

HIDRADENITIS SUPPURATIVA

What are the aims of this leaflet?

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?

Hidradenitis suppurativa is a long term, recurrent, and painful disease in which there is inflammation (redness, tenderness and swelling) in areas of skin containing apocrine sweat glands. These glands are found mainly in the armpits, breasts, groin, abdomen folds and buttocks. Within HS there is a blockage of the hair follicles. This causes a mixture of boil-like lumps, areas leaking pus, and scarring.

Hidradenitis suppurativa tends to begin around puberty. It is more common in women and in people with skin of colour. It is estimated to affect about 1% of the population.

What causes hidradenitis suppurativa?

It is still not clear why some people get this disease, but it is thought the inflamed spots or lumps develop when there is a blockage of the hair follicles. As the fluid or pus in the spots and lumps cannot escape, the hair follicles may swell up and burst causing the area to become inflamed or form abscesses and become severely infected.

Contributory factors include the following:

- Hormones may be involved in the control of apocrine sweat glands and might play a part in the disease. In women, HS may be worse before menstrual periods. Some patients may benefit from hormone treatments (see below).
- Bacteria (germs) that normally live on the skin may become trapped in the blocked gland or hair follicle. It is not clear whether this causes the disease or just contributes to the inflammation.
- The immune system is involved in producing inflammation and treatments that reduce the immune system activity may be helpful (see below).

- In some people with HS there is a link to the bowel conditions such as Crohn's disease and ulcerative colitis. It is important to seek medical attention if you develop any symptoms such as persistent diarrhoea, blood in the stools, unexplained weight loss or persistent abdominal pain.
- There may be a link with acne, dissecting scalp cellulitis (scarring and inflammation of the scalp) and pilonidal sinus (a chronic abscess at the base of the spine).
- Smoking and obesity are linked with HS (up to 60% of patients with HS are smokers), but the condition can also affect non-smokers of normal weight.
- People with HS are at increased risk of developing other disorders such as high cholesterol, high blood pressure and diabetes. These do not cause HS but your doctor may consider checking your weight, blood pressure and blood tests for your sugars and cholesterol.
- Poor hygiene does not cause hidradenitis suppurativa.

Is hidradenitis suppurativa hereditary?

Hidradenitis suppurativa runs in the families of about one third of those with the condition.

Is hidradenitis suppurativa contagious?

No, it can't be passed on to another person by contact.

What are the symptoms of hidradenitis suppurativa?

Hidradenitis suppurativa abscesses are usually painful. The main affected areas are the armpits, groin, genital and pubic regions. The skin around the anus, buttocks, thighs and breasts can also be affected. The pain may make it uncomfortable to sit or move one's arms. Discharge of pus can be a problem and may require daily dressings. Hidradenitis suppurativa can have a severe psychological effect such as depression and can sometimes be associated with inflammation of the joints (arthritis).

In the early stages of HS, there are a mixture of blackheads, pus spots or red lumps which look like boils or cysts (also known as abscesses). In the later stages of HS, tunnels may form under the skin that leak pus with wounds that may not heal easily. As time goes by, more and more scarring appears.

How will hidradenitis suppurativa be diagnosed?

The diagnosis is usually made by a doctor examining the area, and the history and symptoms described by the patient. There is no specific test on which the diagnosis can be made. The condition is often misdiagnosed initially as an infection or inflammation of the hair follicles which can result in delayed treatment and progression of the disease with scarring.

Can hidradenitis suppurativa be cured?

No, it usually persists for many years, but can become inactive eventually. Treatment usually helps even though it generally cannot switch the HS off permanently.

How can hidradenitis suppurativa be treated?

Treatment is tailored for each individual. In general terms, early HS is usually treated with medication, whereas more longstanding and severe HS may benefit from both medication and surgery, especially if multiple sites are affected.

What treatment is available for a sudden flare of HS, such as a new painful boil?

- A warm flannel applied to the affected skin or taking a bath may encourage drainage of pus.
- Painkillers, such as non-steroidal anti-inflammatories (NSAIDs), can help with the pain and inflammation.
- A mild topical steroid can sometimes reduce the inflammation (redness, swelling and pain).
- A course of antibiotics may be needed if there is any evidence of infection.
- Surgical treatment to lance the boil (incision) and drainage of the pus.
- A steroid injection into the boil is sometimes considered by dermatologists.

Medical treatment to try to prevent flares of HS:

- Antibacterial lotions and washes: Patients are frequently prescribed an antiseptic such as 4% chlorhexidine wash, to reduce the spread of bacteria on the skin. An antibiotic lotion such as clindamycin may be recommended for affected skin.

- Antibiotic tablets: These may be prescribed for a prolonged time (usually 3 months) in order to try to help suppress further attacks. Tetracycline antibiotics such as lymecycline and doxycycline are often tried initially. The combination of clindamycin and rifampicin is another option for a 10-week course; potential side effects include an upset stomach, orange tears and urine, and reduced effectiveness of the oral contraceptive pill. In HS, antibiotics may work by suppressing inflammation rather than by killing bacteria therefore longer courses are thought to be more beneficial.
- Retinoids (vitamin A derived tablets) such as acitretin may help by unblocking the hair follicles. They are available only from dermatology clinics. Women who have taken acitretin should avoid pregnancy for three years after stopping the medication and so this treatment is usually avoided in women of child-bearing age.
- For women who have flares of HS before each period, tablets known as anti-androgens can sometimes be useful. Anti-androgen treatment can be as part of a contraceptive pill or a separate tablet called spironolactone which can cause irregular periods, breast pain and low blood pressure/light-headedness.
- Anti-diabetic medications such as metformin have shown some improvement for patients and may be used in patients who have pre-diabetes, diabetes and in females with polycystic ovarian syndrome (PCOS) or during pregnancy. These are thought to work by changing the way the body responds to insulin. Metformin can be associated with abdominal pain and diarrhoea.
- Tablets to alter the immune system: some tablets such as dapsone and ciclosporin may be considered to try to improve HS by dampening down the immune system. Benefits are balanced against potential side effects and blood test monitoring is needed.
- Immunosuppressive injections: injection treatments designed to suppress the immune system are used for HS that has not improved with other medical treatment. These 'biologic' treatments include adalimumab, injected under the skin, and infliximab, given as an intravenous infusion. Some newer biologic treatments have been tried for hidradenitis suppurativa such as ustekinumab and guselkumab but these are not yet licensed in the UK and Ireland for HS.

Surgical treatment:

Persistent discharge or inflammation in the same site despite medical treatment can sometimes require surgery, either to remove small areas of repeated inflammation, or wider procedures to take away all the affected tissue. Wider procedures are more likely to reduce the chance

of HS coming back in the treated area, compared to smaller procedures, but healing times are generally longer. Surgical treatment is often more effective in combination with medical treatment.

Self-care (What can I do?)

The following measures may be beneficial:

- losing weight and stopping smoking (if relevant)
- washing with antiseptic soaps or bath additives
- avoiding tight clothing
- stress management
- consider joining a support group

Where can I get more information about hidradenitis suppurativa?

Patient support groups:

Hidradenitis Suppurativa Support Network UK and Ireland

Email: hssnUKandIreland@outlook.com

Facebook: The HS Support Network – UK and Ireland

Instagram: the_hs_support_network.

Web links to detailed leaflets:

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

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

BRITISH ASSOCIATION OF DERMATOLOGISTS

PATIENT INFORMATION LEAFLET

PRODUCED SEPTEMBER 2004

UPDATED MAY 2011, JUNE 2013, JANUARY 2017, MAY 2021

REVIEW DATE MAY 2024