

**Patient
Information**

Hidradenitis Suppurativa

Introduction

This leaflet is for people whose daily lives are affected by Hidradenitis Suppurativa (HS). The aim is to provide you with a basic understanding of HS, and introduce you to some of the more common symptoms and treatments.

What is Hidradenitis Suppurativa (HS)?

Hidradenitis Suppurativa (HS) is a chronic, inflammatory, recurrent skin disease of the hair follicle that usually occurs after puberty, and although rare, cases of HS in children do exist. It often starts as painful boil-like abscesses. These boils can cause scarring in the armpits, genitals, groin, breasts, perianal region and buttocks.

It is estimated that between 1 and 4 people per every 100 will have HS. It is possible that many more have the condition, but have not told their doctor about their symptoms. It is recognised HS effects patients' quality of life more than other skin conditions.

What causes HS?

We do not know for sure what causes HS but some doctors and researchers believe it is probably linked to inflamed sweat glands and blocked hair follicles. There is research being carried out to see whether HS is an autoimmune condition (where the immune system mistakenly attacks and destroys healthy body tissue). HS runs in some families, which means there is sometimes a genetic link. HS is **not** contagious.

What are the effects of HS?

Physical effects:

HS is associated with a number of uncomfortable and unpleasant symptoms which vary from person to person and from flare-up to flare-up. Symptoms include:

- Visible lumps and abscesses which may leave scars.
- Pain and discomfort from the abscesses.

Reference No.

GHPI1624_10_23

Department

Dermatology

Review due

October 2026

Patient Information

- Discharge (pus) from the lumps which can be smelly.
- Infection - but remember that not all abscesses with discharge are infected, this can lead to feeling generally unwell and disturb your sleep causing tiredness.
- Unwanted side effects of the medications used to treat HS – steroids may cause weight gain and fluid retention, for example, while antibiotics may result in yeast infections.
- Acne and/or unwanted excess hair (hirsutism) together with the symptoms of HS.
- Pain or discomfort due to treatments such as surgery, cryotherapy or laser therapy.
- Difficulty sitting or moving about due to painful lumps.
- Other symptoms, including fever, fatigue and sleep disturbance.
- Steroid medication can lead to unwanted side effect which include, weight gain.

How is HS diagnosed?

There are no tests used to diagnose HS. The diagnosis is usually made by your dermatologist after discussing your symptoms.

What are the treatment options?

There is no one treatment that works for everyone who has HS. Sometimes, a patient will need to try a few different treatments to find one that helps. Most treatments are to reduce flare ups and manage symptoms. Some treatments may continue over several months or years, and may include a combination of different medications and therapies. Treatment options include creams, antibiotics and surgery.

Emotional effects of HS:

- **Embarrassment:** Because HS is a visible illness with sometimes unpleasant symptoms, there may be times when you feel embarrassed.

Patient Information

- **It is never easy managing an illness which everyone can see:** You may have to deal with other people's misunderstandings about the condition (the idea that it is contagious, for example) or be worried about what other people might be thinking (that the condition is in some way your fault because of your lifestyle or your personal hygiene habits). This may even have stopped you from telling your doctor about your symptoms, meaning a delay in getting a diagnosis and treatment.
- **Anger and irritability:** You may feel angry about having this condition and how it affects your daily life. You may also feel irritated when another new lump develops or when you have to deal with symptoms such as pain and discharge.
- **Anxiety:** You may experience a range of worries that cause anxiety and stress. You may worry about the next abscess or about the condition getting worse over time. You may worry about how the condition is affecting you now or how it might affect your work life, family life and close relationships in the future. Also, you may worry about what other people might be thinking about you, even if these concerns are unfounded.
- **Depression:** Living with a chronic health condition can increase your chances of experiencing low mood or depression. You may have stopped doing the things you enjoy such as hobbies, social outings or having an intimate relationship because of HS, and at times you may feel bad about yourself and the future.

Perhaps others have not always been kind or understanding about your HS. All of this can contribute to low mood and depression. If you are experiencing depression and have had thoughts that your life is not worth living, it is important to talk to your GP or healthcare professional about these feelings and ask for some support.

- **Feeling disappointed or disheartened:** If you have had surgery and followed all of the medical advice given to you, but are still suffering recurrent symptoms of HS, you may feel disappointed and disheartened, and may begin to feel helpless.

**Patient
Information**

How having HS can affect you

Having HS may mean that you think you have to stop doing the things you used to enjoy doing, like socialising and engaging with hobbies. In the short term, this can work well because you do not have to face difficult situations like worrying about what other people think or being faced with the risk of unkind reactions. However, this strategy can lead to isolation and boredom. It can make you feel worse physically and emotionally because you are missing out on opportunities for pleasure, fun, activity and achievement.

You may have avoided:

- Social situations in case other people notice the abscesses, discharge or odour.
- Physical intimacy with sexual partners.
- Physical closeness with friends and family.
- Work place opportunities, like giving a talk or taking the lead on a demanding project.

As well as opting out of things, your HS may mean that you have to do things you would rather not do. These might include:

- Avoiding moving about due to painful lumps.
- Spending lots of time trying to cover up the abscesses or scars.
- Having to choose your clothes carefully (for some people tight clothes can affect their HS symptoms).
- Having to be careful about the products and cosmetics you use.
- Missing work, school or college due to flare-ups.
- Changing or postponing activities you were looking forward to when the symptoms are bad.

Having to make these changes may lead to lots of different reactions and emotions, such as feeling frustrated, overwhelmed or downhearted.

On the other hand, you may have come to accept some of these adjustments over time. If you find that you suffer any of the above, please do not hesitate to speak to your healthcare professional.

**Patient
Information****Further information****The Hidradenitis Suppurativa Trust**

This is resource of information and advice about HS, and includes an online support group.

Website: www.hstrust.org

Changing Faces

This is a charity for everyone with a scar, mark or condition on their face or body that makes them look different.

Website: www.changingfaces.org.uk

You may find the following resources available from Changing Faces useful:

'Living with Confidence', by Changing Faces, is a booklet for people who live with a visible difference.

'Intimacy, Love and Relationships' (Parts 1 and 2), by Changing Faces, is a booklet for people who live with a visible difference that affects their intimate relationships.

Contact information

If you have any concerns or questions, please contact either of the numbers below.

Maria Barfoot**Lead Inflammatory Dermatology Nurse Specialist**

Tel: 0300 422 5589

Monday to Friday, 9:00am to 4:00pm

Email: nicohola.dobson@nhs.net

Content reviewed: October 2023

Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85



<https://aqua.nhs.uk/resources/shared-decision-making-case-studies/>