



**Raynaud's Association**<sup>™</sup>  
Providing warmth and comfort against the cold



## FREQUENTLY ASKED QUESTIONS

### **What is Raynaud's?**

Raynaud's (ray-NODES) is a disorder of the small blood vessels of the extremities, reducing blood flow. When exposed to cold, the blood vessels go into spasms, which may cause pain, numbness, throbbing and tingling. Emotional distress may also trigger such a response.

The fingers are usually the primary affected areas, although toes, nose, ears and other extremities may be involved. In a typical case, fingers turn from white or blue (or both) within minutes of cold exposure then become red when they warm up. These color changes, which may vary from person to person, are an exaggeration of a normal response to cold exposure. A normal cold response in the hands is a blotchy red and white pattern. Raynaud's-type color changes are distinctively different.

The disorder has been called Raynaud's "phenomenon," "syndrome" or "disease." Although physicians have used these terms to identify different types, today the words are used interchangeably. There are, however, two major kinds of Raynaud's that are important to recognize:

*Primary Raynaud's*, the most common type, is not linked to another underlying medical condition or disease. There is no apparent cause for the phenomenon to occur. Primary Raynaud's is not usually "disabling" in the typical sense, but sufferers can experience great discomfort and pain – requiring lifestyle adjustments to minimize exposure to cold and stress.

Secondary Raynaud's is the term used when Raynaud's is associated with another medical condition or disease, often of a rheumatic nature such as scleroderma (also known as systemic sclerosis) or systemic lupus erythematosus. Often, Raynaud's symptoms are the first sign that such an underlying connective tissue disease exists. Patients with the secondary form are more likely to suffer more serious problems from Raynaud's, such as skin ulcers (which can cause serious long-term damage to the blood vessels) or even gangrene.

### **How do I know whether I have Primary or Secondary Raynaud's?**

The form is determined by a careful examination from your physician, who looks for signs of an underlying disease (for example, thickened skin in scleroderma, or sun-sensitive skin rashes in lupus). A blood test known as the ANA (antinuclear antibody test) is usually done. If the workup is negative for symptoms of other diseases, and the ANA is negative, it is likely that the Raynaud's is primary. However, it may take years for other disease signs to develop, so your physician may want to follow you for a few years before assuring you that nothing else is likely to happen.

A positive ANA is only a marker for the presence of an underlying connective tissue disease. However, some people have a positive ANA for many years, but never develop any symptoms of scleroderma, lupus or another rheumatic disease. In most of these cases, the patient is said to have an "undifferentiated connective tissue disease." Other than watching the patient closely for signs of another disorder, the treatment is virtually the same as for primary Raynaud's.

As common as Raynaud's is in the general population, fortunately only a small percent of people with Raynaud's are classified as having the secondary form.

### **Where did the name Raynaud's come from?**

Dr. Maurice Raynaud was a French physician who published a report in 1862 of a young woman whose fingertips changed colors when she was cold or under stress. He is credited with the discovery of the condition.

### **How common is Raynaud's?**

Raynaud's is very prevalent, affecting as much as 5-10 percent of the population. Fortunately, some 90 percent of these are classified as Primary Raynaud's patients. The overwhelming majority of Raynaud's patients are women, for reasons not yet clearly understood.

For such a widespread condition, awareness is very limited. Only 1 in 5 sufferers will become aware their discomfort is medically related and actively seek treatment.

## **Is it hereditary?**

Researchers haven't determined a specific genetic link for Raynaud's, although in many families, more than one member has the condition. Usually, however, it is the more benign, "Primary Raynaud's."

As a true genetic factor has not been clinically proven, it is uncertain as to whether or not family connections are based on increased awareness of the condition among relatives or true heredity.

## **If Raynaud's is so common, how come I've never heard of it?**

For many people, symptoms are mild and not particularly troublesome. They may think they are merely "cold-sensitive" or have "poor circulation." These individuals often don't seek medical attention, or may not consider it noteworthy to mention to their physicians.

Often, people with Raynaud's symptoms don't seek medical attention until they experience painful attacks and/or develop fingertip sores or ulcerations that don't heal after weeks or months.

The Raynaud's Association was created primarily to raise awareness of this disorder: to help people identify their condition and to seek medical intervention to determine whether or not an underlying -- potentially serious -- medical condition exists. In addition, the mission of the Raynaud's Association is to provide support, resources and credible information to Raynaud's sufferers.

## **How is it diagnosed?**

Doctors often make the diagnosis based on the patient's description of the color changes that occur suddenly after being exposed to cold temperatures. Sometimes doctors immerse the patient's hand in ice water to provoke an episode. However, this test doesn't always work because usually the whole body needs to be exposed to cold before an attack occurs.

There is no single blood test that identifies Raynaud's. However, doctors might order bloodwork to rule out the presence of auto-antibodies associated with scleroderma, lupus, mixed connective tissue disease, undifferentiated connective tissue disease, Sjogren's syndrome, and other diseases that have Raynaud's as a possible component.

Some specialists (usually rheumatologists) perform a nailfold capillaroscopy, a simple microscopic examination of the small blood vessels at the base of the fingernail. This test is used also to look for the presence of an underlying connective tissue disorder.

## **I have been diagnosed with primary Raynaud's. Could I develop secondary Raynaud's?**

It's possible. Sometimes the onset of Raynaud's occurs months or years before a secondary, connective tissue disease presents itself. That's why it's important to have regular medical checkups. Again, the chance that Raynaud's symptoms indicate a serious disease is low.

## **What type of physician is most familiar with Raynaud's?**

Rheumatologists are the most knowledgeable specialists about Raynaud's because they regularly treat people with the connective tissue diseases most closely associated with the condition (such as lupus, scleroderma and rheumatoid arthritis). Keep in mind that only a fraction of Raynaud's sufferers have one of these diseases, but – as an overwhelming number of these autoimmune patients also have Raynaud's – rheumatologists see Raynaud's more often than most doctors. They therefore have a better understanding of the problems patients face and how best to treat them.

Patients usually are referred to rheumatologists once their general physicians (internists, family doctors, general practitioners, etc.) determine there is probable cause to suspect Raynaud's. Another excellent referral source is the American College of Rheumatology, whose website provides names of qualified specialists within specific geographic areas: <http://www.rheumatology.org/directory/geo.asp>.

## **What causes Raynaud's?**

Although we know many of the common triggers that create Raynaud's episodes in individuals, the basic cause of Raynaud's in most cases is still a mystery. However, there has been a link established between Raynaud's and some autoimmune diseases (although it must be emphasized that the vast majority of Raynaud's patients do *not* have those diseases). Raynaud's may precede such diseases by years.

Raynaud's also may signal damage to the blood vessels caused by occupational injuries (from using jackhammers, for example), trauma, excessive smoking, circulatory problems, drug use or exposure to certain chemicals and toxic substances.

## **Who gets Raynaud's?**

Raynaud's is seen in all population groups. We do know that women are affected nine times more than men. Men and children – even babies – also get Raynaud's. When it occurs in teenagers (mostly female), they tend to develop Raynaud's around the time of puberty. Often, the symptoms disappear when the individuals are in their twenties.

## **Is there a cure?**

Until the cause is found, a cure will remain elusive. Various treatments, however, work to control the severity and frequency of Raynaud's episodes.

## **If there's no cure, what can a doctor do for me?**

If you have Raynaud's symptoms, a doctor can confirm the diagnosis and rule out any underlying medical causes that require treatment. Raynaud's lesions (or ulcers, as they are often called) can do permanent damage to blood vessels. Proper treatment is required to help them heal.

Doctors also can provide information to help minimize the frequency and severity of Raynaud's episodes.

## **What is the treatment for Raynaud's?**

Most experts agree the best way to handle Raynaud's is to avoid cold temperatures and stress. Such avoidance measures, obviously, are not always practical.

To date, there is no medication that eliminates Raynaud's attacks, but there are some medications that decrease their severity or frequency. The standard medication offered severe Raynaud's sufferers is in the family of calcium channel blockers. These drugs work to open up or dilate the blood vessels so the blood circulates more freely. They are the same medications given to people with high blood pressure. Topical antibiotics or nitroglycerin paste or patches may be prescribed to protect against infected skin ulcers. If your blood pressure is already low, you may not be a candidate for some of these treatments. These medications can cause side effects such as ankle swelling, light-headedness and headaches. As different brands and generic forms of these drugs are available, work closely with your doctor to determine what works best for your body. Should you choose to go on medication, be aware it does take time to see results.

Self-help, relaxation techniques, such as biofeedback and tai chi, work for some people to minimize the severity of Raynaud's attacks. These methods require a great deal of practice and commitment to achieve real results. They won't be effective for everyone, particularly for more severe Secondary Raynaud's sufferers.

Tai Chi is a Chinese martial art that generates a strong flow of internal energy (chi) throughout the body. Being aware of this internal energy allows one to direct more heat to the body extremities. The practice of tai chi can help to calm the mind, relax the body and improve your health.

A regular exercise regimen helps to increase blood supply to body tissues. Some people claim to have success with natural and holistic remedies, but these have not been verified as effective for everyone. Be sure to make your doctor aware if you are taking, or plan to use, any such supplements, as they may interact with other medications or have negative side effects.

The importance of receiving medical help when ulcers are present cannot be overemphasized. Untreated ulcers could become infected or cause permanent blood vessel damage. In the most severe instances, surgery or amputation of fingertips or toes may be necessary.

### **I have bad reactions to cold temperatures, but my symptoms don't sound like Raynaud's. What could they mean?**

A condition known as chilblains results from defective blood circulation when the person is exposed to cold. The symptoms are swelling, inflammation, severe itching and a burning sensation. After the skin becomes itchy, it might turn red and swollen, then become tender to the touch.

Cold Urticaria or Physical Urticaria is a condition in which red allergic skin lesions and itching are produced by exposure to cold temperatures, water or mild trauma.

One condition with symptoms and triggers (cold and stress) very similar to Raynaud's is called Acrocyanosis - a chronic circulatory disorder resulting from spasms of the small arteries of the skin. The skin goes through color changes from the lack of oxygen to the fingers or toes similar to the discoloration seen in Raynaud's sufferers. Other symptoms are severe sweating and swelling of the digits.

As with Raynaud's, seek a diagnosis and treatment from your physician if you suspect any of the above conditions apply to you.

### **How does biofeedback work?**

Biofeedback is a technique whereby individuals train themselves to increase the blood supply to their extremities. Often, a wire is taped to the fingers. The wire is attached to a gauge or computer that indicates whether the finger temperature is going up or down. The person is then asked to imagine he or she is in a warm room, at the beach, etc. Relaxation tapes may be used. With practice, the person can learn to raise his or her finger (and overall body) temperature. After a while, the response becomes automatic. This technique appears to work better for people with primary, as opposed to secondary, Raynaud's.

## **What else can I do to avoid a Raynaud's attack or provide quick relief?**

Here are some simple techniques that may help:

- Dress warmly, and in layers. Wear a hat when outdoors in cold weather. Try to stay indoors during cold weather.
- In cold weather or when exposed to air conditioning or cold temperatures (in the refrigerated section of a supermarket, for example), wear gloves. Mittens are even better protection. Use these even when handling frozen or refrigerated foods.
- Carry hand and foot warmers (found in many sporting goods and ski shops). One form of warmers, charcoal packs, heat up when they're exposed to air. Others have a metal disk that must be bent to activate the heat, caused by a resulting chemical reaction. The Raynaud's Association has discovered a variety of useful devices for keeping hands and feet warm.
- Use insulated drinking glasses or mugs. Place a napkin or insulating material around them to protect your fingers from becoming cold.
- Place hands under warm (not hot) water to warm them up quickly.
- Don't smoke. Smoking narrows blood vessels even more, and makes Raynaud's worse.
- Swing arms around in a windmill fashion to get the circulation going quickly.

The Raynaud's Association is a wonderful clearinghouse of information about such methods, products and services (and where they may be obtained). Many of our members share valuable tips, resources and insights. [Go to the Search section of this website, review the "Hot Products" and "Member Tips" columns in our Cold Cuts newsletters, or check out our Marketplace listings for more information about products with the potential to offer warmth and comfort.](#)

## **I've heard that there's a surgical procedure to improve Raynaud's. What is it?**

When Raynaud's is very severe, resulting in intolerable pain and ulcers that don't respond to medications, your physician may suggest a surgical procedure called a digital sympathectomy. -In this procedure, a surgeon cuts the tiny nerves to the arteries of the fingers. The procedure isn't always effective, and the benefits generally will not last. However, this "last ditch" approach may preserve the finger or toe from amputation. Some patients report that the procedure reduced their pain, healed their ulcers and/or prevented new ulcers from forming.

## **Will it help if I move to a warmer climate?**

Bitter cold winters make life miserable for many Raynaud's sufferers, but warmer climates also present challenges. Attacks can occur in air-conditioned spaces or when it's a breezy day. Take into consideration the degree of control you'll have over your environment during the day (i.e., in an office or retail store for work).

In the end, look at the full relocation opportunity from a lifestyle/family perspective and think through the environmental elements that you'll be dealing with at home, at work, and other venues.

## **Why do stress and emotional factors trigger Raynaud's episodes?**

Blood vessels are normally constricted when someone experiences strong emotions. Patients with Raynaud's have overactive vessels that become too narrow. The adrenaline that is released during strong emotions triggers the spasm.

## **I get migraine headaches. Could they be related to Raynaud's?**

There is some evidence that Raynaud's may be part of a generalized disorder of the body's overall vascular system. Headaches occur when blood vessels open too much (ironically, just the opposite of what occurs during a Raynaud's episode). Headaches also may occur as a side effect to some of the medications taken for Raynaud's.

## **Will my Raynaud's get worse over time?**

Not necessarily. Sometimes Raynaud's improves or symptoms simply disappear. Unfortunately, there is no clear pattern for either future prognosis.

## **What research is being done?**

Unfortunately, most research to date has focused on treatment, as opposed to cause and cure. One of the most promising research studies to date is written up in our Spring 2002 newsletter about Dr. Flavahan's work at Ohio State involving Alpha 2 receptors. You can access the article on our web site at:

### **[Ohio State Research News New Therapy Breakthrough - Cold Cuts, Spring 2002](#)**

*Dr. Nicholas Flavahan's research study focused on the body's blood vessels and how they interact with norepinephrine -- a chemical produced by the body to maintain blood pressure.*

[www.raynauds.org/support/newsletter/pdf/2002\\_spring.pdf](http://www.raynauds.org/support/newsletter/pdf/2002_spring.pdf)



## **Does the Raynaud's Association fund research?**

At present, we do not directly fund research. Our initial goals are to develop greater awareness of the disorder and to provide support and education to Raynaud's sufferers. These measures will create a broader base with which to launch an effective fundraising program to promote qualified research.

## **I want to talk to other people who have Raynaud's, those who understand what I'm going through.**

That's why the Raynaud's Association was created. We offer support, advice and resources via this website and our quarterly newsletter, "Cold Cuts." We're also here to help you provide a support group in your own area. If you'd like more information about Raynaud's and membership in the Raynaud's Association (we rely on membership dues), contact us at [info@raynauds.org](mailto:info@raynauds.org), or call our toll-free number, (800) 280-8055.

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