



Reflex Sympathetic Dystrophy/ Complex [Chronic] Regional Pain Syndrome

- What is RSD
- What are some treatment options?
- What will this affect my life?
- What can I do to help?
- Who's USARSD.org?

USARSD.org

'No Pain IS All Gain'

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What is RSD?

Reflex Sympathetic Dystrophy (RSD) also known as Complex Regional Pain Syndrome** (CRPS) is a chronic, painful and sometimes debilitating condition (sometimes also referred to as a disorder and/or a disease) that affects the nerves essentially causing them to 'malfunction' and leading to other problems in the body such as, possible bone changes, skin changes, and lack of motor function and more*.

While the exact cause of RSD is not known, it is known that the pain is very real and that you're not just imagining it. Even though this syndrome was identified 25 or more years ago there is still little information about it. In fact there is a decent chance that your doctor may not even know of it's existence and that is why educating yourself about RSD is not only a good idea but very essential to your management of this syndrome.

*Due to the varying areas affected, RSD is also referred to as a multi-symptom, multi-system syndrome

**CRPS is fast becoming the more common name for this ailment, we will aim use both terms together to be accurate.

How RSD is Diagnosed

Due to the fact that not every symptom is present in every case all the time, RSD can be especially difficult to diagnose. Below are a just a few different ways that it can be diagnosed*:

- Fine detail X-Ray
- Bone Scan(s)
- Thermo-graphic studies
- Nerve Tests
- Clinical Evaluation of Symptoms
- MRI's
- Patient history

*It is the express opinion of USARSD.org that, many times the results of one or more of the tests mentioned above may come back normal. Due to this your doctor may order many of the above mentioned tests, or others, to aid them in their diagnosis. Please remember that we ARE NOT experts in this field and have provided this information only as a starting point for your research. Please, please we urge you to consult the qualified and trained doctors who have experience in this field.

RSD Symptoms

There are 4 main symptoms in RSD (CRPS), but there are many more affects that is has on the body.

1. Pain.

This is the major symptom of RSD, which is extremely intense, often leading to a lack of sleep.

Described usually as severe, constant and burning in nature; like the affected area was on fire or in a pot of boiling water. You can also suffer from throbbing, aching, stabbing, crushing, sharp or tingling pain in the affected areas. The painful areas are not limited to the original accident or trauma site. The pain is more severe than what is expected for the type of injury sustained.

Allodynia usually accompanies this pain. This is an extreme sensitivity to a stimulus that would not normally cause pain. A slight touch, clothing, even a breeze can cause extreme pain.

2. Inflammation.

Inflammation is present in MOST cases of RSD and can be present in many forms. These include swelling (edema), color changes (mottled skin, discolorations, etc.), skin rashes, bleeding in the skin, bruising easily, patches of dark and/or dry skin, swelling in and around the joints, freezing of the joints and ice cold skin.

Inflammation is not always present.

3. Spasms.

The blood vessels of the skin and muscles spasm causing a feeling of coldness. This can also result in tremors, muscle weakness or fatigue, movement disorders, weakness and clumsiness of the extremities and the tendency to fall.

4. Insomnia and Emotional Disturbances.

RSD affects the limbic system, the part of the brain in which the sympathetic nerve fibers carrying the pain and other impulses terminates. This is positioned between the brain stem (at the base of the neck) and the brain's cerebral hemispheres.

Disturbance of the limbic system can causes depression, agitation, irritability, insomnia, short term memory loss and lack of judgment or concentration.

SOME Other Symptoms of RSD:

Movement Disorders - Difficulty in beginning movement of the affected area or the inability to move the area. Development of dystrophy and/or atrophy may sometimes occur.

Skin/Hair/Nail Changes - Skin may change color. May be mottled. Can become shiny, dry and tight. Rashes and sores can occur (neurodermatitis). The skin can become thin and fragile or may become quite thick, developing elephantiasis. Hair/Nails sometimes grow at an increased rate and/or grow brittle around affected areas.

Eye Sight - Visual disturbances can occur including blurring, difficulty focusing and dizziness.

Miscellaneous - loss of libido, relationship problems, anxiety and panic disorders. Immune system disturbances.

Some Treatment Options for RSD/CRPS:

We are **NOT** Dr.'s, this list has been compiled by patients to give you a starting point for discussion with your Dr. We do **NOT** endorse **ANY** treatment listed below.

Some of the medications and/or procedures on this list may be viewed as controversial. Please understand we thought it only fair for us to attempt to make a semi-comprehensive list of possible options for you (or your loved one).

Everything on this list has been, or is being used by, at least 2 or more members of USARSD.org. We felt that based on our size, this list is a fairly accurate depiction of commonly used treatments for RSD/CRPS. Keep in mind though, that there are far more medications and treatment options available than we could list in this pamphlet. Also there will undoubtedly be new options that became available after we published this pamphlet. With each new edition of our material we will update the list, for the most up to date list please refer to our website where we not only have the options listed, but we have links to where you can learn more about many of the options available!

Medical	Non-Medical (and/or not as accepted/tested)
<p style="text-align: center;"><u>Medications:</u></p> <p>Opioids: Vicodin/Norco Percocet HydroCodone (also OxyCodone) Morphine (Varrious types) Ultram/Ultracet (Tramadol)</p> <p>Muscle relaxers: Flexeril Soma Tizanidine</p> <p>Sleep Aids: Trazadone</p> <p>Depression Medicines/ Tricyclic Antidepressant: Zoloft Cymbalta Nortriptyline/Amytriptyline</p> <p>Off Label Use Medications: Lyrica (Nerve Pain, labeled for Fibromialgia) Clonidine (Blood Pressure) Topamax (Migraine)</p> <p>Other: Ketamine Infusion</p>	<p><u>Common/Proven Non-Medicinal Treatments :</u></p> <p>Physical Therapy/Water Therapy T.E.N.S. Machine</p> <p>More Rare/Not as Tested Non- Medicinal Treatments: Acupuncture (many with RSD can NOT handle needles) BioFeedback Mirror Therapy High Power Laser Treatment Hypnotherapy</p> <p>Invasive Procedures: Nerve Block Spinal Cord Stimulator Morphine Pump</p>

From something so small:

In 2003, at the age of 22, I tripped over a child's gate while helping a friend do some work at his house. I knew I had at least sprained my foot/ankle but oh well I thought I've done it before. So I just kept on doing as I was.

Five days later I went to ER because in the 5 days since I had hurt my foot temperature had not normalized, my right foot (the injured one) was swollen, purple and much, much cooler than the left one. (Like summer and winter). The doctor on call could not diagnose it, nor could the next 4 doctors I saw. Then, after many, many months of pain and various doctors telling my that I would just have to deal with it, or that it was all in my head, I was diagnosed with a severe plantars sprain.

Well the injury did not heal like it was supposed to. Finally, 13 months after the initial injury I was finally diagnosed with RSD. I thought things would get better once I had a specific diagnosis but I was so wrong. 3 months after being diagnosed with RSD in my right foot, "the beast" spread into my right arm and hand. Then after another 6 months the symptoms started to show up in my left arm and hand. So now here I am, in constant pain and discomfort (like many people with this "Beast") that is only just bearable with a mix of 3 different pain medications. I try to console myself though, after all this could be

worse, couldn't it?!?!
~Jason, Washington State

From a bad back, to surgery then to RSD:

I started having back problems which led to a first surgery in '96. In the summer of '03, the back problems returned. I had no more quality of life and could barely get out of bed. The surgeon who had performed my first surgery had retired and not one back specialist wanted to take over my case in fear of liabilities. I had some screws that had to come out but they all refused saying, "I didn't put them in so I will not get them out." My husband started searching the internet and found a private clinic in Munich, Germany where a surgeon was willing to take care of me. After sending my medical information, a date was set for me to meet him and perform the surgery on my back.

The first surgery was to remove 2 screws. It went fine. Seven days later, I had my 2nd surgery to fix my back. After a 6 hour surgery, I was put in recovery but the surgeon noticed that I had no strength in my left leg. He suspected strongly it was due to scar tissue from my '96 surgery. Two hours later, I was rolled back into surgery. The pains were still so atrocious and it felt like I was hurting everywhere. Even though I started having burning sensations in both feet and legs they sent me home one month later. I kept putting an ice pack on for the burning, little did I know it is one of the worst things I could have done.

So, here I was, home and bedridden. After another month my husband, contacted a US doctor we had met in Germany. Greg described all my symptoms and in less than one minute, I had a diagnosis of probably RSD. A number of days later this was confirmed by a pain doctor. I was put on a lot of medications to try and manage the pains which eventually resulted in having to quit my job... that was a hard decision to accept.

~Pat, Tennessee

Living with Reflex Sympathetic Dystrophy (RSD)

You now have a name for this pain you've been living with. Now what? Education, education, education! Dr. John G. Hibben once said, "Education is the ability to meet life's situations." Well if ever a life situation has arisen, it's now!

Educate yourself. Learn everything you can about RSD. Keep a log of what causes you pain and what doesn't. Know how your RSD reacts to cold or heat. Some people find cold temperatures causes their RSD pain to skyrocket out of control. Others find cold temperatures help soothe the burn. Know how your RSD reacts to changes in weather. Are your pain levels lower when the barometric pressure is high? Does sounds such as thunder cause pain? How do you handle vibrations from a simple car ride? The more knowledge you have about RSD, and what affects your pain levels, the more empowerment you have over your RSD.

Educate your loved ones and friends about RSD. The more they know about RSD, the more they can help you lead a more pain free life. Let your friends and family know what causes you pain and why it does. Help them, help you. Don't be afraid to show the pain you are having. The more they see, the more they can help. A little education can go a long way.

Educate your employer and co-workers about RSD. Your employer may even let you work from home on days your pain levels are high. They may be willing to offer you a flexible work schedule to work around doctor's visits. Co-workers are more prone to help out when they know the situation. They might even trade off job duties in the event one particular job causes you too much pain.

If you are unable to work, start the Social Security Disability process as soon as possible. Be prepared to hit some brick walls and don't lose hope if it takes a while as it usually does. Be patient and persistent. Remember to retain all your medical records, and good luck!

Living with RSD is not an easy life. There will be times that the pain will seem unbearable. You will face hurdle after hurdle. Life will never seem fair. You have to take it slower and will probably be able to do less than you could before. Just know that there are people out there that are willing to listen and help whenever possible. Meet this life situation head on and know it will never own you, because you are armed with education.

Helpful Hints

(compiled from social network survey)

Living with RSD is not an easy task and so we decided to poll fellow sufferers for their best helpful hints. The results are not surprising.....we need support of family and friends first and foremost.

Learning distraction techniques is key to coping with pain. The most commonly used are: chatting online, music, prayer, reading, games, relaxation and breathing exercises, meditation, watching TV and talking on the phone. Being prepared while on the go is imperative. Put together a bag with soft socks, comfy slippers and/or shoes, a sweatshirt, extra meds, a lap blanket etc.....whatever could make you more comfortable. Having a "pain book" with all your medications, doctors, recent side effects, pain levels and activities is also helpful when visiting the pain doctor. There is no right answer and what works today may not tomorrow.

About USARSD.org

We here at USARSD.org like to think of ourselves as a 'grassroots organization' in the sense that we were founded by 2 best friends. One who has RSD, Jason, and one who does not have RSD, Nikolai. Neither one of the co-founders had any experience in running a non profit organization. Neither one worked in any medical field. Far from it in fact, all they were was two young guys who wanted to help fill a perceived need in our nation, a need to raise awareness of this nerve disease and to connect patients, family and loved ones of patients with one another.

Our primary means to accomplish our goal(s) has always been our website and FREE web forum. (for patients, family and loved ones of patients and anyone else connected to RSD and/or chronic pain) Since our founding in September of 2006 (Our website went 'live' on September 1, 2006 but we didn't formally become a non profit until the following June) our website has seen great success! While there are plenty of RSD related sites that have more traffic, we feel we've done well and offer some features that were not available when we were founded. (One major one being our completely FREE user forum and our unique and open licensing)

We now have 'representatives' in ever region of the United States of America except Hawaii, Alaska and our outlying territories. Our rep's attempt to be the face of our organization in their specific areas. They help make sure our publications, such as this, get distributed, they look for ways to raise awareness in their area. They try to connect with medical professionals and those afflicted with RSD and so much more.

USARSD.org is ran by a board of directors and a group of officers. (Jason, Nikolai and Ben [another man they brought on board at an early stage to help organize the group] are our 3 'permanent directors') Members have a great say in what we do as an organization. (We're committed to being very transparent, democratic and open in all we do) In fact, our preferred means for someone becoming a member is for them to 'render in kind service' to help run the organization!

This publication in your hands marks our first 100% non web project. We feel we've established ourselves online fairly well. We offer many services online and hope to have an equal, or near equal presence off line as we do online. If there's a need to be filled we want to at least 'help' fill it.

We hope that this brochure helps answer some of your questions about RSD/CRPS and about USARSD.org. If not please don't hesitate to call us at: **(708) USA-RSD1 [872-7731]** (can also be accessed for free on our website) our phone lines are manned by volunteer operators Monday thru Friday from 8:AM to 8:PM Pacific Time and we also have voice mail.

You can also email us at: admin@usarsd.org and of course you can always (we have a 99% uptime) check out the website: www.USARSD.org

We also encourage you to check out our free monthly e-newsletter and our web forum. Beyond the main website we also do our best to maintain a presence on a few social networks as well.

What's being done for the cause?

USARSD.org is not the only group in the United States of America working towards goals relating to RSD. Below is a list of some other organizations working for the cause. We are in **NO WAY AFFILIATED** with any group listed. While we do try to work together we have no official or legal relationship/partnership with any other organization. We also have nothing to gain from including the various organizations in this brochure.

RSD/CRPS Treatment & Research Center:

Located in Tampa, FL this facilities is fully dedicated to RSD research and Treatment. the center is directed by Dr. Anthony Kirkpatrick and has some exclusive (only available there) treatment options. They also devote a lot of time to education.

Website: www.rsdhealthcare.org

American RSDHope:

This national non profit organization is dedicated to CRPS/RSD education and awareness. Their website is full of information for patients, loved ones, and medical professionals. Definitely worth checking out!

Website: www.RSDHope.org

Legal Disclaimer

We at USARSD.org want to make sure that you, the readers, remember that we are NOT medical professional. While we make every attempt to verify the presented info as valid and/or medically accurate, since we're no trained professionals we can't guarantee that it is. Please understand that we HAVE made every attempt to verify the presented info for you.

We're fellow sufferers, patients who have RSD and/or know someone with RSD. We hope you find the info presented helpful and please discuss this and EVERY medical dissension with you Dr. We accept NO LIABILITY regarding the info in this brochure, and we're sure you understand our position!

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