

### 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 (HS) is a chronic (longterm), recurrent, and painful condition in which there is inflammation (redness, tenderness, swelling and lumps). HS can occur in any skin area but tends to occur in the areas of skin containing a certain type of sweat gland, called apocrine sweat glands. These glands are found mainly in the armpits, breasts, abdominal (tummy) fold, groin, genital area, and buttocks. Within HS areas, there is a blockage of the hair follicles and inflammation. This causes a mixture of boil-like lumps, areas leaking pus, and scarring such as skin tunnels (an opening underneath the surface of the skin).

HS affects around 1% of the UK population. It can affect anyone but is more common in women and in people with darker skin. HS is rare before puberty. Most patients notice the onset of lumps in early adulthood.

#### WHAT CAUSES HIDRADENITIS SUPPURATIVA?

The cause of HS is not well understood. It is thought to start with blockage of the hair follicles. When the fluid within cannot escape, the hair follicles swell up and burst, causing the area to become inflamed or form abscesses.

A common misconception is that HS is related to hygiene. Poor hygiene does <u>not</u> cause HS.

#### Things that can lead to HS include:

• Hormones may be involved in the control of apocrine sweat glands and might play a part in the condition. 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 producing inflammation.
- An over-active immune system is involved causing inflammation and so treatments that reduce immune system activity may be helpful (see below).
- Smoking is linked with HS (up to 60% of people affected by HS are smokers), but the condition can also affect non-smokers.
- HS can affect people of normal weight but is more common in people who are overweight or obese. Reducing weight through lifestyle changes (such as improving the diet) and medications which are licensed for weight loss may improve HS symptoms: for example, semaglutide and tirzepatide.

#### WHAT OTHER CONDITIONS ARE ASSOCIATED WITH HIDRADENITIS SUPPURATIVA?

- HS can contribute to developing depression and anxiety. If you feel worried, anxious, embarrassed or unhappy, it is important to speak with a healthcare professional, such as your GP.
- There may be a link with acne, dissecting scalp cellulitis (scarring and inflammation of the scalp) and pilonidal sinus (a chronic abscess at the top of the buttock crease).
- HS is also linked to other medical problems such as high cholesterol, high blood pressure and diabetes. These do not cause HS, but your healthcare professional may check your weight, blood pressure, and

carry out blood tests for sugar and cholesterol levels.

- In some people affected by HS, there is a connection with inflammatory bowel disease such as Crohn disease and ulcerative colitis. If you experience bowel symptoms such as persistent diarrhoea, blood in the stools, unexplained weight loss or persistent abdominal pain, it is important to seek medical attention.
- There is also a link with inflammatory arthritis, so seek medical attention for persistent joint pain or swelling.

### IS HIDRADENITIS SUPPURATIVA HEREDITARY?

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

## IS HIDRADENITIS SUPPURATIVA CONTAGIOUS?

No, it cannot be passed on to another person at all.

# WHAT DOES HIDRADENITIS SUPPURATIVA FEEL AND LOOK LIKE?

HS abscesses are usually painful. The pain may make it difficult to perform regular activities such as sitting or walking. Discharge of pus can be a problem and may require daily dressings.

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 (also called sinus tracts or fistulas) may form under the skin that leak pus with wounds that may not heal easily. As time goes by, more and more scarring may appear.

# HOW WILL HIDRADENITIS SUPPURATIVA BE DIAGNOSED?

The diagnosis is usually made by a healthcare professional examining the area, the patient's history and symptoms described by the patient. There is no specific test for this diagnosis.

The condition is often misdiagnosed initially as an infection or inflammation of the hair follicles. This can result in delayed treatment and progression of the condition with scarring.

# CAN HIDRADENITIS SUPPURATIVA BE CURED?

No, it usually persists for many years but can become inactive eventually. Treatment usually helps the management of symptoms and reduces the amount and severity of flares.

# CAN PREGNANCY AFFECT HIDRADENITIS SUPPURATIVA?

The impact of pregnancy on HS activity varies. In most cases, HS is unchanged or improves during pregnancy, however there can be more flares soon after delivery.

# HOW CAN HIDRADENITIS SUPPURATIVA BE TREATED?

Treatment is tailored to 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 areas are affected.

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

- A warm flannel applied to the affected area or taking a bath may encourage drainage of pus.
- Painkillers, such as non-steroidal antiinflammatories (NSAIDs), can help with the pain and inflammation.
- A topical steroid (cream/lotion) can sometimes reduce the inflammation (redness, swelling and pain).
- A course of antibiotics may be helpful.
- Surgical treatment to lance the boil (incision) and drainage of the pus can reduce pain and provide temporary improvement.
- A steroid injection into the boil is sometimes considered by dermatologists.

### *Medical treatment to try to prevent flares of HS:*

 Antibacterial lotions and washes: While not evidence-based, some patients find antiseptics such as 4% chlorhexidine wash helpful. An antibiotic lotion such as



clindamycin may be recommended for affected skin.

- Antibiotic tablets: These may be prescribed for a prolonged time (3 months or longer) in order to help suppress further attacks. Tetracycline antibiotics such as lymecycline and doxycycline are often tried initially. The combination of clindamycin and rifampicin for 10-12 weeks is another option; potential side effects include an upset stomach, orange tears and urine, and preventing hormonal contraceptives from working. In HS, antibiotics may work by suppressing inflammation rather than by killing bacteria so 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. People of childbearing potential who have taken acitretin should avoid pregnancy for three years after stopping the medication and so this treatment is usually avoided in people of child-bearing potential. People of childbearing potential must use effective contraception.
- For people who have flares of HS before each menstrual period, anti-androgen tablets can sometimes be useful. Antiandrogen treatment can be included in your contraceptive pill. Alternatively, a tablet called spironolactone may be prescribed.
- Anti-diabetic medications such as • metformin have shown some improvement for HS and can provide additional benefit in those who have prediabetes, diabetes and in females with polycystic ovarian syndrome (PCOS). These are thought to work by changing the way the body responds to insulin. These medications can be associated with nausea, abdominal pain and diarrhoea. Metformin can be taken during pregnancy. Newer medications such as semaglutide may be taken by patients to treat diabetes or for weight management but are not currently available for HS.

- Tablets to alter the immune system such as dapsone, may be considered to improve HS by reducing over-activity of the immune system. Benefits are balanced against potential side effects and blood test monitoring is needed.
- Biologic injection treatments are designed to suppress the immune system and are used for moderate to severe HS that has not improved with other medical treatment. These 'biologic' treatments include adalimumab, secukinumab and bimekizumab which is injected under the skin, and infliximab, initially given as an intravenous infusion.

#### Surgical treatment:

- Scarring such as skin tunnels usually requires surgery for correction. One option is deroofing under local anaesthetic, where the roof of tunnels is removed, which allows them to heal naturally over a few weeks.
- Larger or deeper areas of scarring may require wide-scale removal under general anaesthetic. 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.
- HS surgery is more effective in combination with medical treatment and biologic therapy is usually continued. Biologic therapy may be paused if non-HS internal surgery is needed.

#### Wound care:

Dressings should be prescribed for people with HS experiencing drainage of fluid. There are many dressing types available, and these often include a non-adhesive absorbent part and an adhesive border. There are also dressings designed to be held in place by clothing.

### SELF-CARE (WHAT CAN I DO?)

The following measures may be beneficial:

- If relevant, try to lose weight and stop smoking.
- Avoid tight clothing and tight underwear.

- Use antibacterial or antiseptic soap or shower gel.
- Avoid shaving affected areas, such as underarms.
- Try to reduce anxiety and stress levels.
- 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

*HS Ireland* Website: www.hsireland.ie

### Web links to other relevant sources:

patient.info/skin-conditions/hidradenitissuppurativa-leaflet#what-is-the-long-termoutlook

dermnetnz.org/topics/hidradenitis-suppurativa

Jargon Buster:

www.skinhealthinfo.org.uk/supportresources/jargon-buster/

Please note that the BAD provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links. 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

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