

lupus  **FACT SHEET**

Lupus Canada

Other Conditions Seen in Lupus

Systemic lupus erythematosus (SLE or lupus) is often referred to as the disease with a thousand faces because it is associated with a wide variety of symptoms and related conditions.

Three conditions that may be seen in lupus are Raynaud's phenomenon, Sjögren's syndrome and gastrointestinal problems. While the symptoms can be troublesome, there are steps you can take to reduce or prevent them.

Raynaud's phenomenon

Cold hands are a sign of a warm heart – or so the saying goes. But sometimes, cold hands are a sign of Raynaud's phenomenon, a condition that makes it difficult for blood to reach the extremities because of tightening of the blood vessels. About one-third of people with lupus have Raynaud's phenomenon or secondary Raynaud's syndrome (if the condition exists on its own, it is referred to as primary Raynaud's syndrome or Raynaud's disease).

Symptoms: Changes in skin colour occur suddenly when the extremities (fingers, toes and sometimes ears and nose) get cold; it may also occur with stress. The skin first becomes white, and then red (this may vary in some people). There may be tingling, painful stinging or numbness in the fingers or toes; these symptoms generally resolve with warming. A Raynaud's episode usually lasts a few minutes, although severe episodes may last longer.

Although Raynaud's phenomenon is common in people with lupus, Raynaud's activity is usually independent of

lupus activity. In other words, a lupus flare may not be associated with a Raynaud's episode and vice versa.

Although uncomfortable, Raynaud's phenomenon is usually mild and rarely results in permanent damage. People with severe Raynaud's phenomenon, however, may develop painful skin ulcers or, even more rarely, gangrene – on their fingers or toes. Be sure to seek medical help if you have cuts or sores on your feet or hands that don't heal promptly.

Diagnosis: To diagnose Raynaud's phenomenon, your doctor will review your medical history, especially regarding the effect of cold on your fingers and toes. He or she may also order certain tests, such as blood flow tests, to help confirm the diagnosis or to distinguish between different diseases.

Management: If you experience a Raynaud's episode, encourage blood flow by shaking or massaging your hands and feet and/or running warm water over your fingers or toes or soaking them in a bowl of warm water. If your fingers and toes have gone numb, they may throb and feel sore as the circulation returns.

Your first line of defense against Raynaud's phenomenon, however, should be prevention. Whenever possible, avoid or reduce your exposure to the cold. Since stress is also associated with Raynaud's episodes (not to mention lupus flares!), it is important for you to learn how to reduce and deal with stress in your life. For some practical suggestions on managing Raynaud's phenomenon, see the sidebar on the next page.

Raynaud's phenomenon is usually mild and rarely results in permanent damage.



PRACTICAL PREVENTION

- Although Raynaud's phenomenon rarely causes permanent damage, the condition can have a significant impact on your day-to-day life. Here are some practical suggestions to manage the condition:
- Know your enemy: cold weather. Check the weather forecast before you head out and dress accordingly. Your cold-weather wardrobe should include a hat. When you have a Raynaud's episode, make note of the temperature so that you become aware of the threshold at which you become affected.
- Insulate your fingers. Mittens keep fingers warmer than gloves. Buy a variety of handwear to suit the weather and occasion: light gloves for mild days or driving, woolly mitts or gloves with thermal liners for colder days, and thermal-insulated mittens for winter's worst.
- Buy several pairs of mittens or gloves in the same style. That way, if you lose one, you will still have a match.
- Wear gloves to reach into the freezer and rubber gloves if you have to immerse your hands in cold water.
- Keep your toes toasty. Choose wool or wool-blend socks instead of cotton or nylon. Wear waterproof boots on wet days. If your feet are cold at night, wear loose-fitting socks to bed.
- It's important to avoid chilling any part of your body, not just your hands and feet, so be sure to dress warmly on cold days.
- Tuck chemical-activated heat packs into your mittens on extremely cold days or if you have to be outside for a long time. If you have numbness, however, be very cautious with the use of these packs to avoid burns.
- Be prepared. Always carry a pair of mittens or gloves in your bag or glove compartment, no matter what the forecast.
- If your fingers are affected by holding a cold glass, use a mug with a handle or an insulated glass.
- Beware of air conditioning. Raynaud's can strike on the hottest summer day if you step into an overly air-conditioned building. Keep a sweater or shawl handy and set the thermostat higher if possible.
- Most importantly, don't smoke. Cigarette smoke causes blood vessels to tighten and will worsen your Raynaud's symptoms.
- It may help to reduce your caffeine intake. Caffeine is found not just in coffee, but also in cola, some teas, chocolate and some medications.
- Check your medications. Some drugs, such as beta-blockers and decongestants can make Raynaud's phenomenon worse. Talk to your doctor or pharmacist about your options.
- Control stress. Try guided imagery, yoga or other relaxation techniques. If necessary, talk to your doctor about medication.

If your Raynaud's is severe or very troublesome to you, your doctor may prescribe medication to help dilate your blood vessels and improve blood flow, for example, nifedipine or nitroglycerine.

Sjögren's syndrome

Saliva and tears. Most people don't give a second thought to these body fluids – until they dry up. Without naturally produced moisture, your eyes and mouth may become so dry that you feel like you're trapped in a desert.

Sjögren's syndrome is an autoimmune condition that attacks glands in the soft lining in and around the eyes, mouth and genitals that secrete fluid to keep these areas moist. This condition primarily affects women, especially those past middle age. About half the time, it occurs alone (known as "primary Sjögren's syndrome"), and about half the time it affects people with other diseases (known as "secondary Sjögren's syndrome"), particularly lupus and rheumatoid arthritis. The secondary form of the disease is usually milder than the primary form.

Symptoms: The hallmark symptoms of Sjögren's syndrome are dry eyes and mouth. You may find that your eyes are sensitive to bright light, or burn or feel scratchy, espe-

cially in the morning. You may have a dry cough or scratchy throat, caused by lack of saliva. Another sign may be an increase in cavities, mouth infections or mouth ulcers. Women may experience discomfort during sexual intercourse due to vaginal dryness. Some symptoms of Sjögren's syndrome are similar to those of lupus – in particular, joint pain and fatigue – making it difficult for you to distinguish which condition is causing which symptom. Symptoms range widely in severity, from barely noticeable to debilitating.

Diagnosis: In addition to reviewing your medical history, your doctor may arrange special eye examinations or test your saliva and tear production to confirm a diagnosis of Sjögren's syndrome.

Possible concerns: Saliva helps protect your gums and teeth, so Sjögren's syndrome can lead to tooth decay and gum disease. It is important to tell your dentist if you have Sjögren's syndrome. Get regular check-ups and brush and floss regularly.

The back of your throat and lungs may be affected by Sjögren's syndrome. Be sure to follow up with your doctor if you have a cough or cold that doesn't go away.

Less commonly, Sjögren's syndrome can also cause complications with internal organs, such as the kidneys, liver and pancreas, and the central nervous system.

Finally, if you are a woman with Sjögren's syndrome, talk to your doctor before becoming pregnant. You may need to be tested for an antibody that can cause heart problems in newborns.



Management: Fortunately, most of the symptoms of Sjögren's syndrome can be managed with over-the-counter medications and practical strategies (see the box on page 2).

MOISTURE MANAGEMENT

These practical tips may help you reduce the annoying symptoms of Sjögren's syndrome:

Some people find that sucking on sugar-free candies or chewing sugar-free gum helps stimulate saliva.

Avoid acidic candies, food or beverages, as they may irritate open sores and damage your teeth.

Take small sips of water throughout the day, but avoid excessive water sipping, as it can reduce the oral mucous film and increase dry mouth symptoms.

Avoid dehydrating foods, drinks and medications, such as coffee, alcohol and foods with a high sugar content and antihistamines.

Talk to your doctor about saliva substitutes or prescription medications to increase saliva production.

Take care of your teeth: brush and floss, and visit your dentist regularly.

Use artificial tears to keep your eyes moist.

Don't wear contact lenses.

Wear protective eyewear to protect against drying wind and irritating sunlight.

Avoid vaginal irritants such as bubble baths, douches, sprays, soaps, etc.

Women may want to use water-based lubricants, such as K-Y Jelly, during sexual intercourse. Don't use oil-based lubricants such as those containing petroleum jelly or baby oil because they may irritate the vaginal lining. Talk to your partner about the need for increased foreplay to promote lubrication.

If you have persistently and extremely dry eyes, your doctor may suggest plugging your tear ducts with collagen to increase moisture.

For severe Sjögren's syndrome, your doctor may prescribe medications such as an anti-malarial, systemic corticosteroid and/or immunosuppressive agent.

Gastrointestinal conditions

Many people with lupus experience a variety of gastrointestinal (GI) problems at one time or another. These might include nausea, vomiting, diarrhea or constipation. The source of these problems may be lupus itself, your medications or another associated condition.

Symptoms and causes: Reflux, or heartburn, is common. It occurs when food and/or acid from the stomach ends up back in the esophagus (the "food tube" that runs from your mouth to the stomach). Reflux can be caused by a weaker-than-normal muscle separating the esophagus and stomach; this is called a hiatal hernia.

Many nonsteroidal anti-inflammatory drugs (NSAIDs), corticosteroids and chemotherapy used to treat lupus are associated with GI problems, ranging from upset stomach to erosions in the stomach that can lead to ulcers. Peptic ulcers can also be caused by bacteria called *H. pylori* (about 5 percent of people with lupus have peptic ulcers). These are treated with antibiotics, bismuth solutions (e.g. Pepto Bismol) or a proton-pump inhibitor (e.g. Prevacid, Pantoloc, Losec, Nexium).

Functional bowel disease, also called spastic colon or irritable bowel syndrome, is also common and may be associated with intermittent abdominal pain.

Diagnosis: You may need x-rays of the upper gastrointestinal tract or an endoscopy (in which a tube is inserted down your throat) in order for your doctor to make a diagnosis of the nature and cause of your GI condition.

Management: Most GI symptoms can be managed with medications and practical lifestyle changes.

Antacids such as Tums or Maalox may offer temporary relief of symptoms. For more serious or persistent problems, your

doctor may prescribe medications such as a proton-pump inhibitor.

If you have an upset stomach after taking medications, try taking them with food. Talk to your doctor or pharmacist about other tips to reduce the chance of GI discomfort caused by drugs.

Another helpful tip is to eat small, frequent meals during the day rather than fewer large ones. To avoid gastric reflux, don't lie down for at least two hours after eating.



FOR MORE INFORMATION

- Lupus Canada: www.lupuscanada.org. This site includes electronic versions of the *Living Well with Lupus* fact sheets.
- *Lupus: The Disease with a Thousand Faces*, edited by Dr. Sasha Bernatsky and Dr. Jean-Luc Senécal, Key Porter Books (2004) ISBN 1-55263-603-8. Contact Lupus Canada to order this book.
- Lupus Foundation of America: www.lupus.org
- Sjogren's Society of Canada: www.sjogrenscanada.org
- The Arthritis Foundation: www.arthritis.ca

Disclaimer

Systemic lupus erythematosus is an autoimmune disease that affects thousands of Canadians, mostly women in their childbearing years. Symptoms vary greatly from person to person and treatment is highly individualized. Patients are urged to contact their physician or healthcare professional with any questions or concerns they might have.

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