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Working With Clients Who Have Reflex Sympathetic Dystrophy Syndrome

By Ruth Werner, LMP, NCTMB

Dear Readers:

My last article on hyperthyroidism prompted some interesting responses. In that article, I mentioned I had an unusually difficult time finding any useful information on alternative treatment options for hyperthyroidism patients who wanted to avoid surgery or radioactive treatments to their thyroids (because of the increased risk of developing hypothyroidism).

As usual, you came through in a big way. Here's an excerpt from one of the most hopeful letters I got:

Hi Ruth,

I would like to share my experience of hyperthyroidism. I've been able to control it naturally, and thought you may be interested.

Once diagnosed with hyperthyroidism, I started to do some research. I was having daily headaches, sweating, night sweats, tremors, heart palpitations, confusion, etc. I would do one massage and be totally exhausted. The doctor suggested radioactive therapy. I gently explained to him that it didn't make sense to zap my thyroid and then try to bring the levels up again with medication. I guess I was trying to avoid being on medication the rest of my life.

I went to a woman who has been treating people for 50 years with reflexology, acupressure and other modalities. The minute she touched the area of my big toe relating to the thyroid I almost died. The pain was unbearable. Almost immediately though, my two-week-long headache ceased. After my second visit with her, my heart rate, which had been around 103-110 beats per minute, went down to the 80s. I also meditated, which was difficult when my heart felt as if it was coming out of my chest. I

didn't have the energy to do my usual walking, so I did gentle yoga.

I started taking flower remedies, particularly Star of Bethlehem, which is the one for grief. That was amazing and almost immediate. My first experience with that was a positive one. I also did self Reiki, and received a few treatments. Basically I had to make my health a priority, because I could not function as a massage therapist while in the "storm." I could not keep up with my client load.

I then went off all stimulants. since my body seemed to be racing out of control and burning up all energy stores. I gave up sugar and coffee and switched to green tea. I wanted to make sure my body wasn't going to waste away, so I ate plenty of good proteins, vegetables, whole grain breads and oatmeal. A few symptoms lingered; then all was quiet. The storm had passed. This took about one month.

I went back for bloodwork; my levels were normal. My doctor, who was ready to do the radioactive treatment, told me to keep doing whatever I was doing, because it worked. I've been tested three times since, and levels are all within normal limits.

Sincerely,

Kate Staley

This month's column is dedicated to a condition quite different from thyroid dysfunction. Over the course of my time with *Massage Today*, many readers have requested some information on a disorder that is not at all well understood, even by the professionals who try to treat it. Reflex sympathetic dystrophy syndrome is a condition involving an initial injury (usually) to an extremity (usually), which results in a disproportionate amount of pain, disability, and trophic (growth-related) changes to the damaged tissue. In some cases the symptoms of RSDS can move progressively through the body and affect areas distant to the original trauma.

In October 1864, a group of doctors compared their observations of Civil War soldiers recovering from gunshot wounds. Their comments were remarkably astute, and constitute a vivid picture of the experience of the condition eventually termed "causalgia" from the Greek *kausis* (burning) and *algia* (pain).

"In our early experience of nerve wounds, we met with a small number of men were suffering from a pain which they described as 'burning' or as 'mustard red-hot' or as 'red-hot file rasping the skin'... Its intensity varies from the most trivial burning to a state of torture, which can hardly be credited, but which reacts on the whole economy, until the general health is seriously affected..."

Reflex Sympathetic Dystrophy Syndrome: What Is It?

RSDS involves tissue damage, overactive sensory neurons, an excess of pain-sensitizing chemicals, and resulting inflammation followed by atrophy of the affected area. Because it is called so many things, and the criteria for making a diagnosis varies by medical specialty (orthopedists use different methods than general practitioners or internists, for instance), it is extremely difficult to pin down and get any solid statistics on its incidence or demographics.

Part of the confusion around this disorder lies its name. Chronic progressive pain syndromes have many labels, and RSDS just happens to be the one that is most popular at this moment in time. Here is a short list of other labels for this or very similar conditions:

- Complex regional pain syndrome type 1 (CRPS-1)
- Sympathetically mediated pain syndrome (SMPS)
- Causalgia
- Algodystrophy
- Algodynia
- Sudek's atrophy
- Shoulder-hand syndrome
- Neurovascular dystrophy syndrome

The most conservative discussions of RSDS limit it to problems that begin in the hand or arm. This discussion won't limit the damage to the upper extremity, but please be aware that clients who live with this condition may have learned to call it by a different name, depending on where it has affected them, and what kinds of professionals they work with for treatment.

Etiology: What Happens?

When a person experiences any stimulus on the skin, a sensory neuron carries that information to the spinal cord, where a reflex response begins. At the same time, that impulse travels up the spinal cord to the brain, where the stimulus is interpreted at a conscious or subconscious level. If the stimulus is perceived as something safe and relaxing, it initiates a parasympathetic response; if it is interpreted as threatening or painful, a sympathetic response follows.

In RSDS, as far as it is understood at this point in time, a stimulus initiates a sympathetic, but this response long outlives its usefulness. The affected part of the body goes through a localized cycle of pain, which causes sympathetic responses, which reinforces the pain, which exacerbates the pain response, ad infinitum. The healing processes that would normally interrupt this sequence are unable to break through the vicious circle of pain - stress - pain. Eventually, the physiological changes that occur when a specific part of the body is stuck in a sympathetic loop cause their own kinds of damage - damage that can be irreversible. Tissue that experiences chronic inflammation will become essentially "walled off" from the rest of the body, and develop severely restricted blood and lymph supply. This leads to atrophy, bone thinning, and permanent loss of function.

Although it happens only rarely, this pain cycle also has the potential to spread proximally on the affected limb, to the eyes, internal organs, and even to the contralateral limb.

Signs and Symptoms

Four main symptoms have been observed in most RSDS patients: constant burning pain with little or no stimulus; local inflammation and sweating; spasm of both skeletal and smooth muscle in nearby blood vessels; and chronic insomnia (which can contribute to increased pain perception, as sleep deprivation can disturb neurotransmitter levels).

RSDS can be broken down into three or four loosely defined stages. Overlap of these stages often occurs, so they are useful mainly as a time reference for how long a person has been affected by this condition, and what treatment options have the best chance of interfering with its progression.

- **Stage I:** Stage I signs and symptoms are prevalent during the first one to three months of pain. They include severe burning pain at the site of the injury, muscle spasm, reduced range of motion, excessive hair and nail growth if the injury is on a hand or foot, and hot, red, sweaty skin.
- **Stage II:** In this stage, changes in the growth pattern of the affected tissues can be observed. The swelling spreads proximally from the initial site, the hair stops growing, the nails become brittle and easily cracked. Skin that was red in Stage I takes on a bluish cast in Stage II. In this intensely painful stage the muscles begin to atrophy from under-use, and the nearby joints may thicken and become stiffer. Stage II usually lasts from three to six months.
- **Stage III:** Stage III RSDS shows signs of irreversible changes to the affected structures. The bones become osteoporotic, the joints become immobile, and the muscles may tighten into permanent

contracture. The condition may spread proximally up the limb, to the contralateral limb, or elsewhere in the body.

- **Stage IV:** Some researchers maintain that Stage IV of RSDS is different from the other stages because at this point, the pain sensation is a self-sustaining phenomenon in the brain. In other words, the neurotransmitter balance and pain sensation centers in the brain are essentially incapable of letting go of this sensation.

Diagnosis and Treatment

Because the diagnostic criteria for RSDS and related disorders vary according to medical specialty, it can be difficult to reach a conclusive diagnosis in the early stages of the disease. This is a problem, because the long-term outlook for someone with this problem is significantly better if he or she can begin treatment in Stage I, rather than Stage IV.

Visible signs and patients' descriptions of symptoms are usually straightforward with this condition.

Diagnosis can be confirmed with thermography: a test that measures blood flow and localized heat in the body. X-rays or bone scans may be used to look for signs of osteoporosis at the site of injury.

Stage I RSDS may be treated with simple analgesics: NSAIDs or short-term steroids if necessary. Patients get good benefit from heat, especially moist heat applications like paraffin baths or hot packs. Ice is generally not useful for RSDS patients in any stage. Stage II and III RSDS patients need to be more aggressive with their pain management. Anti-seizure medications and morphine pumps are used with mixed results. TENS machines are successful for some people but not all. Calcium channel blockers may improve blood flow and relieve pain. Eventually, a patient may consider a sympathectomy: the surgical severing of parts of the sympathetic nervous system in order to stop the endless cycle of repeating pain signals. This intervention can be successful, but many patients report that the benefits are short-lived and the pain comes back post-surgically.

Can Massage Help?

This is where it gets interesting. Usually, when I research a particular topic, I look up that subject plus "massage," and get exactly nothing. Then I try that topic and "alternative treatments" and often have marginally more success. But for RSDS, this acutely painful, poorly understood sensory dysfunction, I found much more information about massage than I usually do. I found testimonials of RSDS patients who

felt their massage therapists had prevented them from developing contractures in their affected muscles; I found suggestions to use massage to help desensitize over-stimulated areas; and massage is frequently recommended along with some other alternative therapies for chronic pain management. I also got some feedback from therapists who specialize in working with RSDS patients; an excerpt from one letter follows:

I have extremely successfully treated a number of RSDS patients using my specialty of medical qi-gong needleless acupuncture, using my fingers on the affected areas. Trauma to an area causes what the osteopaths call a "lesion," or sensitized trigger points or sometimes a "facilitated segment" when it is in the spinal area. It becomes electrically walled off to nutrition, and acupuncture and energy type treatments do the best with these chronic (as well as acute traumas) from my 20 years of experience.

Charles Nohava,

Director, Prisma Center

Kirtland, Ohio

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The upshot of it all is that although RSDS is a painful, inflammatory, potentially progressive condition (all of these qualities raise some cautions for massage), bodywork can serve a useful purpose in the treatment options (or just coping options) for the person who is affected by this disorder. Exactly what modalities to use, and how to avoid causing more pain than necessary while working to maintain muscular and joint health, will depend on the tolerance of the patient and the skills of the therapist.

This is an excellent example of a condition in which a massage therapist should work as part of a health care team, not as a solo practitioner. For more information about RSDS, I highly recommend the following Web sites:

www.rsdhope.org

www.rsd.org

www.rsdcare.org

www.pain.com

Next time, I'll discuss another frustrating, chronic, progressive condition, but one that has a generally more hopeful prognosis: adhesive capsulitis, also known as frozen shoulder. Send me your success - and failure - stories, so we can all benefit!

Click [here](#) for more information about Ruth Werner, LMP, NCTMB.



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