

PATIENT RESOURCES

Lichen Sclerosis

What is lichen sclerosis?

Lichen sclerosis is a disorder of the skin surrounding the vagina and anus that affects approximately 1.5% of women. The word “lichen” means “thick” and the word “sclerosis” means “scarring.” It is considered a chronic condition, meaning once it is diagnosed, it does not go away. It is usually diagnosed in a woman’s early 50s, but can sometimes be found in young girls who have not yet started getting periods. A small number of women with lichen sclerosis may have it in other areas of their skin. While the cause of lichen sclerosis has not been completely proven, it is most likely that lichen sclerosis is an auto-immune disorder. Women with lichen sclerosis have a 4 – 6% risk of developing vulvar cancer—though the risk of cancer is decreased with proper treatment and following closely with your healthcare provider.

What are the symptoms of lichen sclerosis?

While some patients do not have symptoms, most women have itching, vulvar pain, and/or pain with intercourse. On examination there can be white, thin areas of skin that are sometimes described as looking like “cigarette paper” or “wax paper.” There can be areas of bruising under the skin and there are frequently tears or fissures (cracks in the skin). Inflammation from this condition can lead to scarring such as narrowing of the vaginal opening, loss of the labia minora, (the thin skin folds nearest the vaginal opening) and the scarring over the clitoris (phimosis).

Will I need tests?

Most experts suggest that a small tissue sample (biopsy) specimen should be obtained to confirm the diagnosis of lichen sclerosis before starting any treatment. Any areas that do not improve with proper treatment need to be biopsied to see whether lichen sclerosis is the correct diagnosis. A biopsy can help determine if there is a more serious condition present, such as cancer.

How is lichen sclerosis treated?

The most important treatment is ultra-potent topical corticosteroid ointment, such as clobetasol propionate ointment. This is usually used daily until things are improved (less itching, more normal appearance of skin, or both). Patients will need to be seen in two to three months to check for improvement. Once improvement has been demonstrated, the ointment may be used less often. It is important to remember this is a chronic condition and regular follow up with your healthcare provider is very important, as s/he may find signs that the condition is worsening even when you do not have symptoms. Keeping the disease in remission (very well controlled) lowers the risk of developing cancer.

What will my life be like?

Lichen sclerosis is a lifelong condition. However, with consistent treatment, most symptoms can be very well controlled. In addition, consistent treatment reduces further scarring and lowers the chance of developing cancer.