I Hurt My Shoulder... Now I Can't Work!

A Primer on Chronic Regional Pain Syndrome(CRPS) Type I RSD

Try telling this to your boss. Strange, but it happens. It's just one of the mysterious effects of RSD, a crippling and painful disorder that's caused by an overactive sympathetic nervous system after a sprain or other injury. It can strike anyone, as an estimated three million Americans have already learmed. Yet, there's practically no funding to research its causes and cures. Try explaining that one to someone with RSD! To learn more about RSD and how you can help read this booklet.

This booklet has been developed to provide people with some knowledge about RSD. It is not intended for those who want a two minute explanation, but for those want to understand what could cause this type of pain and how it affects those who must live with it daily. This booklet is not intended to replace your physician. It is intended to give you enough information to work with him or her, to choose the correct physician, to ask the correct questions and to understand what is happening to someone with RSD.

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For more information go to RSD On-Line website **http://go.to/rsdpain**

Help!

What causes at least 3,000,000 Americans to experience constant burning pain, as if gasoline had been poured over large parts of their body and then lit, as if hot pokers were being pushed into their skin, as if they suffering from second and third degree burns that will never heal? What causes most of these millions to be totally disabled, to seek medical care that often fails to alleviate their pain; to spend their lives in constant agony? What if I told you that this could happen to you, your spouse, even your child? Wouldn't you want to know how to protect your loved ones from this pain? Wouldn't you want to see a cure or at least treatments developed to control the pain ? One more question- Would you believe that most people who are diagnosed with this disease have never heard of it? Have you heard of Reflex Sympathetic Dystrophy (RSD)? We are painfully aware that we suffer from more than the burning pain of RSD, we also suffer from a lack of publicity, a lack of public knowledge, a lack of support that could help us get research money, as well as help for those who have RSD and those who will get it in the future.

We need help to get the word out and what is the word? **HELP! HELP stop the pain!!**

WHAT IS RSD?

If you ask a suffer of RSD, you may get a one word answer, PAIN! RSD is a debilitating disease which involves the skin, nerves, blood vessels, muscles and bones. It is caused when the sympathetic or autonomic nervous system, which we have no conscious control over, reacts to a stimulus, which may be a minor accident. The sympathetic nervous always reacts to an injury to help healing. Swelling will be caused to prevent you from using an injured limb and further injuring it. Blood flow may be affected in reaction to a burn, cut or severe temperature changes. These are normal reactions of our sympathetic nervous system. But sometimes, and no one knows why, an abnormal, prolonged sympathetic reflex begins in a limb in reaction to trauma. The sympathetic nervous system goes crazy and causes a variety of symptoms that do not stop and cause debilitating consequences. There can be a variety of symptoms, with the only common one being chronic burning pain. Some of the other symptoms include, swelling, color changes, temperature variations; and severe sweating, which usually occurs at the distal or bottom portion of the limb. No definite statement can be made about a set of symptoms because the sympathetic nervous system is totally disoriented and the symptoms are only limited by the multitude of effects this nervous system can have on a body. Therefore, any combination of symptoms may exist. We will discuss many other symptoms as we continue to discuss RSD. The pattern and intensity of symptoms may change with time or they may spontaneously resolve. Any statement made about RSD will pertain to

some cases but not all.

How many people in the U.S. have RSD? The most conservative estimate, which has been given by Dr. John Bonica, who is known as the "guru of pain", is that 3,000,000 Americans suffer from RSD. The Reflex Sympathetic Dystrophy Association of America estimates that 6 to 8 million Americans suffer from some sort of RSD. This number was obtained by contacting pain clinics and extrapolating the data. The most common age to develop RSD is between the late 30's and early 40's but it has been diagnosed in children as young as 3 and in adults as old as 86. More women get RSD than men and it is seen in all races.

There are physicians who will not use the term Reflex Sympathetic Dystrophy because 1) there is so little that they can do to help the patient and these physicians have difficulty admitting failure in face of a disease. Also, if you don't have a disease and you don't get well then it is your fault not the doctors. 2) If the patient knows that she or he has RSD, and discovers that more severe symptoms can come from RSD they become hypochondriacs and imagine that the RSD is getting worse. 3) Some doctors believe that RSD is a psychosomatic disease.

Many people believe that RSD is equivalent to a death sentence because no one is cured and the best that one can hope for is a spontaneous remission, which is rare. But according to the RSD clinic at Thomas Jefferson University Hospital, where thousands of RSD patients have been treated: 50% of their patients have been cured, 30% have had their lives greatly improved with treatment and they have not been able to help 20% of their patients. The figures for cures and improvement are probably low because most patients that go to Thomas Jefferson's clinic have been seen by other physicians and received treatments without improvement before coming to Jefferson, while other RSD patients who have been cured never go to Jefferson and are not counted in the statistics. There are no statistics on how many people with RSD get better even before they are diagnosed, or recover after minimal treatment before coming to one of the RSD centers where statistics are kept.

All patients who see improvement in their condition will need rehabilitation to restore coordination and strength to their affected limbs before they can return to a normal life. RSD patients are advised not to participate in any heavy physical labor even after there has been improvement because their bodies remain sensitive. A rehabilitation program should include:

1. Physical therapy to begin the process of restoring strength and coordination
2. Chronic pain program to help the patient adjust to the pain;
3. A work hardening program to develop the endurance and specific physical skills needed to restore a client to a productive life. A team approach will provide the psychological and physical support which will be needed to restore a shattered life.

Let's take a moment to discuss a controversial point about RSD. Many physicians feel that RSD is never cured. It may go into remission but it is not cured. Others believe that when RSD is first cured, the body remains sensitive for many months or years, but once a normal lifestyle has been resumed and there has been no RSD flare up for many years, then it may be considered a cure and the patient need not fear every little injury. RSD has been known to return after 15 years without any new injury. Whether this is a new episode or a flare up of the old RSD cannot be determined. It isn't important to know if this is a new episode or a flare up. It is only important that the symptoms are recognized and treatment is started quickly.

RSD has probably existed since man has existed. Even though a condition that was probably RSD or Causalgia was described in Maltese soldiers in 200 AD, and one of the English Kings was said to have a condition that caused severe burning and other problems, RSD was not written about before the 1600's, it wasn't until the Civil War that Causalgia (which now refers to symptoms that are basically the same as for RSD but the cause is a partial but definite nerve injury) was first discovered by Dr. John Weir Mitchell. He described the condition using the same words that we use today. He wrote about the suffering that patients had to endure and he spoke about the phenomenon of "mirror image" which refers to the ability of RSD to spontaneously spread to the contralateral or mirror limb. Much of our knowledge about RSD was discovered each war because doctors were faced with the suffering of soldiers who had developed RSD after injuries. RSD has been known by man other names including:

- Sudeck's Dystrophy
- causalgia
- shoulder-hand syndrome
- post-traumatic osteoporosis
- During the last few years, there has been an increased awareness of this condition, which has brought about an increase of early diagnosis, early and proper treatment and total or partial cures.

HOW DOES SOMEONE GET RSD?

RSD usually follows accidental injury, surgical or other iatronic injury (injury caused by a medical procedure or problem), some micro- or macro trauma associated with certain occupations (such as repetitive movement disorder) and certain diseases such as myocardial infarction and neuralgic disorders. Minor traumas, such as a sprain, dislocation, fracture, crush injury, contusions, cuts, pricks of the fingers or toes, etc., have been known to cause RSD. There is no correlation between the severity of the injury and the incidence, severity or course of RSD. According to Dr. Bonica, most RSD cases follow minor injuries to those regions that are particularly rich in nerve endings. These areas are known as "watershed" zones and are the hand, wrist, top of foot, knee, neck and

brachial plexus region. It can also develop from an injury to a peripheral nerve even though significant neurological signs cannot be observed. Surgery or the casting of a limb can cause RSD. A significant number of RSD cases have followed the insertion on a needle into the median nerve while trying to set up an I.V.. There are many ways to get RSD but most patients will have had a minor injury that causes them all of this grief.

Ms. Gayle Bilinsky, in a article about pain in Fortune Magazine, March 22, 1993, believes that we will see more cases of RSD in the future because of the increased incidence of Repetitive Stress Injury (RSI), such as Carpal Tunnel Syndrome. This condition is an excellent example of how physicians, who give the best, most appropriate treatment can be frustrated by their inability to control RSD.

Carpal Tunnel Syndrome is caused by a compression of the hand nerves when they pass through a narrow tunnel in the wrist, an area rich in nerve endings. This compression is painful. RSD often follows a painful injury to an area rich in nerve endings, so if you don't treat Carpal Tunnel Syndrome, you are inviting RSD. After trying Physical Therapy, the next treatment for Carpal Tunnel is surgery. No matter how good the surgeon, any surgery to an area rich in nerve endings can cause RSD. The dilemma: Treat Carpal tunnel and maybe get RSD from surgery or --don't treat and you're inviting RSD. What to do?

When diagnosed with RSD, you may be told that you have Complex Regional Pain Syndrome (CRPS) Type 1, RSD. Complex Regional Pain Syndrome has been defined to include 3 separate syndromes Type 1- RSDS, Type 2- Causalgia, Type 3- Central Nervous System Pain Syndrome. Each of these conditions will maintain it's own ICD9 codes and be handled separately by insurance companies.

SYMPTOMS OF RSD

The first, worst and most universally experienced symptom of RSD. It is usually burning, throbbing, aching or lacerating, but always out of proportion to the severity of the injury. Here are a list of symptoms, each person may not have all of them.

PAIN-People with RSD suffer from many types of pain, including:

- Allodynia: is pain that is provoked by a stimulus that doesn't usually cause pain.
- Hyperesthesia: is when the patient has an increased sensitivity to any stimulus that causes pain especially pressure and touch. This can be so severe that the patient may become preoccupied with protecting the limb from even the slightest touch.
- Hyperpathia: occurs when the threshold to pain is increased but once the

pain is felt it is much more intense than it should be and will continue even when the stimulus is removed

TROPIC CHANGES are skin changes. They may include:

- color changes, (blue, red or ple skin)
- the appearance of tight and shiny skin;
- Hair growth- hair may become thin and sparse or thick and coarse;
- Nails may become ridged, coarse and often quite long because of the pain involved in cutting them.
- Skin may become thin and is prone to all kinds of sores.

SUDOMOTER CHANGES occur when

- The temperature of the injured limb changes. The injured limb is either warmer and red or cooler and bluish. Early in the course of RSD the limb tends to be warm but as time goes on it will usually be colder than the healthy limb.
- The affected limbs may become extremely sweaty even if they are cold to the touch and in later stages sweating may not occur at all at the affected sites.

EDEMA or swelling, is usually present with RSD. In the beginning of the process the edema may be quite large but in later stages the edema lessens and may actually be noted only by measuring the affected limb and comparing it to the healthy limb. Again, no symptoms are universal and some patients have gross edema even in the most advanced cases.

MOVEMENT DISORDERS muscles become atrophied; isolated muscles may become very tense causing contractures. The range of movement may be impaired, spasms and myoclonic jerks can be seen in many patients and bones may decalcify

EMOTIONAL PROBLEMS I hate using this term because it may mislead people. These symptoms are caused by the pain & disability of RSD, not visa versa.

- Lack of sleep,
- Depression
- Relationship problems including: physical, emotional & sexual which are caused by the effects on the libido and thalmus.

These are the major symptoms of RSD. A person doesn't need to have all of these symptoms to be diagnosed with RSD. I refer to it as a grab bag. Most RSD sufferers share common symptoms but are not exactly alike. It is important to note that one sign or symptom is frequently out of proportion to the others. Such as severe pain with little vasomotor changes or the opposite.. Doctors do not

agree on exactly which symptoms need to be present to diagnose RSD but many agree that there needs to be at least three of the general categories mentioned above to confirm the presence of RSD.

Since pain is really the universal and most distressing symptom of RSD, I'd like to discuss it in detail. For this discussion, I will be paraphrasing Dr. John Bonica's definition from: The Management of Chronic Pain "Causalgia and Other Reflex Sympathetic Dystrophies" pg. 223.

The pain of RSD is: severe, burning, knifelike, or lacerating, unrelieved by rest, subject to exacerbation by the slightest emotional or physical stimulation and often is associated with severe vasomotor or sudomotor disturbances.

In mild cases, there is a dull, throbbing, aching, burning diffuse pain with moderate or mild vaso and sudomotor involvement. The mildest and most common form of RSD looks like the normal response of an extremity and because the symptoms are mild and often not seen, these patients may not get treatment. They suffer needlessly, possibly moving into more severe states as time passes

About two thirds of patients also complain of bouts of stabbing, tearing, bursting or throbbing pain felt deep in the affected part, and three quarters or more describe the pain as exhausting and causing the patient to feel wretched and miserable.

In early phases of the process and in milder cases, the pain is limited within the general localized distribution well beyond the confines of the nerve. Unless severe pain disappears spontaneously or is relieved with treatment, in time it usually spreads proximally to involve the entire extremity, and it may even spread to the quarter of the body, and to other parts or to the contra-lateral limb. This devastating ability to spread in space and increase in time is one of the most distressing characteristics.

Factors affect the pain and hyperalgesia and hyperesthesia. Response to changes in the environmental temperature varies, however, in some patients the pain is aggravated by cold and relieved by warmth; some patients have an opposite response; others are either aggravated or relieved by both cold or warmth; and still others are unaffected by changes in temperature.

The pain is aggravated by numerous somatosensory, visual, auditory, emotional, and psychological factors. Almost without exception the pain is aggravated by use of the part, by passive movement, or by touching or tapping the part. In some patients the skin is so hypersensitive that light friction of clothing or bed clothes, even blowing on it, causes excruciating exacerbations. Consequently, the patient learns not to move the part and goes through seemingly absurd extremes to protect the painful limb from touch or any other physical stimuli. Visual and auditory stimuli such as loud and unexpected noise or bright light, rattling of a newspaper, noisy conversation, walking by the patient, whistling, music and high pitched sounds, the sound of an airplane, or

a cry or shout may cause a sudden marked aggravation of pain. Emotional disturbances such as anger, fear excitement, and mental distress invariably aggravate the pain.

Thank you, Dr. Bonica, for such a wonderful description of the type of pain, RSD sufferers must endure daily. This pain can be treated by a physician who develops a multidisciplinary plan that uses the expertise of psychologists and physicians with varied specialties.

HOW IS RSD DIAGNOSED?

Clinical observation is the most common means of diagnosing RSD because there is no definitive test that diagnoses RSD beyond a doubt and the tests that do exist miss many people who have the disease. Most physicians agreed that to confirm RSD there must be a combination of symptoms, at least 1 symptom from 3 of the following categories (these were discussed in more detail above)

- ★ Pain that is constant and burning;
- ★ Vasomotor or Sudomotor Changes a change in sweating, temperature or color
- ★ Tropic Changes -changes in the skin, hair growth or nails
- ★ Edema-a swelling that has been or still is present
- ★ Movement Disorders spasms, muscular weakness or contractures.

Different test can be used to diagnose RSD including

- ★ Medical History- an injury that doesn't heal in the usual time or pain beyond reasonable expectations for that injury.
- ★ A sympathetic nerve block is one way to confirm the diagnosis. If the pain and/or symptoms are relieved then the patient has RSD. In other words, when given a sympathetic nerve block, if the pain goes away, or the temperature increases quickly, or the color of the limb improves, or all of the above happen then the patient definitely has RSD and the disease is still Sympathetically Maintained.
- ★ An intravenous infusion of the drug phentolamine (PhI) may also be used to help diagnose if the pain is sympathetically maintained This drug is given intravenously rather then being injected into the nerve ganglion that controls the painful area.- If no result is gotten from the sympathetic nerve block or PhI test, RSD cannot be ruled out because a significant number of definite RSD cases will not respond to nerve blocks because the disease has progressed to the Sympathetically Independent stage.
- ★ Three phase bone scans are a special type of bone scan that usually shows increased uptake of blood in the RSD limb compared to the healthy limb. The accuracy of the scan can be affected by the patient's age and/or length of time that they have had RSD. There are cases where the scan will show decreased uptake. Bone scans are 80% valid or 20% of people with RSD will not have a positive bone scan. Bone scans are also not valid for Stage

III RSD.

★ EMG's are used to show nerve damage but they do not read the sympathetic or parasympathetic nervous system so they will not diagnose RSD. An EMG can be useful in finding the original site of injury in order to correct it and by correcting the original injury, you may settle down the RSD.

★ Thermography can be used to help diagnose RSD. Thermography measures the temperature on and just below the skin. Healthy people have less than a ½ degree Celsius difference between contralateral limbs. When there is an organic problem, the temperature will be increased or decreased in the injured limb. If the injured limb shows a temperature change of at least 1 degree Celsius over 25% or more of the skin surface, then there is definitely an organic basis for the pain.

Many people who do have RSD may not show a difference in temperature because that may not be one of their symptoms, or the temperature changes may not always be present. Remember that RSD is a chameleon, it is always changing. There may be temperature differential for three hours and then none for the next six. It is easy to see why RSD can be hard to diagnose, the symptoms may not always be present so it is imperative that the physician take a careful and detailed history of each injury that doesn't heal properly or that is causing pain beyond what is expected for that injury.

STAGES OF RSD?

I have put a question mark after the stages because there are controversies about:

- Whether there are actually different stages of RSD;
- When you move from one stage to another
- Why even talk of stages because nobody knows what effect a stages has on RSD.

I have included this discussion so that everyone can see the progression of the disease. While reading about the stages, remember that the lines between stages can be very fuzzy and that one person may move through the stages in a very short time while another may never leave stage 1.

STAGE I OR THE ACUTE STAGE. Symptoms usually begin within days or weeks or even hours of the inciting incident. Usually there is constant burning or aching pain which begins at the injury site or the distal part of the limb (an injured shoulder may cause symptoms in he hand); there may be hyperesthia, localized edema, and pain upon movement. There may be muscle spasms and limited mobility. Vasospasm is noted, usually the skin becomes red, warm and dry in the beginning but may change to cold, cyanotic and sweaty. Increased hair and nail growth may begin. It should be noted that RSD is most curable at this stage so early diagnosis and treatment is important.

STAGE II OR THE DYSTROPHIC STAGE- is characterized by continuous burning, aching or throbbing pain which is more diffuse, hyperalgesia and hyperpathia. The skin is cool and pale gray or cyanotic. The edema changes from soft to a brawny type. The skin is shiny; nails are brittle and heavily grooved; hair becomes scant, there is increased thickness in joints and more muscle wasting so movement is more difficult. Diffuse osteoporosis may begin. Allodynia (stimuli such as hot, cold and movement are extremely painful) begins. Remember, all of these symptoms will not be seen on every patient. Each stage will be accompanied by some of the symptoms.

STAGE III OR THE ATROPHIC STAGE - is characterized by marked atrophic tissue changes that have become irreversible. The skin becomes smooth, glossy, drawn, pale or cyanotic and the skin temperature usually decreases. Nails become increasingly brittle and ridged with lateral arching. The muscles become weak, and have limited motion. Contractures of flexor tendons often develop at this stage. Bone atrophy becomes diffuse and subluxations may occur. Pain becomes intractable and spreads to the entire limb, a contralateral limb or another limb on the same side of the body. The spread of RSD does not happen to most Stage III patients. But it may spread to involve the entire body. Dr. Schwartzman, states that 4% of Stage III will have RSD throughout their body also referred to Stage 4).

When discussing the stages of RSD, it is important to understand the difference between sympathetically maintained pain (SMP) and sympathetically independent pain (SIP). During the earliest stage of RSD, the pain and all of the symptoms are controlled by a malfunction of the sympathetic nervous system which started the problem. The sympathetic nerves do not usually carry pain signals but with RSD they do. If sympathetic nerve blocks are given during this stage, all symptoms, including pain may be relieved for a period of time. Stage I is when RSD is most curable.

When the pain has been present for some period of time, it begins to affect the spinal cord and the Central Nervous System. Then the pain will no longer respond Sympathetic Nerve Blocks and is said to be Sympathetically Independent (SIP) The pain is no longer being generated solely by the original, peripheral injury. Now it has developed a life of it's own and must be treated with treatments that affect the spinal cord and central nervous system, such as lidocaine, implanted pumps and spinal cord stimulators.

One possible explanation for the development of sympathetically independent pain and the spread of RSD has been proposed by Dr. Robert Knobler at Thomas Jefferson University Hospital. Dr. Knobler has shown that when a person develops RSD, they also show an increase in the nerve growth factor within the body. This allows the sympathetic nerve ganglions to grow wildly and possibly get close enough to share their information; spread the

disease into another limb and allow The spinal cord to be affected. Nerve growth factor is present in our bodies during childhood and is no longer produced by the normal adult body. This is one reason for this phenomena but nothing has been proven.

The stages cannot be measured in time even though it is convenient and somewhat accurate to say that each stage lasts between 3 and 6 months. Actually a person may be in Stage I for seven years and another RSD sufferer may pass from Stage 1 to Stage II in two months. If you want to cure RSD, your best bet is to treat during Stage I while the pain is sympathetically dependent.

TREATMENT

We have discussed the importance of treating RSD early, now let's discuss the treatments. I will briefly cover many of the treatments available but these are constantly changing and I cannot possible cover every type of treatment. RSD is a difficult condition to treat because all treatments can:

- make the patient better,
- make the patient worse,
- cause no change in the patient's condition.

MEDICATIONS Many studies have shown that Stage I RSD, may respond to corticosteriods, narcotics, anti-convulsive, calcium channel blockers and, non-steroid anti-inflammatory drugs. TENS units may be used in Stage I to provide stimulation at the skin level to interfere with pain signals being carried to the brain. If they do not cure the RSD, they may help relieve up to 20% of the pain.

Symptoms of RSD may be treated with medication.

- Spasms may be controlled with Klonopin or benzodiazepine.
- Severe dystonia may be relieved with heavy doses of baclofin (lioresal).
- Clondine patches worn on the skin over the area of pain, may lessen the pain markedly. Many of these drugs may have unpleasant or dangerous side effects, so the patient must be constantly monitored and possible removed from the drug even if it is helping the RSD.
- Narcotics (Please read "We Are Nor Addicts" and the "Myth of Addiction) can be used to control pain but they are not believed to control europathetic (burning, nerve) pain but they may relieve enough of the muscle, bone and skin pain that they're usage improves an RSDers ability to function. Dr. Portenoy, of Slone Kettering Cancer Center, believes that if massive amounts of narcotics (he especially means M. S. Cotin) are given, the drug can break through a barrier and actually stop neuropathic pain. Almost all studies on narcotic use that have been done have used terminal cancer patients as subjects so the effects of long term narcotic use isn't known.

NERVE BLOCKS

- Sympathetic Blockade is an effective therapy for many patients who still have sympathetically maintained pain. Marcaine (a long lasting type of novocaine) is injected into the epidural space next to the sympathetic ganglion that affects the extremities with RSD thus blocking the sympathetic nerve messages from reaching the limb. For the upper extremity, the superior cervical ganglia which is located at the base of the neck is used and a paravertebral ganglia is used for a lower extremity. For a lower extremity, the needle will be inserted in the back, next to the spinal cord. These blocks are given in a series every other day. Some physicians use 5 blocks, some 3, and others have no set amount. All types of nerve blocks may need to be repeated even if they are successful and all successful nerve blocks should be followed by intense physical therapy. Some physicians will prescribe the physical therapy for 6 weeks prior to doing any nerve blocks.
- Epidural blocks are used if the physician wants to block the sympathetic nervous system of both legs either because of the presence of crossover fibers or because RSD exists in both lower extremities. The medication is placed in the epidural space so that it will affect all nerves and not just sympathetic nerves. Usually the patient will have a period of numbness in the lower extremities after an epidural block.
- Axillary blocks are another type of block for the upper extremity. It can be helpful, in cases where there is severe dystonia (contractures). In this type of block, the medication is placed in the armpit and will cause numbing and loss of controlled movement for a period of time.
- Bier blocks are used when the RSD is limited to the lower part of any extremity. With a bier block, the limb is squeezed to push as much blood from the arteries and/or veins. Then a tourniquet is applied to prevent the flow of blood and medication is injected directly into the arteries. After about 20 minutes, the tourniquet is removed and the blood returns to the limb as it pushes the medication throughout the body.
- Continuous blocks are used when a series of blocks isn't successful or the symptoms return quickly. In a continuous block, the catheter is inserted into the space and left there for a period of time. The medication is then administered in small but continuous doses by an external pump. The patient will then experience pain and symptom relief for as long as the medication is administered. Some physicians will even send patients home with these pumps for a few weeks. During this period of relative pain relief, the patient does the physical therapy that wasn't possible with the pain. In some cases, this will break the cycle of RSD.

Despite disagreement on how to treat, all physicians agree that the earlier treatment is started, the more chance of success. Successful blocks will leave the

patient either symptom free or with greatly reduced symptoms for a period of time. The period of relief should increase after each block in the series. If these blocks are unsuccessful, other medications can be tried in the sympathetic blockade.

SYMPATHECTOMY is used to disconnect the sympathetic nervous system that controls the limb or limbs that are involved. There are many ways to do sympathectomies including surgical, chemical, radio frequency & laser. The following are the most common.

- Surgical: Patients who respond to blocks and physical therapy completely but relapse or who partially respond should be considered for a surgical sympathectomy which disconnects the sympathetic nerves at the ganglion. Many cures have followed sympathectomies but it should be noted that this surgical procedure may not help the condition, or may make the RSD worse, or even if successful, the nerves may regrow and thus allow RSD to return.
- Chemical sympathetomies may also be preformed by injecting a drug into the nerve ganglion but this may have harmful side effects if the drug touches other tissues or organs. Recently nerve blocks and sympathectomies have been performed using electrical stimulation, radio waves, lasers and endoscopic instruments.. Not much has been written about these methods and few physicians use them but they avoid a surgerical procedure which can make RSD worse.

ALTERNATIVE MEDICINE

The Chinese have always used herbs, natural medicines, as well as acupuncture and other treatments and philosophies that affect the body's Chi (pronounce Chee). Chi is a powerful energy force that circulates through our body and regulates the body's organic functions. We are all born with a certain amount of Chi that is consumed as we age or when we are ill. If there is a blockage in the Chi, the body is no longer balanced and this energy cannot perform it's main function of providing vitality (the Yin chi) and resistance against disease (the Yang chi). A blockage can disturb the balance of the yin and yang which is essential to health. All of the Eastern medical practices strive to unblock the chi and return our bodies to balance and health.

- Acupuncture is the gentle insertion of hair fine needles into specific points on the body to stimulate the flow of one's chi. This can be done with electrical stimulation and lasers. whether acupuncture helps RSD is still unknown but most physicians who treat RSD say it can't hurt.
- Chi Gong can help keep the flow and balance of the chi through breathing and moving exercises (internal chi gong) or by a chi gong healer emitting chi through his hands into the body of a sick person (external chi gong).

RELAXATION THERAPY, SELF HYPNOSIS & COUNSELING

RSD is a condition that is usually defined by pain. Pain is the most common and most severe symptom. If the pain is reduced or eliminated, even temporarily, many of the other symptoms may and often do improve spontaneously. I have seen a patient in an early stage of RSD come for a nerve block using crutches, unable to straighten his knee or place his foot on the floor. After a successful block, the same patient walked out of the office. A patient who had not walked for years was treated with a morphine pump and after a few months the swelling was gone and she was walking. Pain is a part of the cycle of events and symptoms that cause RSD and if you break the cycle anywhere, but most effectively the pain, RSD may improve without further treatment.

All patients with RSD are in severe pain and are incapacitated. They suffer from stress and depression and should be offered pain management therapy, which includes hypnosis and biofeedback. This therapy is usually conducted by a licensed clinical psychologist who has extra training and experience in pain management. At this time, any psychotherapy that is needed can be done so the patient can deal with:

- New problems that are caused by the current illness;
- Old problems which are stirred up and made worse by the current disability;
- Any factors that may stand between the patient and total cooperation with his rehabilitation program;
- New strategies to learn to cope with the pain and loss, and to build a new life from what strengths are left.

LIDOCANE INFUSION

There are other drugs and treatments that have been used to help the severe, intractable pain of RSD. Lidocane administered intravenously has been shown to decrease pain. This can be done by administering a continuous dose of lidocane until an almost toxic level is reached. After one or two of these treatments, a lessening of the pain should be seen. Oral lidocane can be taken daily and if needed the IV treatment can be repeated periodically. Another method of lidocane treatment is to give a lesser dose of IV lidocane every other day for a few weeks until the maximum level of pain relief is found. Oral lidocane cam be taken and an IV treatment can be repeated monthly, if needed. Lidocane affects the hypothalamus region of the brain. The affects of long term usage of large doses of lidocane is still unknown.

HIGH TECH TREATMENTS

- Stimulators: If all of the above mentioned treatments have failed, a dorsal column stimulator can be implanted. These units can be implanted near the spinal cord at the origination point of the nerves that are carrying the pain signals. Through internal electrical stimulation, a dorsal column stimulator can interfere with the transmission of pain signals to the brain. Significant pain relief can be expected in 50% of patients. This pain relief may not be permanent because after years of stimulation the nervous

system may become accustomed to the stimulation and pain may return. Hopefully, by controlling the pain, the patient may be able to use the limb normally and break the cycle of RSD.

- Intrathecal Pumps: Patients with generalized RSD (at least 2 limbs involved) or whose life has been destroyed because of severe RSD in one limb, may be implanted with a pump that delivers narcotics and possibly anesthetics directly into the spinal cord (intrathecal space) continuously. By introducing the drugs directly into the intrathecal space rather than be mouth or intravenously, very small amounts of these drugs are needed to control pain.. There are problems with this form of treatment but it can return the ability to function to RSD patients who are totally dysfunctional.. If the pump fails at. any time, it can be removed.

Any of the treatments should be discussed in detail with the physician. There are potentially dangerous side effects to many of these treatments so they should be administered in a setting that has the proper medical equipment and medications to react quickly if any reaction occurs. You will undoubtedly hear claims that everything from herbs to a magnet can produce tremendous relief of pain for all RSD sufferers. Just remember that if the promised results of any of these treatments seems too good to be true, it usually isn't.

Once RSD is controlled, it is imperative to treat the original underlying problem. First, any carpal tunnel syndrome, thoracic outlet syndrome, or disc problem must be corrected and then through physical therapy, and lots of hard work the patient may resume a normal lifestyle.

THE PSYCHOLOGICAL EFFECTS OF RSD

ARE WE CRAZY?

Did you know that only humans get RSD? This presented a problem for research because animal studies are usually the first step in understanding how a disease works, where it comes from, and how to treat it. Laboratory animals have been bred for generations so that they are the same while each human is a unique individual. You can give 100 laboratory animals the same drug and expect the same reactions. Humans react differently to the same drug because their chemical and genetic makeups vary.

Human studies on RSD have proven inadequate because the results are not standard or able to be duplicated. When you give a nerve block to patients, you'll find all types of reactions. Some of the many variables that must be accounted for when doing clinical studies include: what stage is the RSD?; how was the RSD gotten?; what was the patient's previous health status? Any researcher could list variables that are uncontrollable in humans but must be controlled for accurate studies. An animal model is needed.

At the National Institute of Health (NIH), Dr. Gary Bennet started giving

rats RSD a few years ago. By exposing the sciatic nerve in rats and tying this nerve four times, RSD was induced in rats. The same nerve was exposed on the contralateral leg of each rat but the nerve was not touched. RSD developed only in the leg with the tied nerve. Observation of these rats has shown that the pattern of RSD development and the corresponding behaviors closely resembles what happens to humans.

- Within 1 to 2 days of the operation, the rats begin to hold their paw in a protective position. Rats' claws are usually spread out and placed flat on the floor when walking. Now the claws are pulled together and turned under, some were even contracted.
- When walking, some of the rats with RSD limped badly while others would not place their affected paw on the ground.
- Rats normally sleep huddled together in one corner of their cage. RSD rats slept separately from the others with their paws in a protective position.
- When exposed to heat, the RSD affected paw was not only more sensitive than the healthy paw but it continued to hurt when removed from the heat.

- Exposure to cold also elicited a quick and extreme pain reaction. Remember that the rats reacted in the same way.

All of the rats who got RSD became protective of their RSD limb. All of the rats who got RSD stopped sleeping in the group. All of the rats who got RSD limped. All of the rats who got RSD developed weird behaviors to avoid the possibility of the RSD limb being touched. The rats behaviors were similar to the protective behaviors that humans with RSD develop.

Some physicians point to these behaviors in humans as proof that the patient has psychological and not physical problems. I have one question for these physicians. Can rats be crazy?

All patients who suffer from a catastrophic injury, chronic pain, or a quick and total change in their life do suffer from psychological stress--RSD victims suffer from all of the above conditions. It is not uncommon for RSD patients to develop some maladaptive behaviors but these behaviors are caused by RSD. Actually most of the behaviors did not exist before the RSD so they could not have caused RSD as some frustrated physicians would have us believe.

Many patients who are eventually diagnosed as having RSD were diagnosed as having psychogenic pain, which is a psychological diagnosis stating that there is no organic cause for the pain. Many doctors will use this category for hard to diagnose patients. Actually, very few patients do suffer from psychogenic pain. Study after study of all types of pain patients have shown that less than 1% of all patients suffer from a psychogenic illness.

Did you know that 20 years ago there was no definition for carpal tunnel syndrome? People who complained of waking up with numbing in a glove like pattern were said to be suffering from a psychogenic illness because medical

science had never acknowledged that nerves could cause this pattern of numbing. As we discussed before, RSD does not show up on most diagnostic tests and even bone scans and thermography misses at least 20% of those who definitely have RSD. Because of the need to rely on clinical symptoms to diagnose this debilitating disease, it is important for physician to recognize the symptoms and not push the patient off as having psychological problems

Depression is a major problem for people with chronic pain. In fact, some studies have shown that as many as 99% of chronic pain sufferers are depressed. The question is, was the depression present before the RSD or only after. A study of 168 patients at a well known pain clinic showed that 77% of these patients were depressed but 89% of those had never been depressed before getting RSD. Psychological evaluations usually involve some testing. The MMPI (Minnesota Multiphasic Personality Inventory) is a test that is generally used to provide a picture of a person's traits, underlying dynamics, level of adjustment, and attitudes towards the world. The MMPI as it is currently used has been found to be inappropriate for chronic pain sufferers.

The MMPI (Minnesota tests have limitations when given to chronic pain patients. Since we must use the tests that are available, studies been done with the MMPI and chronic pain patients. It has been shown that patients who are making a good adjustment to chronic pain will show a MMPI profile which is high in the hypochondria and hysteria scales, exactly like someone who has a conversion disorder (a disorder when the patient claims that he cannot walk, etc., even though there is no physical problem). Now it becomes extremely important to use the interview and other tests to evaluate what the proper diagnosis should be.

In the last year or two, a new personality test that has been standardized on chronic pain patients has been released. Restively few psychologists or psychiatrists are trained to administer this test because they need to take 30 hours of training before they can administer the SKID II Personality Inventory. This inventory, tests character pathology. It has been used for a study comparing RSD patients with patients who have lower back pain. RSD sufferers have no more personality pathology than this other group of chronic pain patients

Psychiatry has always accepted pain in it's area of expertise. Many patients may be mistreated by physicians and insurance companies who have either lost their patience, not thought of RSD as a possible diagnosis or have not taken a careful history. A diagnosis of a psychogenic pain gets the patient out of the doctor's hair but dooms the patient to the junk heap of medicine with no treatment to cure or control the pain. Anger, frustration and self doubt usually follow this diagnosis

PHYSICAL DISABILITIES

Now I would like to discuss some of the physical disabilities that RSD causes. First let me define handicapped and disabled. Handicapped is when you can't do something in the normal manner but you can still do it. Disabled is when you cannot do one or many things no matter how you try.

RSD causes severe changes in muscles. Many people suffer from spasms and myclonic jerks. These can cause a steady hand to spill water, draw unwanted lines when writing, drop things and stop all activity. Severe spasms cause pain that requires attention to be drawn away from everything else. In a leg, spasms can cause a fall. I have seen a person in a power wheelchair have a myclonic jerk followed by spasms that caused the wheelchair to jump off of the paved driveway and down a potentially dangerous hill. Besides spasms, many muscles can become atrophied. Sometimes when RSD causes many severe spasms, the muscles may become very hard and strong rather than atrophied. The results of these types of spasms is a strong but uncoordinated limb. Many unknowing persons may question whether a RSD patient cannot do things because they believe that the patient is active even though the spasms make it impossible to do many normal things.


Hand with dystonia

RSD can cause severe dystonia or contractures of all limbs. These contractures originate out of the spinal cord as cerebral palsy contractures do. The cannot be stopped by splinting, in fact many RSD sufferers cannot tolerate splinting because of extreme pain when anything touches the skin. Others cannot tolerate the splinting but contractures still develop. Any splinting that is attempted should be limited to sleeping hours because the splints interfere with normal usage of the limb and all RSD patients should use their affected limbs as normally and as often as possible.

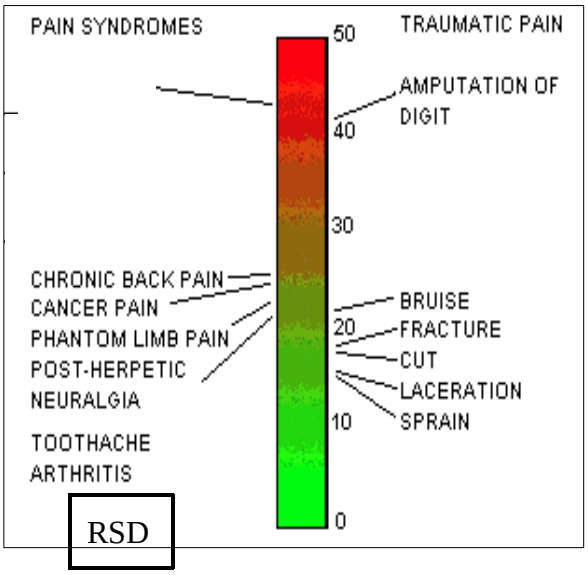
The range of movement of an affected limb may be reduced and become quite limited. Physical therapy may help but cannot stop the reduction in the range of movement permanently. Bones may decalcify in second and third stage RSD. This may cause hairline fractures. It has been found that many RSD patients have difficulty initiating or beginning movements. They will think, fingers pick up the glass, but there is a definite delay between the thought and the corresponding movement. This causes reflexes to be poor. Repetitive movements cause increased pain and spasms. Circulation is usually impaired.

Many patients with RSD feel that they develop cognitive problems because of their condition. Memory loss, inability to concentrate, and loss of some reasoning ability are all areas that many patients complain about. No scientific studies have been undertaken to confirm or deny cognitive changes

caused directly by RSD but it is possible that many of these symptoms could be caused by: the pain; narcotics taken to relieve the pain; or the lack of sleep that many RSD sufferers experience.

RSD causes physical changes that cause disabilities but the one symptom that causes the most disability is the pain. RSD pain is different than other types of pain. Laura, a member of our support group, has had disc problems in her back. She had two surgeries to correct herniated discs that were impinging on nerves. As long as she took her pain medications, she was able to attend college classes and hold down a part time job as a waitress until the day before each surgery.

RSD has stopped Laura completely. The RSD pain started when she was teaching in a missionary school in Japan. She was bedridden and knew that something was terribly wrong because this was much worse and dehabilitating than herniated discs. She came back home because she couldn't work. The pain was in her right leg and back. Laura and her physician had no idea what was wrong. Eventually she was diagnosed as having RSD. It has spread into her other leg, and into her hand and chest wall. Now this teacher needs a walker, a hospital bed and many medications just to get through each day. She tries to help teach a one hour Bible class each week but then she increased pain for days.



RSD PAIN

RSD pain seems to have a unique and severe quality when compared to other disabling conditions. In 1981, Dr. A.J. Tamoush gave the McGill Pain Questionnaire to patients attending pain clinics. He found that the Pain Rating Index (PRI) among patients was 42. The higher the rating the more intense the pain. This compares to a PRI of 25 for phantom limb pain, 26 for end non-end stage cancer and back pain, 23 for pain associated with arthritis, dental and menstrual disorders. Yes, RSD pain is more severe and unrelenting than most chronic pain conditions.

RSD pain is unpredictable.

In the early phases of this process and in milder cases, the pain is limited within the general territory of the initial injury, while in severe cases, the pain, while most intense in the original area, becomes diffuse and poorly localized. Often symptoms will be seen in the distal portion on the affected extremity. If the right shoulder sustains the original injury, the right hand will develop. RSD

symptoms even though it was never injured.

Unless the pain disappeared spontaneously or is relieved with treatment, in time, it will usually spread to involve the entire extremity and may even spread to the quarter of the body, to other parts of the body or to the contralateral limb. This devastating ability for the pain to spread in space and increase in time is one of the most distressing qualities of RSD. Studies by Dr. John Bonica were used to develop this information. Dr. Bonica states that RSD can exist anywhere in the body. Dr. Robert Schwartzman, who is director of the RSD clinic at Thomas Jefferson University Hospital and University, has found that 4% of the stage III RSD patients he has seen, have had RSD spread throughout much of their bodies. They have had a generalized RSD which Dr. Schwartzman refers to as stage IV. When considering the possibility of a spread, it is important to rely on an experienced physician's diagnosis, because many patients believe that whenever they develop new areas of pain, it is RSD, even though there may be many other explanations. This is the result of fear and it's important that a diagnosis be made because if it is not RSD, maybe the new pain can be treated, and if it is RSD, it can be treated early.

RSD has many subgroups which will react to the same stimulus in different ways. One example of this is the way persons with RSD will react to the environmental temperature. In some patients, the pain is aggravated by cold and relieved by warmth; some patients have an opposite reaction; others are either aggravated or relieved by both cold and warmth; and still others are unaffected by changes in temperature.

Almost all RSD sufferers find that their pain is aggravated by use of the affected limb, by passive movement, or by touching or tapping the part.

Although these sensory disturbances are common to many nerve problems, they are usually more resistant, worse and cover a larger area in RSD patients. It is difficult to ascertain whether other sensory or motor disturbances are present because the pain often prevent examination.

Remember that the quality and degree of pain is different for everyone. Also remember that RSD can spread. The National Reflex Sympathetic Dystrophy Association has collected data from over 1,000 RSD patients and have found that 33% of these patients have had RSD spread into more than one limb.

REHABILITATION

This section is written for Rehabilitation Professionals. Please give a copy of this to any Rehabilitation nurse, or counselor, or even Judge . Copy this separate from the book because it is short and even the busiest people can find time to read this.

According to the data base established by the RSDSA of America(1990)

- 58% of RSD sufferers are unable to work even though 20% of them have jobs

- 10% of RSD survivors have had to change to part time work
- 7% had to change their careers.

Let's look at these in real numbers.

- 58% of 3,000,000 (this is the most conservative estimate of persons with RSD in the U. S.) Is 1,740,000 persons are unable to work
- 17% or 510,000 have had to change their jobs in some way.

If you use the most common estimate of 5 to 6 million persons with RSD in the US, you can see that this syndrome cost our country dearly.

Why are so many unable to work, even though they may be affected in only one limb? After all, persons who have had a limb amputated are able to work. Why can't someone who doesn't even have swelling work. Even I have asked myself this question. I am a rehabilitation counselor who truly believes that work is restorative for those who are disabled or in pain. I understand why because I know how people with RSD must live.

WHY RUTH CAN'T WORK

Let's take a make believe person, Ruth, who has RSD in her right hand. She always has burning and aching pain. Sometimes the pain gets very severe. Ruth has no contractors and recently the pain has begun to spread up her arm to her shoulder. Why can't she continue to work as a clerk with the responsibilities of answering the phone, filing and data processing?

Ruth needs to have stella ganglion blocks to control the pain she has needed a series every 5 to 6 months. She sees her treating physician every month and she goes to physical therapy three times a week for three hours each time. Blocks are given in a series of five to seven, usually every other day. She cannot work on a block day. Physical therapy departments are not open in the evenings and even if they were, Ruth's therapist wants to see her in the evening when her pain is less. Some days her pain is so severe after physical therapy that she must go home and rest for a few hours before going to work. Because of the necessary treatments, Ruth's time at work is severely limited and it is probably this aggressive treatment regime that has keep Ruth's RSD from getting worse.

Typing, filing and writing are repetitive movements which causes Ruth's pain to increase and her hand to swell enough to interfere with her range of movement. Her physician and therapist are constantly reminding Ruth to limit repetitive movement. Because of the RSD, Ruth is sensitive to heat. When it is hot, the burning pain in her hand intensifies and the hand gets red and swollen. Luckily, the office is air-conditioned. The other people in the office set the temperature to make them comfortable but the movement of the cool air causes Ruth's hand to get cold and ache intensely. After a while. Ruth cannot stand the air conditioner.

At times, especially when she does the wrong things, such as repetitive movements, Ruth's pain get severe and she cannot concentrate. She drops things

because of spasms and she needs to lay down in a quiet place sometimes while the pain passes.

Some fellow employees don't believe Ruth. They think that she is putting it on just to get out of work even though she comes to work when she could be home collecting Workers' Compensation. These people upset Ruth and everyone knows that RSD is exacerbated by stress.

Ruth is trying to work but as you can see, it is nearly impossible. Ruth has a limited case of RSD and her job requires a minimum of manual labor. You can imagine the difficulties facing more severely affected person and those with manual labor jobs.

WHERE DO YOU, THE REHABILITATION SPECIALIST, COME IN?

Many of you will be working with the client before the diagnosis of reflex sympathetic dystrophy is made. If you see symptoms that make you think of RSD, especially pain and/or swelling that is out of proportion to the injury, either you or the client should ask the physician if it could be RSD. RSD will not be diagnosed unless it is thought of. After RSD has been mentioned to the physician he/she should look for the symptoms and possibly do a 3 phase bone scan, thermography or a sympathetic block to help with the diagnosis. Once a diagnosis of RSD is given ask the physician how this conclusion was reached.

Always give your client the benefit of doubt when he or she complains s of pain. The pain is very real to your client, unless he is a malingerer. A malingerer is someone who does not feel the pain but uses past experiences with pain to fake this one. The only way to separate a malingerer from an undiagnosed chronic pain patient is to examine the person's pre-morbid psychological condition.

It is important to be nonjudgmental when getting to know your chronic pain patients because only by winning his trust can you:

- Identify malingerers
- Help your chronic pain patient live as normal a life as possible
- Once RSD is diagnosed. the rehabilitation specialist needs to:
- Help the client assess his/her diagnosis,
- Help decide which treatments are proper
- Help decide which treatments are proper

Now you have a client who has RSD, he or she has probably had RSD for at least 6 months. The client is probably confused as to : what RSD is; how it will affect his/her life; and the unresolved doubts and mistrust towards those who have questioned the pain. You should give your client as much information about RSD as you can. Be hopeful when discussing RSD because 50% of those with RSD will see their condition get better or spontaneously resolve itself.

Your major goal is to help that client achieve the highest functioning level

possible. This will often include vocational rehabilitation in order to help the client find a new career and return to work. This is to be achieved while trying to keep expenditures down.

REMEMBER:

- Believe the patient unless he/she is clearly a malingerer.
- Get a diagnosis as soon as possible especially if the pain and/or swelling is out of proportion to the injury. If you see possible RSD, ask the physician and push harder for a diagnosis.
- Once a client has been told that he/she has RSD, make sure that treatment starts immediately. Usually blocks and or physical therapy is the first treatment.
- If the treating physician does not have a good working knowledge and experience with RSD, switch to one who does. There is a list of some possible treatments in this book so consult it. There are controversies about treatment and each case is different so this list may not be the only answer.
- The initial injury should be identified. Just because RSD is found, the search is not over because if the initial injury is not treated, the RSD may never settle down. Even if treatment settles down the RSD, it may be reactivated by an untreated initial injury.
- Use all services available.
- Use the strength of the client and remember that **EVERYONE WITH RSD HAS BEEN THROUGH HELL!**