

What You Should Know About Hidradenitis Suppurativa (HS) Information for Patients

What is HS?

Hidradenitis suppurativa (pronounced "high-drad-en-eye-tis/sup-your-uh-tee-vah") is a chronic skin disease that is characterized by occlusion (blockage) of the hair follicles and subsequent inflammation of the sweat glands.

The lesions occur most commonly on areas of skin-to-skin contact: under the arms (axillary area), in the groin, around the buttocks, in the region around the anus and genitals, and on the skin between and under the breasts. In women, the underarms, groin, and breast areas are most commonly affected. Men most often have HS lesions around the anus and under the arms and may also have HS at the back of the neck and behind and around the ears.

What does HS look and feel like?

The first thing that someone with HS notices is a tender, raised, red bump that looks like an under-the-skin pimple or boil. Sometimes HS lesions have two or more "heads." These lesions often tingle and burn and may be associated with increased sweating.

Without medical attention, HS usually becomes more severe over time. It becomes more painful, and the lesions become larger and may open, oozing a thick, foul-smelling fluid possibly mixed with blood. Later, deeper abscesses develop and may connect with each other under the skin to form tunnel-like tracts (sinuses). Bacteria grow within these sinuses, which then drain fluid to the surface of the skin. In people who have had sinus tracts for some time, scars form that feel like ropes under the skin. In the very worst cases, networks of sinus tracts can form deeper in the body, including the muscle and other tissues. Many people with severe HS have scars that can limit their ability to freely move their arms or legs.

Clinicians usually classify or "grade" HS using the Hurley staging system according to the severity of the disease:

- Hurley stage I: one or more abscesses are present, but no sinus tracts have formed and no scars have developed
- Hurley stage II: one or more abscesses are present that resolve and recur; sinus tracts and scarring are seen
- Hurley stage III: an entire area of the body is involved; multiple abscesses and interconnecting sinus tracts are present.



Photos courtesy of Robert G. Micheletti, MD.

What causes HS?

The cause of HS is not yet known. It is clear that some people are more prone than others to develop this disease, also for unknown reasons. HS most commonly occurs in people in their 20s and 30s; it is rarely seen in children and adolescents and is not common in older adults. Women are three times more likely than men to develop HS.

Finally, certain activities and conditions seem to be associated with HS. Although there is no evidence that these factors actually cause HS, controlling seems to reduce the number of HS flare-ups that patients have. The factors most commonly associated with HS include:

- Cigarette smoking
- Overweight/obesity
- Mechanical and environmental factors, such as skin-on-skin friction in the skin folds, irritation from antiperspirants, and trauma to the hair follicles from shaving

It is very important to know that HS is not contagious, and it is not caused by poor hygiene, poor nutrition, or being overweight.

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How do clinicians treat HS?

Clinicians use both medication and surgery to treat HS. The choice of treatment—or combination of treatments—is made according to an individual patient's needs. Clinicians consider several factors in determining the most appropriate plan for therapy:

- Severity of disease
- Extent of disease
- Chronicity (how often the lesions recur)
- Location of the lesions

A number of different surgical methods have been developed that are useful for certain patients under particular circumstances. In addition, many medical treatments have been tried—some with more success than others. No medication is effective for all patients, and you and your clinician may have to try several different agents or combinations of agents before you find the treatment plan that works best for you.

The goals of therapy with medications that are either topical (used on the skin) or systemic (taken by mouth) are:

1. to clear the lesions or at least reduce their number and extent, and
2. to prevent new lesions from forming.

Some of the types of medications commonly used are antibacterial skin washes and the topical antibiotics to prevent secondary infections and corticosteroid injections into the lesions to reduce inflammation.

Other medications that may be used include retinoids, hormones, immunosuppressive agents (such as methotrexate), the antidiabetic medication metformin, and biologic anti-inflammatory medications such as infliximab and adalimumab.

What self-help measures are useful?

A number of measures seem to help many individuals with HS. Your clinician can help you determine which are likely to be best for you. However, two of these probably apply to most patients with HS:

1. if you smoke cigarettes, quit and
2. decrease your body weight.

Although there are no studies showing that quitting smoking and losing weight improve HS, both of these factors have a negative effect on overall health. Also, weight loss may help prevent HS from worsening—the smaller the area of skin-to-skin contact (and, therefore, of sweating and rubbing), the smaller the target for the development of HS lesions.

Some other self-help measures are:

- Avoid skin trauma (such as shaving in areas, such as the armpits, where breakouts occur)
- Wash your skin gently, using a cleansing agent recommended by your clinician; cleansers such as benzoyl peroxide wash, used by patients with acne, may be appropriate for many patients
- Apply topical medications as directed and as often as prescribed
- Avoid tight-fitting or irritating clothing or bandaging
- Follow your clinician's guidance about antiperspirants or deodorants
- Keep your skin cool (becoming overheated and sweating can contribute to an HS flare)
- To reduce the pain of cysts or nodules, apply hot compresses for 10 minutes at a time (use a clean washcloth or a teabag soaked in hot water)

Finally, know that you are not alone. Coping with the pain and other symptoms of HS can be very difficult, so it may be helpful to connect with others who live with HS. Patient groups and networks can be sources of important information and support. Some Internet resources for information and connections are provided below.

Resources for Information

American Academy of Dermatology

<http://www.aad.org/dermatology-a-to-z/diseases-and-treatments/e-h/hidradenitis-suppurativa/signs-and-symptoms>

National Library of Medicine

<http://www.nlm.nih.gov/medlineplus/hidradenitissuppurativa.html>

NORD: National Organization for Rare Disorders, Inc

<https://www.rarediseases.org/rare-disease-information/rare-diseases/byID/358/viewAbstract>

Trials of new medications for HS

<https://www.clinicaltrials.gov>