

*Questions
& Answers
about . . .*

**Lichen
Sclerosus**

*National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
National Institutes of Health
Public Health Service • U.S. Department of Health and Human Services*

For Your Information

This publication contains information about medications used to treat the health condition discussed here. When this booklet was printed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration at 1-888-INFO-FDA (1-888-463-6332, a toll-free call) or visit their Web site at www.fda.gov.

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You can also find this booklet on the NIAMS Web site at www.niams.nih.gov/hi/topics/lichen/lichen.htm.

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This booklet contains general information about lichen sclerosis. It describes what lichen sclerosis is and how it is diagnosed and treated. If you have further questions after reading this booklet, you may wish to discuss them with your doctor.

What Is Lichen Sclerosis?

Lichen sclerosis (LIKE-in skler-O-sus) is a chronic inflammatory skin disorder that can affect men, women, or children, but is most common in women. It usually affects the vulva (the outer genitalia or sex organ) and the anal area. While lichen sclerosis appears predominantly in postmenopausal women, this skin condition is also known to develop on the head of the penis in men. Occasionally, lichen sclerosis is seen on other parts of the body, especially the upper body, breasts, and upper arms.

The symptoms are the same in children and adults. Early in the disease, small, subtle white spots appear. These areas are usually slightly shiny and smooth. As time goes on, the spots develop into bigger patches, and the skin surface becomes thinned and crinkled. As a result, the skin tears easily, and bright red or purple discoloration from bleeding inside the skin is common. More severe cases of lichen sclerosis produce scarring that may cause the inner lips of the vulva to shrink and disappear, the clitoris to become covered with scar tissue, and the opening of the vagina to narrow.

Lichen sclerosus of the penis occurs almost exclusively in uncircumcised men (those who have not had the foreskin removed). Affected foreskin can scar, tighten, and shrink over the head of the penis. Skin on other areas of the body affected by lichen sclerosus usually does not develop scarring.

How Common Is It?

Although definitive data are not available, lichen sclerosus is considered a rare disorder that can develop in people of all ages. It usually appears in postmenopausal women and primarily affects the vulva. It is uncommon for women who have vulvar lichen sclerosus to have the disease on other skin surfaces. The disease is much less common in childhood. In boys, it is a major cause of tightening of the foreskin, which requires circumcision. Otherwise, it is very uncommon in men.

What Are the Symptoms?

Symptoms vary depending on the area affected. Patients experience different degrees of discomfort. When lichen sclerosus occurs on parts of the body other than the genital area, most often there are no symptoms, other than itching. If the disease is severe, bleeding, tearing, and blistering caused by rubbing or bumping the skin can cause pain.

Very mild lichen sclerosus of the genital area often causes no symptoms at all. If the disease worsens, itching is the most

common symptom. Rarely, lichen sclerosus of the vulva may cause extreme itching that interferes with sleep and daily activities. Rubbing or scratching to relieve the itching can create painful sores and bruising, so that many women must avoid sexual intercourse, tight clothing, tampons, riding bicycles, and other common activities that involve pressure or friction. Urination can be accompanied by burning or pain, and bleeding can occur, especially during intercourse. When lichen sclerosus develops around the anus, the discomfort can lead to constipation that is difficult to relieve. This is particularly common in children. It is important to note that the signs of lichen sclerosus in children may sometimes be confused with those of sexual abuse.

Most men with genital lichen sclerosus have not been circumcised. They sometimes experience difficulty pulling back the foreskin and have decreased sensation at the tip of the penis. Occasionally, erections are painful, and the urethra (the tube through which urine flows) can become narrow or obstructed.

What Causes Lichen Sclerosus?

The cause is unknown, although an overactive immune system may play a role. Some people may have a genetic tendency toward the disease, and studies suggest that abnormal hormone levels may also play a role. Lichen sclerosus has also been shown to appear at sites of previous injury or trauma where the skin has already experienced scarring or damage.

Is It Contagious?

No, lichen sclerosis is not contagious.

How Is It Diagnosed?

Doctors can diagnose an advanced case by looking at the skin. However, early or mild disease often requires a biopsy (removal and examination of a small sample of affected skin). Because other diseases of the genitalia can look like lichen sclerosis, a biopsy is advised whenever the appearance of the skin is not typical of lichen sclerosis.

How Is It Treated?

Patients with lichen sclerosis of nongenital skin often do not need treatment because the symptoms are very mild and usually go away over time. The amount of time involved varies from patient to patient.

However, lichen sclerosis of the genital skin should be treated, even when it is not causing itching or pain, because it can lead to scarring that may narrow openings in the genital area and interfere with either urination or sexual intercourse or both. There is also a very small chance that skin cancer may develop within the affected areas.

In uncircumcised men, circumcision is the most widely used therapy for lichen sclerosis. This procedure removes the affected skin, and the disease usually does not recur.

Prescription medications are required to treat vulvar lichen sclerosis, nongenital lichen sclerosis that is causing symptoms, and lichen sclerosis of the penis that is not cured by circumcision. The treatment of choice is an ultrapotent topical corticosteroid (a very strong cortisone cream or ointment). These creams or ointments may be applied daily for several weeks, which will be sufficient to stop the itching. However, long-term but less frequent applications (sometimes as infrequently as twice a week) will be needed to keep the lesions from reactivating and to help restore the skin's normal texture and strength. Treatment does not reverse the scarring that may have already occurred.

Because prolonged use of ultrapotent corticosteroid creams and ointments can cause thinning and redness of the skin, give rise to “stretch marks” around the area of application, and predispose individuals to vulvar yeast infections, periodic followup by a doctor is necessary.

Young girls may not require lifelong treatment, since lichen sclerosis can sometimes, but not always, disappear permanently at puberty. Scarring and changes in skin color, however, may remain even after the symptoms have disappeared.

Ultrapotent topical corticosteroids are so effective that other therapies are rarely prescribed. The previous standard therapy was testosterone cream or ointment, but this has been proven to produce no more benefit than a placebo (inactive) cream.

Prolonged use of the testosterone cream or ointment can cause masculinization (low-pitched voice, increased coarse facial hairs). Another hormone cream, progesterone, was previously used to treat the disease, but has also been shown to be ineffective. Retinoids, or vitamin A-like medications, may be helpful for patients who cannot tolerate or are not helped by ultrapotent topical corticosteroids.

Tacrolimus (Protopic^{*}) ointment has been reported to benefit some patients, but more research is needed to confirm this. Tacrolimus is a steroid-free ointment; it is not a corticosteroid. Tacrolimus has no apparent side effects other than local irritation in some patients.

There are some early indications that different forms of ultraviolet light treatments, with or without psoralens (pills that intensify the effect of ultraviolet A light), may be effective and well-tolerated treatments for some patients with lichen sclerosis on nongenital skin.

Patients who need medication should ask their doctor how the medication works, what its side effects might be, and why it is the best treatment for their lichen sclerosis.

For women and girls, surgery to remove the affected skin is not an acceptable option because lichen sclerosis comes back after removal. Surgery may be useful for scarring, but only after lichen sclerosis is controlled with medication.

* Brand names included in this booklet are provided as examples only, and their inclusion does not mean that these products are endorsed by the National Institutes of Health or any other Government agency. Also, if a particular brand name is not mentioned, this does not mean or imply that the product is unsatisfactory.

Sometimes, people do not respond to the ultrapotent topical corticosteroid. Other factors, such as low estrogen levels, an infection, irritation, or allergy to the medication, can keep symptoms from clearing up. Your doctor may need to treat these as well. If you feel that you are not improving as you would expect, talk to your doctor.

Can People With Lichen Sclerosis Have Sexual Intercourse?

Women with severe lichen sclerosis may not be able to have sexual intercourse because of pain or scarring that narrows the entrance to the vagina. However, proper treatment with an ultrapotent topical corticosteroid can help restore normal sexual functioning, unless severe scarring has already narrowed the vaginal opening. In this case, surgery may be needed to correct the problem, but only after the disease has been controlled.

Is Lichen Sclerosis Related to Cancer?

Lichen sclerosis does not cause skin cancer. However, skin that is scarred by lichen sclerosis is more likely to develop skin cancer. The frequency of skin cancer in men with lichen sclerosis is not known. It is important for people who have the disease to receive proper treatment and to see the doctor every 6 to 12 months, so that the doctor can monitor and treat any changes that might signal skin cancer.

What Kind of Doctor Treats Lichen Sclerosus?

Lichen sclerosus is treated by dermatologists (doctors who treat the skin) and by gynecologists if the female genitalia are involved. Urologists (a specialist of the urinary or urogenital tract) and primary health care providers with a special interest in genital diseases also treat this disease. To find a doctor who treats lichen sclerosus, ask your family doctor for a referral, call a local or State department of health, look in the local telephone directory, or contact a local medical center. The American Academy of Dermatology also provides referrals to dermatologists in your area, and the American College of Obstetricians and Gynecologists can refer you to a gynecologist. The Directory of Medical Specialists, available at most public libraries, lists dermatologists, gynecologists, and urologists in your area.

Where Can People Find More Information About Lichen Sclerosus?

- **National Institute of Arthritis and Musculoskeletal and Skin Diseases**
NIAMS/National Institutes of Health
1 AMS Circle
Bethesda, MD 20892–3675
301–495–4484 or
877–22–NIAMS (226–4267) (free of charge)
Fax: 301–718–6366
TTY: 301–565–2966
E-mail: niamsinfo@mail.nih.gov
www.niams.nih.gov

NIAMS provides information about various forms of skin diseases; arthritis and rheumatic diseases; and bone, muscle, and joint diseases. It distributes patient and professional education materials and also refers people to other sources of information. Additional information and updates can be found on the NIAMS Web site.

- **American Academy of Dermatology**

P.O. Box 4014

Schaumburg, IL 60168-4014

847-330-0230 or

888-462-DERM (3376) (free of charge)

Fax: 847-330-0050

www.aad.org

This national professional association for dermatologists provides patient information and referrals to dermatologists.

- **American College of Obstetricians and Gynecologists**

409 12th Street, SW

P.O. Box 96920

Washington, DC 20090-6920

202-638-5577

Fax: 202-484-5107

www.acog.org

This professional association provides referrals to gynecologists and has patient education materials.

- **American Urological Association**
1000 Corporate Boulevard
Linthicum, MD 21090
410-689-3700 or
866-RING AUA (746-4282) (free of charge)
Fax: 410-689-3800
www.auanet.org

This professional association provides physician referrals to urologists through its Web site. Many public libraries provide access to the World Wide Web. Ask a librarian for assistance.

- **National Vulvodynia Association (NVA)**
P.O. Box 4491
Silver Spring, MD 20914-4491
301-299-0775
Fax: 301-299-3999
www.nva.org

This association provides information and support to women who have vulvovaginal pain, including pain caused by lichen sclerosus. The NVA maintains a network of support groups throughout the United States, as well as in Canada, England, and Germany. The association also publishes a newsletter.

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