

SHINE A
LIGHT
ON 

Understanding
Hidradenitis
Suppurativa

HS



Not an actual patient.

Understanding Hidradenitis Suppurativa

HS

Hi-drah-den-i-tus Super-uh-tee-vah

Learning how to pronounce hidradenitis suppurativa (or HS, as it's often called) just might be the first step toward getting the right treatment.



Visit us at
ShineALightOnHS.com
to learn more about HS.

You're not alone

 in **100**

One in 100 people in the United States may be affected by hidradenitis suppurativa (HS).

HS is a chronic, or long-lasting, inflammatory skin condition. Living with HS can not only be physically painful, it can be emotionally challenging, causing frustration and embarrassment.

HS may also interfere with your ability to have relationships, make plans, and enjoy everyday life. Here is information that can help you better understand HS and ways to manage it.

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What is HS?

Hidradenitis suppurativa (HS) is a systemic inflammatory skin condition with painful bumps or boils that come and go, mostly on areas of the body where skin meets skin, like the armpits, the groin area, inner thighs, buttocks, and under the breasts. These bumps lead to sores (or abscesses) that can leak and leave scars. HS can be a painful and draining vicious cycle.

In HS, it is thought that the immune system is to blame. It becomes overactive and produces too much inflammation throughout the body, but symptoms show up primarily on the skin.

...and what HS is not.

It's not a rash, it's not contagious, and it's not caused by poor hygiene. While it's not curable, HS can be managed with proper treatment.

On average, it takes up to 10 years and seeing 4 doctors for HS symptoms to be properly diagnosed. That's why it's important to see a dermatologist experienced with diagnosing and treating HS.



HS signs and symptoms

Recurring bumps and boils that hurt could be HS.

The bumps, boils, and sores (abscesses) of HS often come back more than once in the same area, or areas, in a 6-month period. HS outbreaks can flare and rupture, leaking blood and pus that may have an odor. Over time, they may connect to each other under the skin, forming deep and painful tunnels that can lead to extensive scarring.

The symptoms of HS can look like other, more well-known conditions. That's why it's often misdiagnosed as acne or an infection of the hair follicle (such as an ingrown hair).

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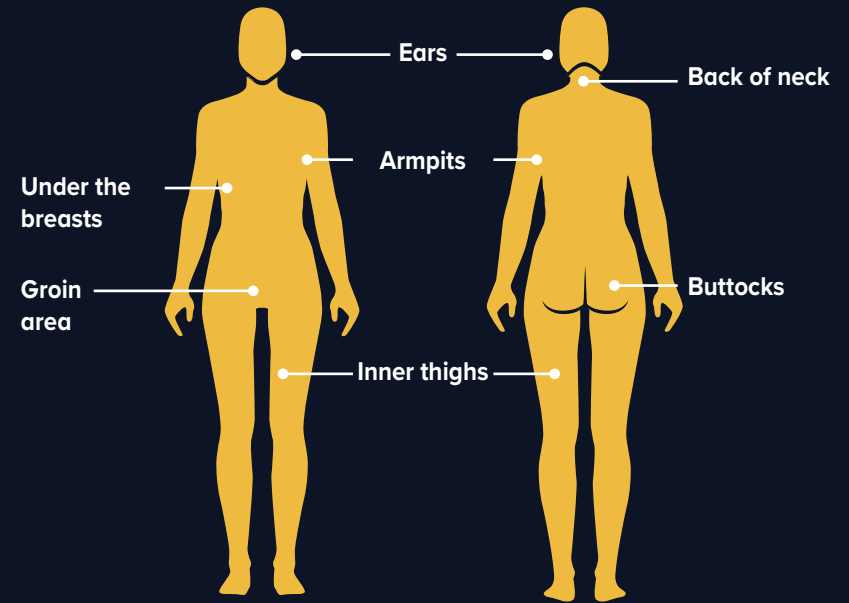


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Where you might find HS



Bumps and sores can appear on different parts of the body, but most frequently occur where skin rubs against skin or against clothing.

People with HS may also have one or more health issues at the same time, such as:

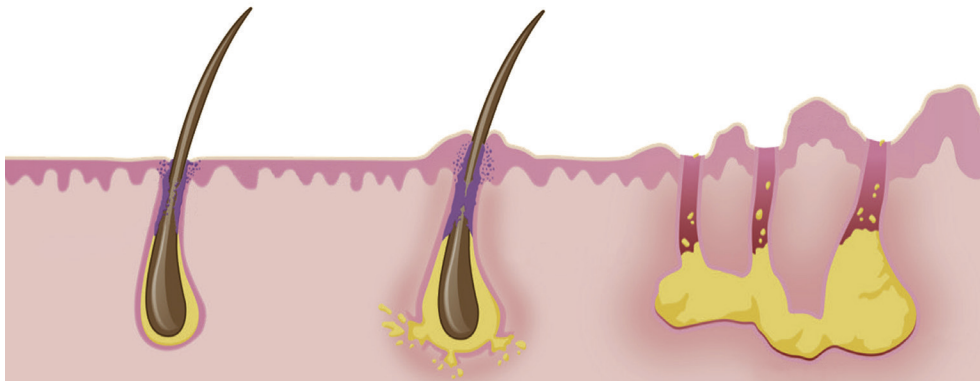
- Metabolic syndrome
- Axial spondyloarthritis
- Crohn's disease or ulcerative colitis
- Depression
- Anxiety
- Polycystic ovary syndrome

If you think you may be suffering from any of these conditions, it's important to take care of your whole self by talking with your doctor.

What causes HS?

Hidradenitis suppurativa (HS) is a systemic skin condition associated with inflammation throughout the body—not just the skin—that often affects the hair follicles and sweat glands. While the exact cause of HS is unknown, it is thought that too much inflammation builds up where skin rubs together, causing bumps, boils, and sores (abscesses) that may burst and can leave scars. It's a physically draining and painful process that may be caused by an overactive immune system.

In HS, it is thought that an overactive immune system attacks blocked hair follicles.



Inflammation can cause hair follicles to become blocked and enlarged.

Blocked and enlarged hair follicles can rupture, causing painful bumps, boils, and sores (abscesses).

These sores may leak blood and pus and can connect, forming tunnels that may lead to scarring.

It's not your fault. It can happen to almost anyone.

HS may run in the family. The condition is mostly seen in women, and disproportionately affects people of color. Other factors thought to contribute to HS include one's weight, and smoking.

HS almost exclusively occurs after puberty, usually beginning in a person's 20s, but in rare cases can start as early as puberty or as late as their 50s.

Women are
3x
more likely to
develop HS.

1 in **100**
One in 100 people in
the United States may
be affected by HS.

Up to
40%
have a family
member with
the condition.

Hormonal changes
can contribute to
the development of
HS symptoms and
may make them
worse.

HS is more common in women with polycystic ovary syndrome (PCOS), a condition that causes hormonal imbalances. Some women may also experience HS flares around the time of their menstrual period.

Living with hidradenitis suppurativa (HS) is hard to describe

More than anything, HS can be painful, with open wounds that may leak blood or pus and be uncomfortable when they rub up against the skin or clothing.

Understanding how HS may progress over time can help.

Stages of hidradenitis suppurativa (HS)

HS may be classified into 3 stages based on how severe the signs and symptoms are. Even mild or moderate HS symptoms can have a negative impact on a person's physical and emotional health, and affect their quality of life.

Mild

Sometimes called Hurley stage I. Typically shows up as one bump or multiple bumps (inflammatory nodules) and sores with no scarring or tunnel (sinus tract) formation.

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Moderate

Sometimes called Hurley stage II. Typically shows up as multiple sores, along with limited tunnels and/or scarring.



Severe

Sometimes called Hurley stage III. Typically shows up as multiple or extensive interconnected tunnels, sores, and scarring.



After someone sees symptoms for the first time (usually after puberty), they may keep seeing them on and off—for years.

HS symptoms may look different on darker skin.

The condition disproportionately affects people of color.

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Having hidradenitis suppurativa (HS) can be stressful

Living with HS can not only be physically painful; it can be emotionally challenging, causing frustration and embarrassment. HS may also interfere with your ability to have relationships, make plans, and enjoy everyday life, which may lead to social isolation and depression.

HS may leave you:

- Feeling like you're not accepted
- Missing out on social activities
- Depressed because of how your skin looks
- Lacking self-confidence
- Concerned about your sexual health
- Unable to work, with possible loss of income

HS symptoms can make it difficult to manage your day-to-day responsibilities. It's important to recognize signs of stress, as stress may impact your health and ability to take care of yourself. Reach out for support or get in touch with your doctor if you notice changes in your well-being.

“

Once I was diagnosed, I was able to keep calm, stay focused, and have hope. I wish I'd gone to a dermatologist sooner.”

Brian was diagnosed with HS in 2015 and was compensated for his time.

What can you do about HS symptoms?



People with HS are advised to wear loose-fitting clothing to help reduce sweat and keep moisture from causing further irritation and pain to HS bumps and open wounds.



Quitting smoking and managing one's weight may help with the symptoms of HS.



Avoid using washcloths, loofahs, or any abrasive material, as they may irritate the skin. Do not squeeze bumps and sores. Avoid shaving or using hair-removal creams.



Keeping a journal to track your HS symptoms can help you understand how the condition is impacting your life, and may help when you speak with your dermatologist.



Treating HS early can help

Early treatment can help reduce flares and lowers the risk of future sores, tunneling under the skin, and scarring. *A flare prevented is a good thing.* Treating early may also help avoid the need for surgery down the road.

There's hope when it comes to treating hidradenitis suppurativa (HS). Although there is no cure, there are more effective treatments for HS today than ever before.

Seeing a dermatologist is the first step

If you've found a dermatologist experienced with diagnosing and treating HS, you're on the road to finding answers and the help you need.

If you're still trying to figure out what's going on, visit **ShineALightOnHS.com to take the quiz** to help you determine if your skin symptoms might be HS. Your quiz results will generate a discussion guide that can help you get the conversation started with your dermatologist.



Take the quiz

Scan the code with your smartphone's camera.

HS treatment options

Your dermatologist will likely prescribe different medication(s) based on the severity of your condition. The following list of treatment options may not be comprehensive.

Antibiotics: Mild symptoms may be managed with oral or topical antibiotics.

Biologics are medications that are produced from living organisms or that contain components of living organisms, and are used to treat many types of systemic inflammatory conditions like HS. They are taken by injection or infusion.

Creams and ointments: Topical corticosteroids in the form of creams and ointments may also be used.

NSAIDs: Non-steroidal anti-inflammatory drugs may provide temporary relief of HS symptoms, including pain.

Surgery is another way to manage HS when a tunnel and sores (or abscesses) are present. Different surgical approaches are available depending on the extent and severity of your condition. After surgery, sores might recur or appear in other areas.



HS support can help

Find us on social media to stay connected.



When you're living with HS, or think you may have HS symptoms that have yet to be diagnosed, it can be challenging. Knowing you're not alone can make the road ahead easier.

There is strength in numbers

HS community support can be enlightening. Here are a few websites you can visit for more information, resources, and a community that may help make living with HS more manageable:

- HS Connect (hsconnect.org)
- HS Foundation (hs-foundation.org)
- International Association of HS Network (iahsn.org)

“

My HS symptoms would come and go, then escalate like a monster...sharing my story and helping other people have helped me.”

Donna was diagnosed with HS in 1996 and she was compensated for her time.

HS glossary

Below, you'll find hidradenitis suppurativa (HS) terms to help guide the conversation with your dermatologist:

Abscess: a swollen area within body tissue, characterized by a painful, swollen lump that's filled with pus.

Blackhead: a dark plug of oil from skin in a hair follicle that has been exposed to oxygen.

Bump: a swelling of the skin. Some bumps get bigger, break open, and drain pus with an odor.

Boil: an inflamed, pus-filled swelling on the skin, typically caused by the infection of a hair follicle.

Cyst: a sac-like pocket that contains fluid, air, or other substances.

Flare: a sudden outburst or worsening condition.

Hurley stages: Alternate name for the 3 stages of HS used by dermatologists. See page 12.

Immune system: a complex network of cells and proteins that defends the body against infection.

Ingrown hair: an ingrown hair occurs when a shaved or tweezed hair grows back into the skin.

Nodule: a bump or small inflammatory swelling made up of abnormal cells in the body.

Scarring: a mark left on the skin after a surface injury or wound has healed.

Sores: sores can form in areas of the body where the skin rubs together, like the groin, the armpits, and under the breasts.

Systemic: something that affects multiple organs or parts of the body, possibly affecting the entire body.

Tunnels (also called sinus tracts): over time, tunnels might form under the skin, connecting the sores/abscesses. These wounds heal very slowly, if at all, and drain blood and pus.



Not an actual patient.

Jump into the Driver's Seat

Sign up for Driver's Seat, your guide to navigating HS. It's full of enlightening and empowering resources to help you:

- Learn more about HS and treatment options
- Discover how to talk to your dermatologist about HS
- Identify HS triggers and healthy lifestyle changes
- Find support and tips for living well



Visit ShineALightOnHS.com/sign-up or scan this code with your smartphone's camera.

