

Amplified Musculoskeletal Pain

or

Reflex Neurovascular Dystrophy (RND)

A Guide for Parents of Children with RND

David D. Sherry, MD

What is Amplified Musculoskeletal Pain?

Amplified Musculoskeletal Pain, or Reflex Neurovascular Dystrophy (RND), is a very painful medical condition. It usually affects a limb (a foot or leg more commonly than a hand or arm), but can cause pain anywhere on the body. Some children have pain all over and a few have intermittent attacks of pain. The pain these children experience, however, is much more intense than one would normally expect because the pain signal is amplified. It has multiple manifestations and each form can be named separately, but herein I will use the term RND to encompass the spectrum of amplified musculoskeletal pain syndromes.

How is the pain signal amplified?

First, look at the figure to see how we normally feel pain. Usually pain is in response to tissue damage, such as stepping on a tack. The damage sends a signal through the pain nerve (1) to the spinal cord (2). The signal is then transferred up to the brain (3). The brain then recognizes the signal as being painful.

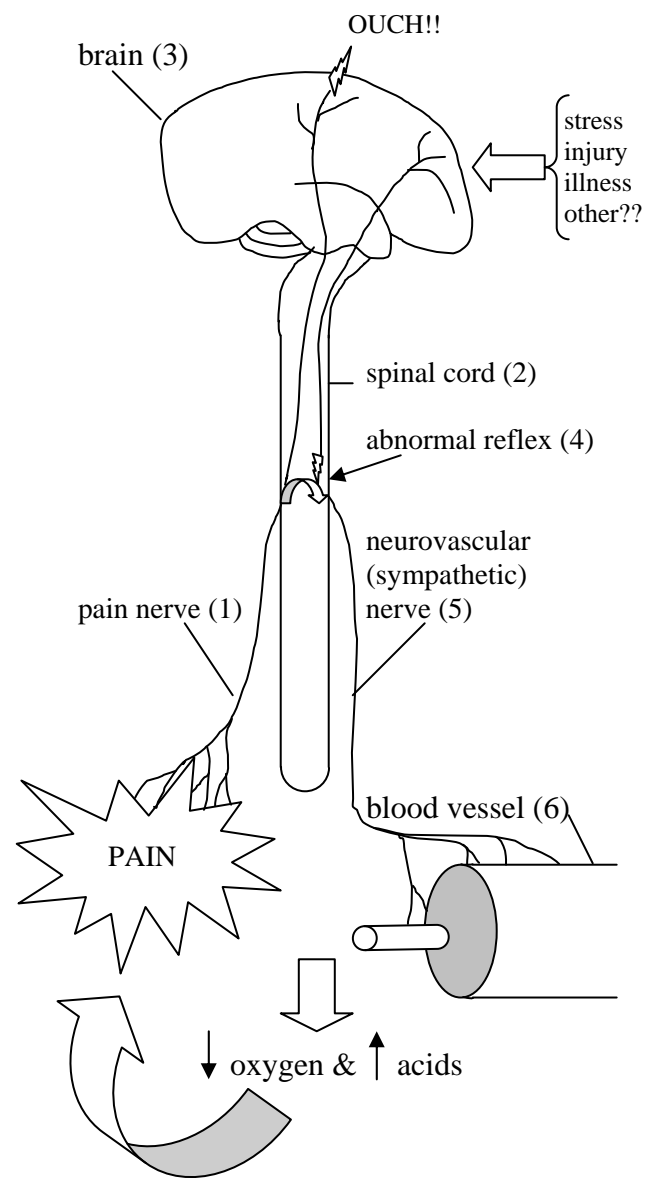
In RND there is an abnormal short circuit in the spinal cord (4). Therefore, the pain signal not only travels up to the brain, but also goes to the neurovascular nerves (5) that control blood flow through the blood vessels (6). These nerves cause the blood vessels to constrict thus decreasing blood flow. The decreased blood flow deprives the skin, muscles, and bones of oxygen and leads to a build-up of acid waste products such as lactic acid. This lack of oxygen and acid build-up causes pain. This new pain signal also goes across the abnormal reflex and causes a further decrease in blood flow, leading to more pain. Thus, the pain is greatly amplified through this vicious cycle.

Frequently the part of the body with RND will become cold, blue or purple, and even swollen due to the decreased blood flow. Some children will have a test called a bone scan that may show this decreased blood flow (although this test may be normal – there is no specific test for RND). Other findings frequently seen are osteoporosis due to a decrease in calcium

from the bones and muscle wasting (atrophy). Rarely, the skin will become thick and waxy, a so-called dystrophic change that gives RND part of its name.

What causes the abnormal reflex?

There are 3 major reasons for the abnormal reflex: injury, illness, and psychological stress. There may be other reasons such as age, genetics, or hormones (80% of children with RND are girls). More research needs to be done.



What kind of injury leads to RND?

Injury is the cause of RND in approximately 10 - 20% of children with RND. The majority of children with post-traumatic RND have a specific injury such as a broken bone, crushing or piercing injury, or surgery. The symptoms develop immediately or within a few weeks after the injury. Not uncommonly, as the injury begins to heal the pain starts and then continues for weeks to months after the injury has fully healed.

What kind of illness leads to RND?

Illness is an infrequent cause of RND. Most commonly it is seen in conjunction with inflammatory illnesses of the musculoskeletal system such as arthritis, tendinitis, myositis or enthesitis. Other illnesses may be the initial cause of pain; most are infections such as mononucleosis, influenza, or gastroenteritis.

What kind of psychological stress leads to RND?

In at least 80% of children with RND, psychological factors seem to play a role. There is a whole host of possible stresses that may play a role in causing (or perpetuating) RND including the psychological consequences of having the pain (and perhaps not having a timely diagnosis). All change is stressful, even a change for the good. Feelings such as fear, worry and shyness are stressful as are the stresses world events. The most common stresses we see in children with RND are those that arise from family and school issues. Many families are undergoing changes such as an older sibling leaving home, new jobs, or marital issues. Additionally, school is more demanding and peer pressure and social demands can be quite intense. Developmentally, most children with RND are gaining more independence and responsibilities and may be going through puberty. Some children deal with stress by keeping it inside and this stress can lead to bodily symptoms including RND.

Is the RND all in my child's head?

No. The pain is very real and very intense. Even in those children in whom psychological

stress plays a major part in causing the RND, the decreased blood flow to the area of RND causes the extreme pain.

Are there any laboratory tests to prove it is RND?

No. Blood tests are normal unless there are other conditions present (for example, an infection can alter the blood counts and sedimentation rate). In some children a bone scan or MRI can show abnormalities that are very suggestive of RND, but the results may be normal.

What can be done to help my child?

It is most important that someone with RND begin to use his or her body in a normal way. The abnormal reflex is broken by intense physical and occupational therapy (PT/OT). Some children are able to do this on their own by exercising at home. Although it hurts to do the therapy, it does not cause damage, and some children are able to work through the pain.

Most children will need to have a formal PT/OT program, 5 hours of therapy, daily. It just hurts too much for him or her to do it on his or her own. Most require daily out-patient therapy. A few children require hospitalization, especially those who are severely incapacitated, those who have marked pain behaviors such as night time screaming, and those who need a behavior modification program.

The intense formal PT/OT program is just the *first part* of our program. Most children will be fully functional at the end of this part but most will still have pain, though the pain usually starts to decrease. The *second part* of the program is to maintain normal function (school, chores) and continue to do a home exercise program with or without stress counseling (depending on the results of our evaluation). It is during the second part of the program that most children will resolve their pain. The *third part* of the program is to graduate away from a formal home exercise program and to have normal function without pain.

In addition to the PT/OT therapy we do an evaluation to see if stress plays a role in your child's RND. This involves filling out questionnaires and talking to the psychologist. Our education specialist will need your child's academic record and may administer academic testing. After this evaluation we can give you more specific advice about the role stress may play in your child's RND and whether counseling is advisable.

A few children need a behavior modification program. If we think your child needs this, it will be discussed with you in depth.

How long does the program take?

The average is 3 weeks for the formal first part. Occasionally, a child will respond quickly and only need 1 or 2 weeks. However, a few children will require many weeks. The duration of treatment needed is impossible to predict until we see the rate of your child's progression once in the program. Function comes back first; the pain usually takes longer to decrease. Some children will resolve their pain during the first part but most will do so during the second part, once they are in school, maintaining normal function, and perhaps receiving counseling. The pain usually diminishes gradually over 2-6 weeks; rarely it takes many months. It is not uncommon for the pain to increase at first or move or spread to different locations.

What will my child be doing?

Your child will have an individualized PT/OT program designed specifically for him or her. It will be intense and will focus on the body areas that are painful or do not function properly. If there are body areas that are painful to touch, these areas are desensitized with rubbing and massage. In the beginning this program is 5 hours a day. Physical and occupational therapists who are experts in RND direct this therapy. A program of exercises to do at home is part of the treatment, especially over the weekends. There will be scheduled appointments with the psychologist for the child and parents, music therapy, and there may be an educational evaluation including standardized testing.

Are parents allowed in the exercise sessions?

No. We have found it is best that the parents not be present. Children often respond differently in a parent's presence. While the child is being treated the parents should go about their usual activities as much as possible.

Can parents eat lunch with the children?

During the first week we usually allow the parents to lunch with their child but after that we want to more closely simulate school and, unless there are extenuating circumstances, your child should have lunch without parents.

What about school?

School is put on hold during the program. Some children can benefit from homebound instruction during the evenings. We will contact the school to help the child reenter school with appropriate educational accommodations so that he or she will not be overly stressed and overworked. We will contact the school to obtain the child's academic records and other pertinent information. We frequently do a few academic tests to ensure that your child's educational goals are appropriate. We expect that all children will return to school full time without physical accommodations at the end of the intense first part of the program.

What is music therapy?

Music therapy helps your child gain coping skills to help work through and decrease the pain. It may help with sleeping. Music therapy includes breathing exercises, progressive muscle relaxation, and imagery, and also allows your child to express himself or herself through music production. It is administered by a music therapist with extensive experience with children with RND and is usually conducted 2-3 times a week.

What happens if my child gets sick or injured?

We will fully assess the nature of the illness or injury and treat it appropriately. We want to see the child even if he or she is thought too ill to proceed. Most of the time, we can continue the program with modifications.

Do the exercises have to be done here?

For most of the children seen in Philadelphia, yes. The type of therapy is different from what most physical and occupational therapists are taught. Most local therapists are not able to deliver the amount of therapy required. However, there are situations where we can work with a local therapist and, as stated above, not all children need the full 5-hour a day program. We are very supportive of having other therapists develop an expertise in treating children with RND. More treatment centers need to be established so children can be adequately treated close to home and in a timely fashion. We can supply your physician and therapist with written descriptions of our exercise program. A video (VHS or DVD) for physical and occupational therapists explaining the exercise program in detail is available for purchase through a non-profit organization, the Childhood RND Educational Foundation, Inc. at www.childhoodrnd.org.

What do I tell others?

In simple terms you can explain that RND is a medical problem involving the nerves going to the blood vessels. These nerves are overactive and cause the pain. The treatment is a special series of exercises to retrain the nerves.

Are medicines used for pain?

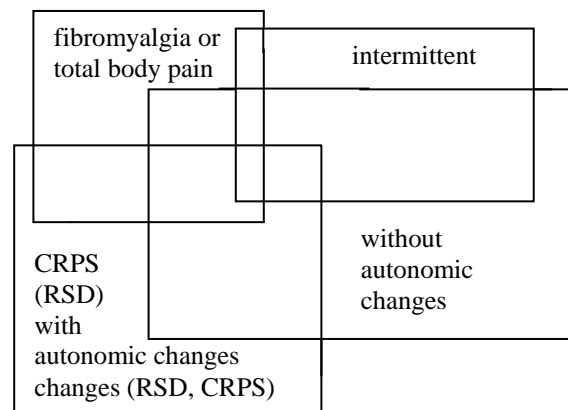
No. Most patients take no medication because it seems to hinder the retraining of the nerves. This includes herbs, vitamins and other complementary treatments taken for pain. Also, medication frequently causes side effects in these children and has minimal, if any, benefit. A very small number of children are depressed and will need anti-depressant medication. Some children may have sleeping difficulties and will need medication to help restore a normal sleep pattern; however, initially we try to avoid this since most will sleep better once they begin the PT/OT program. Before we use any medications, the risks and benefits will be fully discussed with you.

What other names does RND or amplified musculoskeletal pain go by?

There are various patterns or kinds of amplified musculoskeletal pain that are called a variety of names. I prefer the term RND since it refers to the abnormal reflex and neurovascular nerve. Most of the other names are related to where the pain is or to changes in the skin temperature and color (autonomic changes). These names include reflex sympathetic dystrophy (RSD), fibromyalgia, allodystrophy, complex regional pain syndrome types I and II (CRPS I & II), causalgia, Sudeck's atrophy, shoulder-hand syndrome, localized or diffuse idiopathic musculoskeletal pain, neuropathic pain, psychogenic pain or psychosomatic pain. Information in the literature and Internet is quite confusing; most of it applies to adults with specific syndromes, especially fibromyalgia and reflex sympathetic dystrophy. The term sympathetic can be mistakenly construed to suggest these children are just looking for sympathy. Children are different than adults in the presentation of the illness, the response to treatment and the long-term prognosis; children fare much better.

Various forms of RND can coexist in the same child or, if there is a reoccurrence, the second form may be different from the first form. A pictorial representation of the overlapping nature of the forms of RND is shown below:

Forms of RND – These overlap and a child may have one or more at the same time or have a reoccurrence with a different form from the original form. Autonomic changes include coldness, blueness, swelling or excess perspiration.



How can I prevent RND from happening again?

Your child is going to have illnesses, injuries, and psychological stress in the future. However, if he or she starts to have excessive, increasing pain you should suspect RND. Also, if the area is tender to very light touch, suspect RND. Half of the children with a second attack of RND will say that the pain feels just the same as the first time; however, half will say that it feels different. Even if the pain feels different, it still may be RND. If you suspect RND, restart an exercise and desensitization program. If it is tender to light touch, desensitization with rubbing and massage should begin. The majority of second attacks occur within the first 6 months of the first episode. Therefore, when illness or injuries occur, be sure that the pain is not out of proportion to the illness or injury.

If some form of psychological stress is present, having the stress addressed through formal counseling can be of great help.

It is important not to reinforce the sick role. When a child is hurt or in pain, the normal response is to give sympathy and make allowances for the child such as not having to make his or her bed if they have a broken arm. Children in chronic pain, especially RND, either consciously or unconsciously, receive benefits, or secondary gain. This can take the form of missing school, increased parental attention, getting out of sports, dance, music lessons, etc. Even though the child may truly enjoy these activities, it is still somewhat of a relief that he or she does not have to perform. We have children with RND who have parents sleep with them, miss work to take care of them, and excuse the child from all chores and limitations. It is important for the family to stop enabling the pain and disability. Frequently it is hard to recognize what is enabling and what is just normal caring. Sometimes having either the parents or family work with a counselor is helpful in this regard.

Why did it take so long to diagnose the RND?

Early diagnosis may be difficult for several reasons:

1. Not all the RND symptoms may be present at first but may evolve over time.
2. Urgent problems such as fractures or infections need to be ruled out first to be 100% sure before starting an exercise program.
3. It may be hard to recognize since there is a wide spectrum of RND so unless the doctor has seen a variety of children with RND he or she may not diagnose it.

What is the long-term outcome?

There are few studies of long-term outcome. In one study where the children were treated with an intense PT/OT program, 88% of the children were pain free and fully functioning after an average of five years.

If psychological stress is a cause of RND, we have seen children subsequently develop a wide variety of other psychologically driven disorders such as anorexia nervosa, bulimia, other amplified pain syndromes (such as abdominal pain, headache, eye pain, sinus pain, tooth pain), pseudo-seizures, uncontrollable shaking or muscle spasms, suicide attempts and conversion reactions. In a conversion reaction, the body converts feeling and emotions into neurological symptoms such as paralysis, blindness, shaking, or numbness.

What is being done to find out more about RND?

The Children's Hospital of Philadelphia is one of the few places doing research on children with RND. You and your child may be asked to take part in research. Before participating in any research project, it will be fully explained to you and is always entirely voluntary. Contributions toward research are always appreciated.

Web site: www.childhoodrnd.org