



The Basics

Fighting for people affected by
Hidradenitis Suppurativa



What is the purpose of this leaflet?

This leaflet is for people whose daily lives are affected by Hidradenitis Suppurativa (HS). It has been produced in order to provide you with a basic understanding of HS, and to familiarise you with some of the most common symptoms and treatments. The information in this leaflet is not intended to replace the advice of your doctor.

What is Hidradenitis Suppurativa?

Hidradenitis Suppurativa (HS) is a chronic, inflammatory, recurrent, debilitating skin disease of the hair follicle that usually occurs after puberty, and although rare, cases of HS in children do exist.⁽⁶⁾

It presents itself as distinctive painful boil-like abscesses and scarring in the armpits, genitals, groin, breasts, perianal region and buttocks⁽⁵⁾, although it can affect other areas as well.



Typical underarm HS

Severe HS has the highest impact on patients' quality of life among all assessed dermatological conditions⁽¹⁾. It is generally accepted that HS affects an estimated 1% of the UK adult population, although this may be higher due to misdiagnosis, and patients being too embarrassed to seek treatment.^(2,3)

HS was first described in 1833 by the French anatomist and surgeon Alfred-Armand-Louis-Marie Velpeau, which is where the name Velpeau's Disease originates.

It was later investigated by another French Surgeon called Artistide Auguste Stanislas Verneuil from 1854 to 1865, earning it the name Verneuil's Disease, and it was he who conducted the first clinical studies of HS.

Verneuil later renamed the disease Hidrosadenite Phlegmonous in 1864, which translates to the English Hidradenitis Suppurativa, meaning the inflammation of a sweat gland (Hidradenitis) containing or associated with pus (Suppurativa).

In other countries, it is also widely known as Acne Inversa.

What is the cause?

The exact cause of HS remains unclear. Although the name hidradenitis suppurativa suggests that it is the inflammation of the sweat glands, it is now thought to be related to the blocking of the hair follicle, resulting in the inflammation of the apocrine sweat glands⁽⁶⁾.

Some research suggests that it may be a type of auto-immune/auto-inflammatory disorder. Others suggest that it is a genetic disorder, as it has been shown to run in some families, with approximately 40% reporting an affected first degree relative.⁽⁶⁾

HS is NOT contagious.

What are the symptoms and effects?

HS affects patients in different ways, varying in severity from person to person, both physically and emotionally. Some of the physical symptoms and effects can include⁽⁵⁾:

- Boil-like abscesses
- Severe pain and discomfort that can be severe
- Discharge (pus)
- Scarring, and discolouring of the skin
- Work disability
- Diminished sexual activities
- Difficulty with walking, sitting, lifting or reaching

The emotional side effects of HS can often be the most difficult to recognise. HS can have a high emotional impact and may result in isolation due to fears of stigma associated with HS. Shame and frustration arise frequently and may relate to odour, scars, itching and pain. Quality of life impairment in patients with HS exceeds that of other skin diseases that generally are perceived to have a high burden and substantial disability.⁽⁵⁾ The most common psychological effects are:

- Depression and anxiety
- Poor self-esteem
- Unable to socialise
- Embarrassment
- Stress and fatigue
- Feeling helpless
- In rare cases, suicidal thoughts

If you find that you suffer any of the above, please do not hesitate to speak to your healthcare professional.

Are there any tests to diagnose HS?

There are no tests used to diagnose HS. The diagnosis is usually based on the typical clinical presentation. The criteria for diagnosis consists of:

- Lesions – Are they deep-seated nodules and/or scarring?
- Location – Armpit, groin, breasts and/or buttocks
- Relapse.
- Chronicity.

Sometimes HS is confused with other similar-looking skin conditions such as common boils, collections of pus (abscesses), skin infections and ingrowing hairs. Other diseases can cause tunnels (channels) known as sinus tracts - for example, Crohn's disease.

Tests might be needed to exclude these other conditions, though they often have many other symptoms.

Sometimes, if there are signs of infection, small samples (swabs) can be taken. This is to see what germs (bacteria) are growing in the pus. This can help in deciding whether antibiotic medicines (and which ones) should be used.

Occasionally, it might be helpful to test your blood for sugar (glucose) to make sure you do not have diabetes. This is because skin infections are more common in people with diabetes. Your doctor might also take blood to make sure you are not anaemic and to monitor the level of infection or inflammation.

Scans, such as MRI (magnetic resonance imaging) scans, are not needed to diagnose the condition.

They may however be used in very severe disease to plan surgery, as it is important to know where the sinus tracts go, and how deep they are.

When assessing HS, clinicians commonly use the Hurley staging system⁽⁴⁾. This allows them to “grade” the condition according to the severity of the disease:



Hurley stage I: Solitary or multiple isolated abscess formation without scarring or sinus tracts

Hurley stage II: Recurrent abscesses, single or multiple widely separated lesions, with sinus tract formation

Hurley stage III: Diffuse or broad involvement across a regional area with multiple interconnected sinus tracts and abscesses

Some individuals do not progress beyond stage 1 and the rate of any progression is hard to predict.

What can I do to self-manage the condition?

There are a few ways that you can help to ease the condition and reduce flares. Your clinician may also have some suggestions for you to try. Population studies have found a link between HS and smoking and obesity, however HS can affect non-smokers of normal

weight. Also, weight loss may help prevent HS from worsening, as the smaller the area of skin-to-skin contact, the less chance of skin aggravation.

Other methods of self-management may include:

- Apply topical medications as directed and as often as prescribed.
- Wash your skin gently, using a cleansing agent recommended by your clinician; cleansers such as Hibiscrub, may be appropriate for many patients.
- Avoid skin trauma (such as shaving in areas, such as the armpits, where breakouts occur).
- Avoid tight-fitting or irritating clothing or bandaging.
- Avoid using perfume and deodorants on affected areas.
- Keep your skin cool, (as heat may aggravate the skin).
- To reduce the pain of cysts or nodules, apply warm compresses for 10 minutes at a time.
- Try to reduce stress where possible. Flares can be linked to stressful events, but eradicating stress is hard to achieve.
- While some report that cutting out certain foods can help, there is currently no convincing medical evidence and so the best advice is to eat a healthy, balanced diet.

What is the treatment?

Clinicians offer patients who have HS many treatment options. There is no one treatment that works for everyone who has HS. Sometimes, a patient needs to try a few different treatments to find one that helps.

Some treatments may continue over several months or years, and may include a combination of different medications and therapies.

Common treatments include:

Antiseptics and topical treatments: Such as hibiscrub and clindamycin lotion.

Oral antibiotics: Such as tetracyclines and the clindamycin/rifampicin combination. These may offer anti-inflammatory effects as well as acting against bacteria.

Biologics (reserved for severe HS only): These medicines work on the immune system. Some biologics require self-injections; others require an infusion at a hospital or clinic. Some patients see long-term control of their HS.

Corticosteroid injection into a breakout: Your dermatologist may inject this into a painful cyst to reduce pain and swelling.

Diabetes drug: Metformin has been approved to treat adult-onset diabetes. It may also help people who have HS and a condition called metabolic syndrome.

Hormone therapy: Some women who have HS get relief by taking birth-control pills, such as Dianette, or another medicine that regulates hormones. These medicines can decrease pain and the amount of fluid draining from the breakouts.

Methotrexate (severe HS only): This medicine is used to treat cancer and certain other medical conditions, such as severe psoriasis. It works on the immune system and may help control HS in some patients.

Oral retinoid: Such as acitretin (not suitable for woman of a child-bearing age), and isotretinoin (more effective for acne and less effective for HS)

Radiation therapy: This exposes the body to radiation, and is not commonly used in the treatment of HS.

Wound dressings: Various dressings are available that may encourage wound healing. Your dermatologist or wound care specialist can discuss options available.

Common Surgical Procedures:

(When HS grows deep into the skin, medicine alone may not be effective. Your dermatologist may recommend a surgical procedure.)

Incision and drainage: A dermatologist or surgeon may drain 1 or 2 lesions or cut them out. This can bring short-term relief, but HS may return.

Narrow margin excision/deroofing: This surgery may be an option for patients who have painful HS that repeatedly returns. The surgeon opens sinus tracts and abscesses to encourage scars to form.

Wide scale excision: This involves surgically removing HS and some normal-looking skin.

Laser surgery: Some patients improve after several treatments. Lasers are proving effective at clearing new and deep HS breakouts. This treatment may be helpful as the hair follicles are destroyed. Most centres do not have laser treatment facilities.

As the wound is deep, the area may be covered with a skin graft (skin removed from another part of your body) or skin flap (skin from nearby is pulled over to cover the wound). HS generally does not return to the treated area, but it can develop nearby.

Helpful Links

The Hidradenitis Suppurativa Trust

Unit 6

Fort Horsted

Chatham

ME4 6HZ

www.hstrust.org

www.facebook.com/TheHidradenitisSuppurativaTrust

www.facebook.com/groups/hstrust

www.twitter.com/Hidradenitis

HS-UK

Yahoo based support group, administrated by The HS Trust

www.hs-uk.org

Mind

We provide advice and support to empower anyone experiencing a mental health problem

<http://www.mind.org.uk>

Disability information and advice lines (DIAL)

DIAL information and advice services are based throughout England and Wales. They provide information and advice to disabled people and others on all aspects of living with disability, 0808 800 3333, weekdays 9am to 5pm

Citizens Advice

We provide free, independent, confidential and impartial advice to everyone on their rights and responsibilities. We value diversity, promote equality and challenge discrimination.

www.citizensadvice.org.uk

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- (6) Inge E. Deckers, Hessel H. Van der Zee, Errol P. Prens. Epidemiology of Hidradenitis Suppurativa: Prevalence, Pathology, and Factors associated with the development of HS. *Curr Derm Rep* (2014)3:54-60



Raising the profile of Hidradenitis Suppurativa in terms of its impact on physical, psychological and social wellbeing.

The Hidradenitis Suppurativa Trust is a publicly funded charity, providing reliable information and support to both patients and professionals.

www.hstrust.org