

INSURANCE ISSUES IN THE MANAGEMENT OF COMPLEX REGIONAL PAIN SYNDROME (CRPS)

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Abstract: Complex regional pain syndrome (CRPS) is a disease caused by a minor trauma either accidentally or surgically to an extremity. CRPS is a rare disease misunderstood by many in the medical community and the insurance industry. CRPS is a very painful and complicated syndrome in its own right.

This article will discuss the many issues that CRPS patients address from insurance companies, (be it private insurance companies, workers compensation insurance companies, or social security) and also from the medical community.

CRPS patients endure a great amount of stress and abuse from the insurance companies just to receive a proper diagnosis and treatment. These improper actions from the insurance companies result in a great disservice to all patients handling a legal case.

Until the medical community and the insurance industry become educated about CRPS, patients will endure many years of unnecessary issues.

Keywords: Complex regional pain syndrome (CRPS), Insurance denials, Independent medical examiner (IME), Social Security Disability Insurance (SSDI), Workers compensation insurance.

INTRODUCTION

On December 7, 1985, I developed complex regional pain syndrome (CRPS) because of an automobile accident. It has been over 31 years since my accident and I can now say that I am a survivor of CRPS.

In some cases, the delay in diagnosis of CRPS may take up to a few months to a few years. As in my case, it took two and a half years to receive a proper diagnosis of CRPS. After the diagnoses of CRPS, the insurance issues (nightmares) start to begin for the patient, which could last for many years.

While working with the CRPS community for over 27 years, I have received hundreds of thousands of e-mails, letters and telephone calls from CRPS patients worldwide. I am still amazed at how many CRPS cases are similar when it comes to dealing with insurance companies issues.

The stories that I have heard over the years, sounds like the same case scenario from patient to patient. Most CRPS patients share the same story of insurance company denials and abuse. This would not be such a problem if it only happened to a few select cases, but when it is happening to thousands upon thousands of CRPS patients, then it starts to become an issue.

It is vital that patients find a good lawyer (who has other CRPS cases) to assist them to fight the insurance companies to protect their legal rights for proper treatment, medications, and compensation.

Today's insurance company issues are not just a problem for CRPS patients living in the United States, it also affects CRPS patients worldwide.

Addressing these ongoing insurance company issues are a must to aid patients to achieve a good quality of life when dealing with such a life changing disease as CRPS.

SYMPTOMS OF CRPS

In many cases, CRPS can develop after a work-related injury, a car accident, or in some cases from surgery or both. Another way of developing CRPS is from venipuncture injuries (e.g. caused by blood work) (1).

Many symptoms of CRPS may take hours, days, weeks or even months after the initial injury, before the first signs of the disease are even present. Multiple symptoms associated with CRPS can affect each patient differently (Table I). The number one symptom that most patients experience is burning pain in the extremities. Part of the misconceptions of CRPS is that not all symptoms need to be present simultaneously to have the disease.

Table I. Symptoms of CRPS	
Burning pain in the extremities	Edema (Swelling of the extremities)
Chronic pain after injury or surgery	Hypersensitivity to touch
Cold feeling in the extremities	Limited range of motion
Discoloration of the skin	Muscle spasms

STAGES OF CRPS

The stages of CRPS are now divided into four distinct stages depending on the injury. These stages vary in their duration.

In our research of 22 patients suffering from venipuncture CRPS II, deterioration from stage I to stage III appeared in a few weeks up to less than 9 months (1).

- Stage I is a sympathetic dysfunction with the typical dermatomal distribution of the pain. The pain may spread in a mirror fashion to the contralateral extremity or to adjacent regions on the same side of the body (2,3). In stage I, the pain is usually sympathetically maintained pain (SMP) (Table II) (2,4).
- In stage II, the dysfunction changes to dystrophy manifested by edema, hyperhidrosis, neurovascular instability with the fluctuation of livedo reticularis and cyanosis – causing a change of temperature and color of the skin in a matter of minutes. The dystrophic changes also include bouts of hair loss, ridging, dystrophic, brittle and discolored nails, skin rash, subcutaneous bleeding, neurodermatitis, and ulcerative lesions (4).
- In stage III, the pain is usually no longer SMP and is more likely a sympathetically independent pain(SIP). Atrophy in various degrees appears in the extremities. Frequently, the atrophy appears much more prominent by subcutaneous edema. The complex regional pain and inflammation spread to other extremities in approximately one-third of CRPS patients (5-7). At stage II or III it is not at all uncommon for CRPS to spread to other extremities (3,4,8-10).
- Stage IV is almost the flip side of the earlier stages and points to exhaustion of autonomic and immune system's nature (4). Below are the symptoms of stage IV:

- (i). Failure of the immune system, reduction of helper T-cell lymphocytes and elevation of killer T-cell lymphocytes.
- (ii). Intractable hypertension changes to orthostatic hypotension.
- (iii). Intractable generalized edema involving the abdomen, pelvis, lungs, and extremities.
- (iv). Ulcerative skin lesions which may respond to treatment with I.V. Mannitol, I.V. Immunoglobulin, and ACTH treatments. Calcium channel blockers such as Nifedipine may be effective in treatment (11).
- (v). High risks of cancer and suicide are increased.
- (vi). Multiple surgical procedures seem to be precipitating factors for the development of stage IV.

Table II. With the passage of time and types of treatment, CRPS goes through stages with variable time tables and sympathetic responses (2).

Stages	Signs / Symptoms
Stage I: Dysfunction	Hyperpathia; Allodynia; muscle weakness; flexor spasms; thermal changes
Stage II: Dystrophy	Edema; Skin; hair and nail changes
Stage III: Atrophy	Muscle Atrophy; neurovascular instability; cutaneous rash or skin ulcers
Stage IV: Irreversible disturbance of plasticity; autonomic failure	Systemic Autonomic failure; visceral edema; irreversible low BP; MRSA; elephantiasis; cancer

INSURANCE COMPANIES AND CRPS

Many CRPS patients become involved with insurance companies' due to either a worker's compensation claim, a personal injury claim or even a social security claim. These claims are not easy to handle when the patient is dealing every day with the constant chronic pain of CRPS. Dealing with such claims produce an added stress for the patient having to address lawyers, insurance companies, insurance company doctors, worker's compensation case workers and nurses. CRPS patients should try to avoid the added stress from these insurance company issues at all cost.

After the patient's injury and diagnosis of CRPS, the first step that the insurance companies take is to send the patient surprisingly to their "so-called CRPS expert" which the insurance companies classify as an independent medical examiner (IME). These "so-called experts" are paid very well by the insurance companies to provide them with a favorable report stating that the patient does not suffer from CRPS or that the patient is making this whole situation up. This whole case scenario that the insurance companies can demand that a patient needs to see their "so-called CRPS experts" is very unnecessary. No CRPS patient should ever endure such unnecessary treatment from an insurance company.

In some cases, the insurance companies may agree that the patient does have CRPS, but they will still send the patient to their doctors who have no knowledge of what CRPS is or even know how to treat it properly. Some of these "so-called CRPS experts" are not even in the field of neurology or even pain management to render an expert opinion if a patient has CRPS.

The insurance companies will use doctors in other fields such as orthopedic surgery, psychiatry, chiropractic, family medicine, plastic surgery, to render them a favorable report to deny treatment, medication or compensation to the patient.

Most of these so-called insurance company CRPS experts will recommend that the patient should have at least three stellate ganglion nerve blocks or surgery which they claim will cure the patients CRPS.

When these three nerve blocks do not work or provide some pain relief, they will recommend that the patient start on a regimen of strong addicting narcotics (e.g., Morphine, MS Contin, and Methadone, etc.), and also recommend that the patient needs surgery. These “so-called CRPS experts” inform the insurance companies that they can cure the patients CRPS with surgery (e.g., sympathectomy, spinal cord stimulator (SCS), etc.).

So, when the insurance companies are informed by their “so-called CRPS expert” that there may be a cure for CRPS, their eyes light up like a bright flame. They figure that it would be cheaper for them to pay for that unnecessary and destructive surgery, then it would be for them to pay the patient’s insurance claim.

The insurance companies know all too well that these procedures and medications will not cure CRPS, and they also know that it may eventually kill the patient.

MEDICATION AND CRPS

With the high cost of medications today, patients cannot afford the medications they need for treatment. In most cases, they wind up without medication. The insurance companies have become very unpredictable when it comes to covering the cost of pain medications for CRPS patients. They will either refuse to pay for the medications or they tell the patient that it’s not on their formulary list. In some cases, patients are told that the medications they need are not specified for the condition of CRPS.

Insurance company denials can be very frustrating for the patient and the prescribing physician. In the long-run, the patient suffers the most because of these denials. Part of the problem with the insurance company’s denial to cover the medications that the patient needs, stems from their lack of knowledge about CRPS. The insurance companies are more than happy to approve and pay for unsafe medications such as Morphine, Dilaudid, and Methadone.

From 1995-2002 we documented 10 patients suffering from CRPS who died because of Methadone toxicity (MT). Methadone Related Deaths (MRD) has been recognized for decades. It has become a “global epidemic” for many chronic pain patients, including CRPS patients, and patients suffering from drug dependency (12).

Doctor Hooshmand and I had been in personal contact with 10 CRPS families who lost loved ones’ due to MT, which can cause respiratory failure. Three out of the 10 CRPS patients that died, were waiting to go to Doctor Hooshmand’s clinic as new patients (12).

Over the past few decades, Methadone has become an overly prescribed medication because it is less expensive (for the insurance companies) than other opioids prescribed to treat chronic pain and drug addiction (12-15).

Methadone kills and these insurance companies and their “so-called CRPS experts” know this. The insurance companies and their “so-called CRPS experts” act like they are God and they think that they have the right to dictate what medication and what treatment the patient should have.

INSURANCE COMPANY CLAIM DENIAL

Most CRPS patients do experience some form of an insurance company claim denial, may it be for proper treatment or medications to treat their CRPS.

Also, the insurance companies are known to deny payments of medical bills. Patients who have claims with worker’s compensation endure the most difficult time with their claims, with constant denial for treatment, medication or for durable medical equipment (e.g. wheelchairs, crutches, handicap ramps, etc.), recommended by their treating CRPS physician.

Over the years, I have known many CRPS patients stuck in the worker's compensation web of denial and abuse. These patients must fight tooth and nail for their legal rights to receive proper and safe treatment and medication after the state worker's compensation judge ruled in the favor of the CRPS patient.

Most insurance companies think that they can disregard the ruling of the judge and once again deny the CRPS patient of their legal rights for proper treatment and medications. Since when did these insurance companies get their medical degrees and become doctors? How are they able to tell CRPS patients and their treating physicians that the treatments and medications that the patient needs are not going to be approved? This practice is a frustrating issue when dealing with the insurance companies. In addition, they deny patients any form of helpful treatment.

Surprisingly these insurance companies have the power to defy what a judge has ruled on. It seems like the patient has no rights when it comes to worker's compensation laws. By state law, each employee and employer pay into the worker's compensation system. This protects both the employee and the employer if an accident ever does occur.

The biggest problem that most CRPS patients face with these insurance companies is their lack of comprehension of the disease. They don't understand or don't believe that CRPS can develop after a work-related injury, a car accident, a personal injury or surgery. Also, they don't understand or recognize that CRPS can spread to other parts of the body (2).

Insurance claim denials are not just related to worker's compensation cases. Patients with personal injury claims, medical malpractice claims, and even a social security claim also experience these same types of denials.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI) AND CRPS

For many patients who become disabled due to CRPS, will eventually apply for Social Security Disability Insurance (SSDI). In many cases, their claim may not be approved when they first apply for SSDI. When the patient receives a denial of SSDI benefits, they have the right to appeal the decision to the Social Security Administration. The patient has up to three appeals when applying for SSDI. After the patient receives the second denial they must hire a lawyer (who deals with disability law) on the third appeal to assist with the appeal process. This process may take up to a few years before the SSDI claim is approved.

The following are some helpful tips for CRPS patients when applying for SSDI or for a denial claim:

- Obtain a well-documented medical report from your treating physician stating that you do suffer from CRPS and that you are disabled from the disease.
- Submit documentation of all your medical history about your CRPS.
- Include documentation of all the treatments and medications that you use for your CRPS.
- List all your limitations due to your CRPS.
- Submit well-documented published medical articles about CRPS.
- Make sure your doctor and lawyer (that deals with SSDI claims) are well versed in the comprehension of CRPS.
- Last but not least, please don't lose confidence if you get denied a few times after applying for SSDI (this happens to many CRPS patients, so you are not alone). If you have both a good doctor and good lawyer on your side it will aid you with your claim for SSDI.

The following information about the Social Security Ruling, SSR 03–2p can be quite helpful to CRPS patients and their lawyers when applying for or appealing an SSDI claim.

On, October 20, 2003, Social Security published in the Federal Register a ruling [SSR 03-2p]. Titles II and XVI: Evaluating Cases Involving Reflex Sympathetic Dystrophy Syndrome/Complex Regional Pain Syndrome.

This ruling explains the Social Security policies for developing and evaluating Title II and Title XVI claims for disability based on Reflex Sympathetic Dystrophy Syndrome (RSDS), also known as Complex Regional Pain Syndrome, Type I (CRPS) (16).

CONCLUSION

For many patients, dealing with the stress of having such a relentless disease such as CRPS and then adding the frustration of dealing with an insurance company to fight for their legal rights for proper treatment and medications is the worst combination that a person could ever have to address. These insurance issues disrupt the management of CRPS which can cause more stress and pain (e.g. spread of the disease) for the patient.

It's a shame that CRPS patients around the world endure the many insurance issues from someone who works for an insurance company that has no comprehension of what CRPS is or what the patient is dealing with daily. This person should not have the authority to be able to dictate what treatments, medications, or durable medical equipment that a patient can or cannot have. The many helpful and safe CRPS treatments and medications that could eventually aid the patient to have a good quality of life get denied because of the lack of knowledge of the disease. This form of denial and abuse is not appropriate.

It is very frustrating when these insurance companies deny a patient safe medication known to aid CRPS pain. They would rather approve payment for the highly addictive opioids such as Morphine, Dilaudid, and Methadone. The reason for this is that these strong and addictive opioid medications are a cheaper alternative for the insurance companies. Why would they want to pay more money for something safer and that could assist the patient? This is the way these insurance companies think. They feel that paying less or denying a claim is the best plan of action for their yearly operation cost.

Patients must remember they have the right to challenge every denial that the insurance company submits. The insurance companies by law have to provide to the patient their appeal process for the claims that they denied.

There should be more fundamental education about CRPS which should be taught to all insurance companies, the worker's compensation system, worker's compensation case managers and nurses who address these types of cases. When everyone is educated about the disease, it will make life easier for the people who suffer from the disease.

At, some point there needs to be a proposal to change the law to assist and protect the patients and not the insurance companies.

REFERENCES

1. Hooshmand H, Hashmi M, Phillips EM. Venipuncture complex regional pain syndrome. *AJPM* 2001; 11: 112-124. http://www.rsinfo.com/Venipuncture_CRPS-II_Article.pdf
2. Hooshmand H, Phillips EM. Spread of complex regional pain syndrome (CRPS). www.rsdx.com and www.rsinfo.com Feb 2015; 1-11. http://www.rsdx.com/Spread_of_CRPS.pdf
3. Veldman PH, Goris RJ. Multiple reflex sympathetic dystrophy which patients are at risk for developing a recurrence of reflex sympathetic dystrophy in the same or another limb. *Pain* 1996; 64:463-466. <https://www.ncbi.nlm.nih.gov/pubmed/8783310>
4. Hooshmand H, Hashmi H. Complex regional pain syndrome (CRPS, RSDS) diagnosis and therapy. A review of 824 patients. *Pain Digest*. 1999; 9: 1-24. http://www.rsdx.com/CRPS_824_Patients_Article.pdf
5. Chelimsky T, Low PA, Naessens JM, et al. Value of autonomic testing in reflex sympathetic dystrophy. *Mayo Clinic Proceedings* 1995; 70:1029-1040. <https://www.ncbi.nlm.nih.gov/pubmed/?term=Chelimsky+T%2C+Low+PA%2C+Naessens+JM%2C+et+al%3A+Value+of+autonomic+testing+in+reflex+sympathetic+dystrophy.+Mayo+Clinic+Proceedings+1995%3B+70%3A1029-1040>
6. Fredriksen TA, Hovdal H, Sjaastad O. "Cervicogenic headache": clinical manifestation. *Cephalalgia* 1987; 7:147-160. <https://www.ncbi.nlm.nih.gov/pubmed/?term=Fredriksen+TA%2C+Hovdal+H%2C+Sjaastad+O%3A+%E2%80%9CCervicogenic+headache%E2%80%9D%3A+clinical+manifestation.+Cephalalgia+1987%3B+7%3A147-160>
7. Moskowitz MA. The neurobiology of vascular head pain. *Ann Neurol* 1984; 16:157-168. <https://www.ncbi.nlm.nih.gov/pubmed/?term=Moskowitz+MA%3A+The+neurobiology+of+vascular+head+pain+Ann+Neurol+1984%3B+16%3A157-168>
8. Kozin F, McCarty DJ, Sims J, Genant H. The reflex sympathetic dystrophy syndrome. I. Clinical and histologic studies: evidence of bilaterality, response to corticosteroids and articular involvement. *Am J Med* 1976; 60:321-331. <https://www.ncbi.nlm.nih.gov/pubmed/56891>
9. Radt P. Bilateral reflex neurovascular dystrophy following a neurosurgical procedure. Clinical picture and therapeutic problems of the syndrome. *Confinia Neurol* 1968; 30 (5): 341-348. <https://www.ncbi.nlm.nih.gov/pubmed/5732164>
10. Schwartzman RJ, McLellan TL: Reflex sympathetic dystrophy. A review. *Arch Neurol* 1987; 44:555-561. <https://www.ncbi.nlm.nih.gov/pubmed/?term=Schwartzman+RJ%2C+McLellan+TL%3A+Reflex+sympathetic+dystrophy.+A+review.+Arch+Neurol+1987%3B+44%3A555-561>
11. Webster GF, Iozzo RV, Schwartzman RJ, et al. Reflex sympathetic dystrophy: occurrence of chronic edema and non-immune bulbous skin lesions. *J Am Acad Dermatol* 1993; 28:29-32. <https://www.ncbi.nlm.nih.gov/pubmed/8425967>
12. Phillips EM, Hooshmand H (Retired). Methadone Related Deaths (MRD) Among Complex Regional Pain Syndrome (CRPS) Patients. www.rsinfo.com and www.rsdx.com Jan 2017; 1-16. http://www.rsinfo.com/Methadone_Related_Deaths_MRD_Among_Complex_Regional_Pain_Syndrome_CRPS_Patients.pdf

13. Consumer Reports® Health Best Buy Drugs™. Using opioids to treat: chronic pain, comparing effectiveness, safety, and price. *Published by Consumers Union of U.S., Inc.*; July 2012:17-18.
<http://consumerhealthchoices.org/wp-content/uploads/2012/08/BBD-Opioids-Full.pdf>
14. Webster LR. Methadone-related deaths. *J of Opioid Management*. 2005(Sep/Oct); 1(4):211-217.
http://eo2.commpartners.com/users/ama/downloads/130328_Methadone-related_deaths.pdf
15. Lynch ME. A review of the use of methadone for the treatment of chronic noncancer pain. *Pain Res Manag* 2005; 10 (3):133-144. <https://www.ncbi.nlm.nih.gov/pubmed/16175249>
16. Titles II and XVI: Evaluating Cases Involving Reflex Sympathetic Dystrophy Syndrome/Complex Regional Pain Syndrome. [Social Security Ruling, SSR 03–2p], *Federal Register* (68 FR 59971) October 20, 2003.
<https://www.gpo.gov/fdsys/pkg/FR-2003-10-20/pdf/03-26332.pdf>