

# Hidradenitis Suppurativa (HS)

Information for patients

This leaflet has been written to help you understand more about hidradenitis suppurativa (HS). It tells you what it is, what may cause it, what can be done about it, and where you can find out more about it.

## **What is hidradenitis suppurativa (HS)?**

Hidradenitis suppurativa (HS) is a long-lasting and recurring skin condition that causes painful inflammation, including redness, swelling, tenderness, and lump formation. While it can develop anywhere on the body, it most often affects areas rich in apocrine sweat glands, such as the armpits, under the breasts, groin, genital region, buttocks, and folds of the abdomen. In HS, hair follicles become blocked and inflamed, leading to a combination of painful nodules, pus-draining areas, and scarring that may form tunnels beneath the skin's surface.

HS is estimated to impact about 1% of people in the UK. Although it can occur in anyone, it is more frequently seen in women and individuals with darker skin tones. It is more frequently seen in women and may be under-recognised or more severe in individuals with darker skin tones. The condition rarely appears before puberty, with most people first noticing symptoms in early adulthood.

## **What causes HS?**

The exact cause of HS remains unclear. It is believed to begin when hair follicles become blocked.

This blockage prevents normal drainage, leading to swelling and, eventually, rupture of the follicles.

As a result, inflammation and abscesses can develop in the affected area.

A widespread myth is that HS is caused by poor hygiene, but this is not true - hygiene does not play a role in the development of the condition.

### *Several factors may contribute to the development of HS:*

- **Hormonal influences** may affect apocrine sweat glands and could play a role in HS. Many people find that symptoms worsen around the time of menstruation. In some cases, hormone-based treatments can be helpful (see below).
- **Skin bacteria**, which normally live harmlessly on the surface, can become trapped in blocked hair follicles or sweat glands, triggering inflammation.
- An **overactive immune response** also contributes to inflammation, which is why medications that suppress the immune system may be beneficial (see below).
- **Smoking** is strongly associated with HS - up to 60% of those affected are smokers, though it can still occur in non-smokers.
- While HS can affect individuals of any body size, it is more frequently seen in those who are overweight or obese. **Weight** reduction through healthier eating, lifestyle changes, or approved weight-loss medications - such as semaglutide or tirzepatide, may help ease symptoms.

## What other conditions are linked to HS?

- **Mental health challenges** such as depression and anxiety are common in people with HS. If you're feeling anxious, low, embarrassed, or overwhelmed, it's important to speak with a healthcare provider, like your GP.
- HS may be connected to other skin conditions, including **acne, dissecting cellulitis of the scalp** (a scarring, inflammatory condition), and **pilonidal sinus** (a recurring abscess near the top of the buttock crease).
- Although they don't directly cause HS, conditions like **high blood pressure, high cholesterol, and diabetes** are more commonly seen in people with HS. Your doctor may monitor your weight, blood pressure, and run tests for blood sugar and cholesterol levels as part of your care.
- In some cases, HS is associated with **inflammatory bowel diseases** such as **Crohn's disease** and **ulcerative colitis**. If you experience symptoms like ongoing diarrhoea, blood in your stools, unexplained weight loss, or persistent stomach pain, seek medical advice.
- There is also a known link between HS and **inflammatory arthritis**. If you have ongoing joint pain or swelling, it's important to get it checked by a healthcare professional.

## Is HS hereditary?

Yes, HS runs in the families of about one third of those affected by the condition.

## Is HS suppurativa contagious?

No, it cannot be passed on from one person to another.

## What are the symptoms and appearance of HS?

- HS often causes **painful abscesses**, which can make everyday tasks like walking or sitting uncomfortable. The **leakage of pus** is common and may require frequent dressing changes to manage.
- In the **early stages**, HS may appear as a mix of **blackheads, pus-filled spots, or red, tender lumps** that resemble boils or cysts.
- As the condition progresses, **tunnels beneath the skin** - also called **sinus tracts or fistulas**, can develop. These may leak pus and form wounds that are slow to heal.
- Over time, repeated flare-ups can lead to **increasing scarring** and changes in the texture of the skin in affected areas.

## How is HS diagnosed?

- HS is typically diagnosed based on a **physical examination**, along with a review of your **medical history** and the **symptoms you describe**. There isn't a specific test to confirm the condition.
- It's often **mistaken for other skin problems at first**, such as infections or inflamed hair follicles, which can lead to delays in diagnosis and treatment. This delay may allow the condition to worsen and cause permanent **scarring**.

## Can HS be cured?

There is currently no cure for HS. The condition often lasts for many years but may eventually become less active. Treatments mainly focus on controlling symptoms and reducing the frequency and severity of flare-ups.

## Can pregnancy influence HS?

The effect of pregnancy on HS differs among individuals. For many, the condition stays the same or even improves while pregnant, but flare-ups are often more common shortly after giving birth.

## How is hidradenitis suppurativa treated?

Treatment is personalised based on the individual's condition. Generally, early-stage HS is managed with medications, while more advanced or severe cases may require a combination of medication and surgery, especially when multiple areas are involved.

### *Managing a sudden HS flare, such as a painful new abscess:*

- Applying a warm compress or taking a warm bath can help pus drainage.
- Pain relief can be achieved with over-the-counter painkillers, including paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs).
- Magnesium sulphate paste can be purchased in most pharmacies and can be helpful to 'draw out' an abscess that is acutely painful and pointing.
- Topical steroids (creams or ointments) may reduce inflammation, easing redness, swelling, and pain. These will need to be prescribed by your doctor.
- A course of antibiotics might be prescribed to address infection or inflammation.

- Minor surgical procedures, such as making a small incision to drain the abscess, can relieve pain and provide short-term improvement.
- In some cases, dermatologists may inject steroids directly into the abscess to reduce swelling.

### *Medical treatments aimed at preventing HS flare-ups:*

- **Antibacterial washes and lotions:** Although evidence is limited, some people find antiseptic washes like 4% chlorhexidine (Hibiscrub) or Octenisan helpful. Antibiotic preparations such as clindamycin lotion or gel may be recommended for skin areas prone to developing HS lesions.
- **Oral antibiotics:** Long-term antibiotics (3 months or more) are often used to suppress flare-ups ('anti-inflammatory') rather than to kill bacteria directly. Common options include tetracycline antibiotics like lymecycline and doxycycline. A combination of clindamycin and rifampicin may also be used for 10-12 weeks, though side effects such as upset stomach, orange discoloration of bodily fluids, and reduced effectiveness of hormonal contraceptives can occur.
- **Retinoids:** Vitamin A-based pills like acitretin may help by clearing blocked hair follicles. These are prescribed through dermatologists and require strict contraception for people who could become pregnant, as pregnancy must be avoided for three years after stopping treatment.
- **Hormonal treatments:** For individuals whose symptoms worsen before menstruation, anti-androgen medications may be helpful. These can be part of contraceptive pills or prescribed separately, such as spironolactone.

- **Anti-diabetic drugs:** Medications like metformin may improve HS symptoms, particularly in those with insulin resistance, diabetes, or polycystic ovary syndrome (PCOS). Side effects can include nausea, stomach pain, and diarrhoea. Metformin is safe during pregnancy. Newer drugs such as semaglutide, used for diabetes and weight loss, are not yet approved specifically for HS.
- **Immune-modulating drugs:** Tablets like dapsone may be used to reduce immune system overactivity contributing to inflammation, though close monitoring is necessary due to potential side effects.
- **Biologic therapies:** For moderate to severe HS unresponsive to other treatments, biologics that suppress the immune system may be prescribed. These include injections such as adalimumab, secukinumab, and bimekizumab (given under the skin), as well as infliximab, which is administered intravenously.
- **Pain relief:** Simple painkillers such as paracetamol and ibuprofen can be helpful for acute flares. Sometimes, stronger painkillers may be needed that specifically help with wound pain (e.g. duloxetine). Please discuss your pain needs with your GP and the hospital team.

### *Surgical options:*

- For scarring and skin tunnels, surgery is often required. One technique, called deroofting, involves removing the “roof” of tunnels under local anaesthesia, allowing them to heal naturally over several weeks.
- More extensive scarring may need wider surgical removal under general anaesthesia. Larger surgeries tend to lower the risk of HS returning in the treated area but come with longer recovery times.

- Surgery tends to be more effective when combined with ongoing medical treatments, including biologics. Biologic therapy may be temporarily paused if other internal surgeries are needed.

### **Wound care:**

- For those with fluid drainage from HS lesions, dressings are an important part of care. Various types are available, often featuring a non-adhesive absorbent section with an adhesive border, and some can be secured simply by wearing clothing.
- Hidrawear garments can be helpful for patients with draining areas. These are a wearable dressing system and are available on the NHS in Leeds via your GP. More information can be found at: <https://hidrawear.com>.

### **Where will I be treated in Leeds?**

During the **acute flares**, your own **GP** is your first point of contact. If you have an abscess that is painful and needs draining, your GP can arrange for you to be seen by general surgeons at St James's Hospital in the Surgical Ambulatory Care Unit (1st floor, Chancellor Wing). This is done via a service called PCAL (Primary Care Access Line), open to all GPs Monday to Friday 8am - 8pm. This should prevent the need for you to attend A&E during these times.

In **Dermatology at Chapel Allerton Hospital**, we are primarily responsible for the **chronic management** of your HS. This means that we will oversee your overall treatment, give you medication to control the condition and/or refer you for surgery if appropriate. We do not deal with acute flares of HS, which would have to be managed by your GP as explained above.

## Self-care tips (What can I do?)

### *You might find the following helpful in managing HS:*

- Identify your most troublesome physical symptoms (such as pain, wound care, odour from wounds and fatigue), any HS-associated problems, factors that may worsen/help, and the best care solutions for these, whether these solutions involve medical treatment, support or self-care.
- Be kind to yourself and your body. A healthy lifestyle may improve your HS, for example stopping smoking, healthy diet, prioritising rest, sleep and well-being, managing your stress, fresh air and natural daylight, and if possible, movement or exercise that you enjoy. Ask your GP and others for help, resources and support if needed.
- Avoid wearing tight clothing or underwear that can cause friction.
- Use antibacterial or antiseptic soaps and shower gels to keep the skin clean.
- Refrain from shaving areas affected by HS, such as the underarms. Laser hair removal can be helpful for some patients and is generally recommended
- Practice ways to lower stress and anxiety, as these can impact your condition.
- Connect with, talk with, share with and learn from others, that is family, friends, other people with HS. Think about joining a support group to connect with others facing similar challenges (see below for contact details).
- Consider a trial of zinc gluconate daily (recommended dose 90mg once daily for three months, then 40-50mg daily thereafter).

## Where can I get more information about HS?

### *Hidradenitis Suppurativa Support Network UK and Ireland*

- Email: [hssnUKandIreland@outlook.com](mailto:hssnUKandIreland@outlook.com)
- Facebook: The HS Support Network – UK and Ireland
- Instagram: [the\\_hs\\_support\\_network](https://www.instagram.com/the_hs_support_network)

### *Web links to other useful resources:* **Patient - Hidradenitis suppurativa**

**Please scan or click the QR code or visit:**

<https://patient.info/skin-conditions/hidradenitis-suppurativa-leaflet#what-is-the-long-term-outlook>



### **DermNet - Hidradenitis suppurativa**

**Please scan or click the QR code or visit:**

<https://dermnetnz.org/topics/hidradenitis-suppurativa>



### *British Association of Dermatologists - Jargon Buster*

**Please scan or click the QR code or visit:**

[www.skinhealthinfo.org.uk/support-resources/jargon-buster/](http://www.skinhealthinfo.org.uk/support-resources/jargon-buster/)





## What did you think of your care?

**Visit:** [www.leedsth.nhs.uk/patients/support/feedback-complaints/friends-family-test/](http://www.leedsth.nhs.uk/patients/support/feedback-complaints/friends-family-test/)

***Scan or click the QR code - Your views matter***

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