus away from the space in which the limb exists – in essence, ignoring the limb. However, as contrary as it may seem, it is better to use the affected limb, even

though it is painful. People with CRPS must make a concerted effort to be mindful and use their limb, going against the brain's natural impulse to disassociate from the limb.

- The limb is not damaged and does not need to be rested to "heal". One cannot trust the pain sensation as an indication of the condition of the limb. Acknowledging that the limb is not really damaged is the key to overcoming the stress, anxiety, fear, anger, and depression that often accompany CRPS. Negative emotions actually increase the pain; whereas, positive thoughts actually decrease the pain. In conjunction with physical therapy, psychological therapy often is prescribed to teach coping skills and how to replace negative thoughts with positive ones.

- Certain behaviors tend to aggravate the symptoms, and make CRPS more difficult to treat. Persons with the condition are strongly advised to avoid smoking, excessive alcohol and caffeine consumption, and sleep deprivation. Leading a healthy lifestyle will give one the best chance of a good outcome.

- For some patients, there is the option of treatment with spinal cord stimulation, in which an implanted device, like a pacemaker, stimulates the spinal nerves with a mild electrical current that replaces the pain with a tingling sensation, or no tingling sensation as another option. In rare cases where patients also suffer muscle spasms, they may receive intrathecal drug infusion, in which an implanted pump and catheter deliver antispasm medication (Baclofen) directly to the cerebrospinal fluid. Generally, the pain specialist will know who is a candidate for these treatments or not.

- If pain spreads to other areas it is almost always muscle pain, which needs to be addressed with a rehabilitation approach. CRPS spreading to other areas is very rare indeed and patients need not fear this. The general goal in treating CRPS is to decrease the intensity of the pain and/or spasm.

For those who experience it first-hand, CRPS can be a scary condition. Knowing that you are not alone, that your limb will improve if you use it as normally as possible, and that you can ultimately influence your condition by maintaining a healthy lifestyle are all crucial points to remember. The more you learn about CRPS the more control you will feel you have over it.

Please note: *This information should not be used as a substitute for medical treatment and advice. Always consult a medical professional about any health-related questions or concerns.*

For further information see:
WIKISTIM at http://www.wikistim.org – This free-to-use collaborative, searchable wiki of published primary neuromodulation therapy research was created in 2013 as a resource for the global neuromodulation community to extend the utility of published clinical research. The goals of WIKISTIM are to improve patient care and the quality of research reports, foster education and communication, reveal research needs, and support the practice of evidence–based medicine.

Further reading

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Resources

Reflex Sympathetic Dystrophy Syndrome Association of America
https://www.rsds.org/

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