Inspired by **patients.**
Driven by **science.**

Embrace life with confidence:

Your HS smart guide for all stages

EU-DC-2500031
Date of preparation: May 2025

HIDRACENSUS 7.3
Improved HS care starts here

We thank HIDRACENSUS 7.3 Steering Committee members, Dr Barry McGrath (co-founder and manager of HS Ireland, and living with HS) and Dr Fiona Collier (a recently retired general practitioner with special interest in dermatology, Scotland) for their valuable review and input into the HS smart guides.

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How to use this guide

Welcome to **Embrace life with confidence: Your HS smart guide.**

This is a quick-reference guide, containing the key things you need to know to embrace life with confidence when living with hidradenitis suppurativa (HS).

HS is not a rare disease; in fact, it is quite common, affecting one in every 100 people in Europe[1] – but not many people have heard of HS.

In this guide, you can find out what HS is and how to manage it, and get some tips on how to confidently speak about HS to your healthcare team, and your friends, family, and colleagues/classmates.

Everyone is unique: you may have questions beyond what is covered in this guide, and you may also find that some of the content does not apply to you. If you need any more information on any of the topics or if you have any questions, contact your healthcare provider or a local HS group as they may be able to give you more details. There is a lot of information about HS online; however, some of it can be inaccurate or even misleading.

The information provided within this guide has been fact-checked and the links direct you to sources that have been verified as reliable.

Here you can record your healthcare provider's details and/or details of local HS groups:

This guide is one of a pair; there is one for you, and a matching guide for your healthcare provider.

Your healthcare provider may use the guides together to lead your appointments and direct you to relevant and reliable information. Please make sure you know how to access this guide as you may want to refer to it again.

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1. Ingram JR. Br J Dermatol. 2020;183:990–8.

The information provided in this guide is correct as of May 2025.
This guide will be reviewed and updated as understanding and management of HS advances.

Chapter 1

What is hidradenitis suppurativa (HS)?

This chapter introduces HS, including what HS is and why it occurs.

What is HS?

Hidradenitis suppurativa (HS) is a long-term condition that causes swollen, red, pus-filled lumps to come and go on or below the skin. These lumps can be very painful. HS is not contagious – it cannot be spread from person to person.[1] You might also hear HS called acne inversa or Verneuil's disease.[2]

Pronounced
(hi-drad-uh-NIE-tis
sup-yoo-ruh-TIE-vuh)

HS symptoms come and go. The term 'flare' is used to describe a period of time when HS symptoms appear or get worse.[3]

In the past, HS was poorly understood. Not many people knew about HS so it could often be mistaken for other conditions, and people could experience long delays in getting a diagnosis of HS or were wrongly diagnosed with a different skin problem.[4,5]

But now more is being done than ever before to understand and treat HS.

This guide has been developed as part of **HIDRACENSUS 7.3**, a Europe-wide programme, led by a group of HS experts and sponsored by the pharmaceutical company UCB. **HIDRACENSUS 7.3** aims to improve the standard of care for people living with HS by educating everyone involved in HS and making sure everyone knows how to best manage HS.

The HIDRACENSUS 7.3 pledge

7.3

Seven-point-three. The most important number for HS.

Because on average, people with HS wait a staggering 7.3 years for a correct diagnosis[6,7]

7.3 years is too long for HS to go unrecognised by healthcare professionals

7.3 years is too long for HS to be without appropriate treatment and care

7.3 years is too long for HS to deal with the symptoms of HS alone

7.3 years is too long

Seven-point-three is a number. But to us, it's a stimulus for change.

So, from here on, we all work together, healthcare professionals, nurses, those in charge of funding healthcare services, and most importantly, people with HS

A new initiative ensuring that everyone is heard; everyone brings their own experience. Everyone learns.

Everyone benefits.

HIDRACENSUS 7.3 Improved HS care starts here

What does HS look like?

HS shows as swollen red lumps that go deep into the skin and fill with pus forming painful abscesses (pus-filled lumps). You may have one lump, or you may have many. The lumps in HS most commonly occur where skin touches skin, such as in the armpit; underneath, between and on the breasts; in the groin; and between and on the thighs and buttocks.[1]

In severe HS, when the abscesses last a long time or keep reappearing in the same area, the abscesses can connect through tunnels under the skin and release the pus. Because the lumps and abscesses come and go, tough scar tissue can form as the skin heals, which can restrict movement in some people.[1,8]

HS in different areas of the body


Armpit


Breast


Groin


Buttocks

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Severity of disease

We can think of HS in two main ways, depending on how much inflammation (redness, swelling, and pain) is present: The active (inflammatory) and inactive (predominantly non-inflammatory) form. HS severity can be classified using International Hidradenitis Suppurativa Severity Scoring System (IHS4) for active HS or Hurley staging for inactive HS.[9]

IHS4[9]

IHS4 is calculated based on a points-based system:

1 point is assigned for each nodule,
2 points for each abscess, and
4 points for each draining tunnel.

The sum of these points constitutes the final IHS4 score, which will classify the disease as either mild, moderate or severe.

Mild	IHS4 score **≤3**
Moderate	IHS4 score **4–10**
Severe	IHS4 score **≥11**

Hurley staging[4,9,10]

Many clinicians measure the severity of inactive (predominantly non-inflammatory) HS with the Hurley staging system, which ranges from stage I (mild disease) through to stage III (severe disease).

Hurley
stage I

single or multiple abscesses without tunnels or scarring

Hurley
stage II

recurrent abscesses, single or multiple widely separated lesions, with tunnels and/or scarring

Hurley
stage III

diffuse or broad involvement, or multiple interconnected tunnels and abscesses across the entire area

HS in the armpit across Hurley stages

Hurley stage I

Hurley stage II

Hurley stage III

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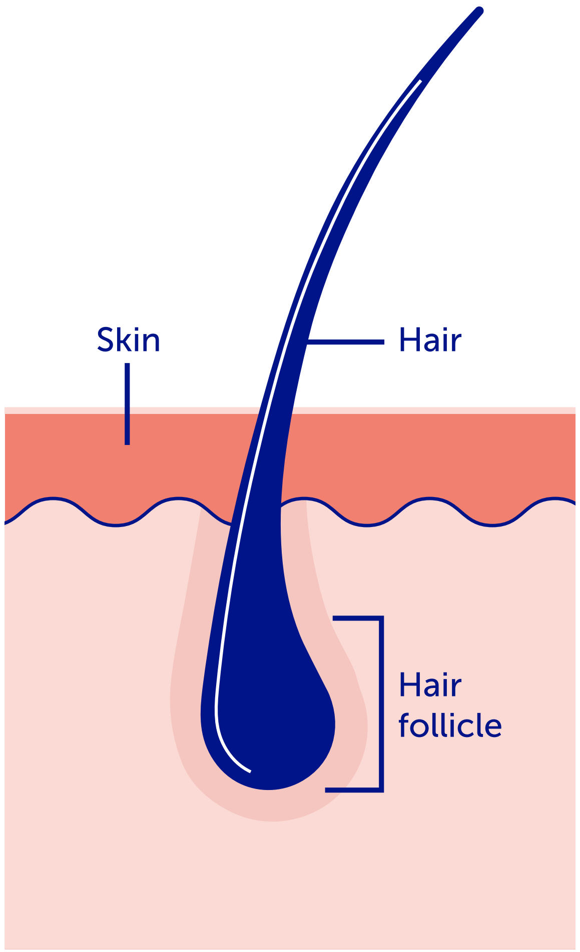
Why does HS occur?

HS is an inflammatory disease caused by an overactive immune system targeting the body's hair follicles.[11]

How HS occurs[12]

1. Each hair on your body grows from a hair follicle
2. Usually, skin cells that line the hair follicle fall off at regular intervals and are removed from the hair follicle[13]
3. However, in HS, keratin – a naturally occurring protein that makes up hair, skin and nails[14] – blocks hair follicles in certain areas of the body
4. Over time, the blockage builds up and causes the hair follicle to swell and eventually burst
5. This triggers the immune system in the skin to attack the hair follicle which causes the swollen red lumps and abscesses
6. The inflammation produced by the immune system can last for a very long time

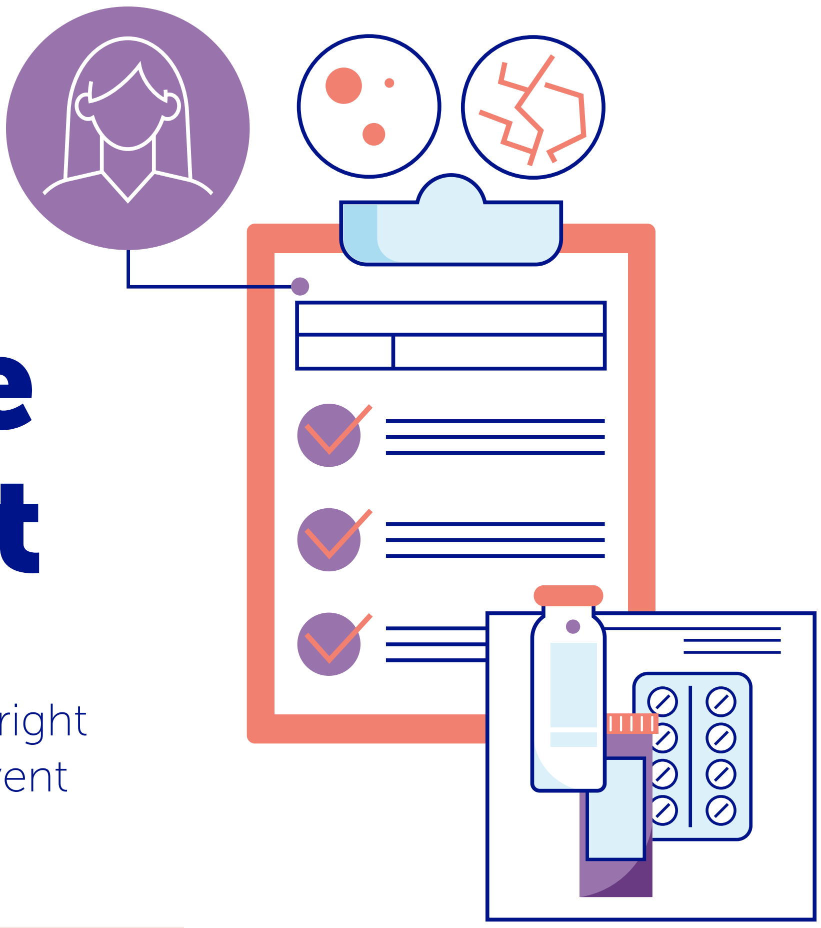


Who gets HS?

Anyone can get HS, and it is unclear why some people get HS over others. As with many diseases, the chance of getting HS is thought to be due to a mixture of genetics and environmental factors.[15]

Sex: In Europe, the risk of HS is approximately three times higher for females than males[16]

Age: HS most often starts at, or soon after, puberty (~11 years old)[16]



The importance of HS treatment

HS is very unlikely to heal on its own. Getting the right treatment as soon as possible is important to prevent your symptoms from getting worse.[4]

People with HS can have mild disease (stage I, IHS4 ≤3).[9] In some cases, HS can progress to moderate (stage II, IHS4 4–10) or severe (stage III, IHS4 ≥11), but not everyone with HS will progress to severe disease (stage III, IHS4 ≥11).[9,17]

Long-term stage III HS can lead to complications such as:[8]

- Restricted movement because of tough scar tissue
- Tunnels inside the body e.g. connecting the inside of the anus to an opening in the skin[18]
- Depression, anxiety, and isolation[16]
- Swelling of the arms and legs due to damage to the lymphatic system
- Anaemia (low levels of red blood cells)
- A rare[16] and aggressive skin cancer called cutaneous squamous cell carcinoma that can spread across the body and be life-threatening. It most commonly affects white men, who were smokers, with long-term HS affecting the buttocks[8]

Seek treatment from a healthcare provider as soon as possible and keep them updated on your progress with your treatment.

HS and other conditions

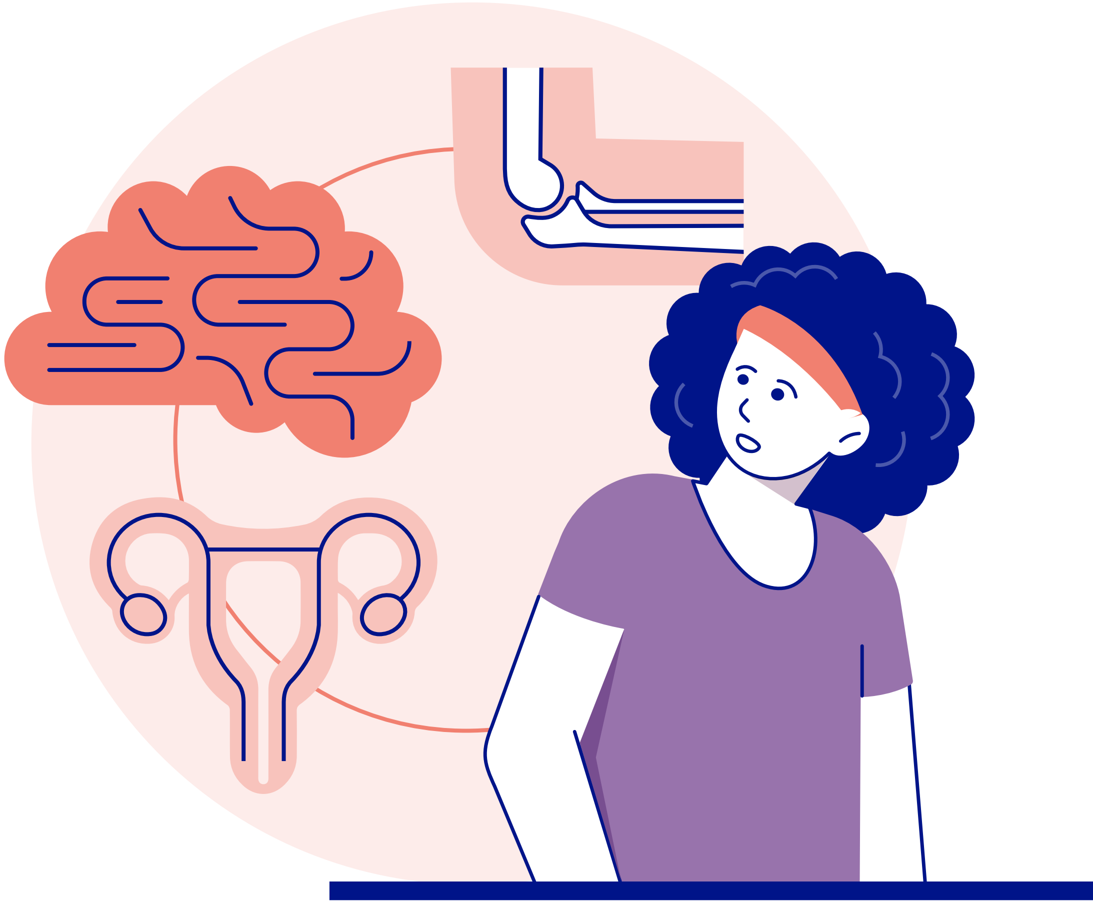
Some people with HS can experience other conditions at the same time as HS; these can start before or after their HS symptoms. There are many reasons that HS is associated with these other conditions:

- HS is an **inflammatory disease** caused by an overactive immune system. Since the immune system exists throughout the body, there is a risk of developing other inflammatory conditions alongside HS, such as arthritis or inflammatory bowel disease[12]
- The **environmental factors** thought to contribute to HS (e.g. smoking, obesity, etc.) are also risk factors for other conditions such as heart attacks and strokes – **long-term inflammation** also increases the risk of these conditions[12,19]
- **Hormones** are thought to play a role in the development of HS, and some females may experience polycystic ovary syndrome associated with this[15,16]
- **Living with HS** can impact mental health, and some people may experience depression or anxiety[12,19]

You should tell your healthcare provider about all the symptoms you have, such as joint aches or stiffness, tummy problems, irregular periods, excessive body hair or putting on weight, or low mood or anxiety, as they may indicate one of the associated conditions listed above.[20]

The sooner you tell your healthcare provider, the quicker you can get the right treatment for all your symptoms. More information on the conditions associated with HS can be found here.

See Chapter 4 to learn about the different healthcare professionals who may be involved in managing HS and the associated conditions.



HS summary grid

HS is...

A long-term inflammatory disease of the hair follicles caused by an overactive immune system[11]

Painful, swollen, red, pus-filled lumps that may connect and leak pus[1]

Potentially disruptive to daily life[12]

See Chapter 2 for tips on how to share your knowledge and experiences of HS with those around you, so that they can understand what HS is, how it affects you, and what they can do to help.

Manageable with appropriate treatment or surgery[9] (see Chapter 3) and multiple specialists working together (see Chapter 4)[21]

HS is NOT...

Contagious[11]

A sexually transmitted infection[11]

Acne[22]

A cyst[4]

An ingrown hair[22]

Caused by an infection[11]

A simple boil[22]

Caused by poor personal hygiene[11]

Curable[23]

Your fault[11]

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Chapter 2

Sharing your experiences

This chapter provides some helpful tips on how to speak confidently about HS with those around you.

Talking to family, friends, colleagues, or classmates

Even though HS affects around one in every 100 people in Europe,[1] not many people know about it. You may not have heard of HS before getting your diagnosis, and it is likely that your friends, family, colleagues, or classmates will not have heard of HS either.

Sharing your knowledge and experiences of HS with those around you can help them to understand what HS is, how it affects you, and what they can do to help. You may like to send Chapter 1 of this guide to your contacts so that they can learn more about what HS is.

Here are some suggestions for how to start talking about HS with family, friends, colleagues, or classmates:[2]

Top Tips

- Decide how much information you want to share – you don't have to tell them everything
- Pick a time to talk when people are not rushed or distracted
- It may help to rehearse exactly what you are going to say
- You may like to reassure them that HS is not contagious; you may want to specify to your partner that HS is not a sexually transmitted disease[3]
- You could explain that HS is not rare. About 1% of people in Europe have HS,[1] but not many people have heard of it
- Let them know what they can do — whether you want questions, advice, a listening ear, or practical help
- Explain that you may need a break from events sometimes, or that you don't feel like being intimate with your partner, and that it's not because of them — it's about taking care of yourself
- Tell them that you will share results about a treatment or procedure when you are ready, and not to ask about results if you find it frustrating to be asked frequently

The HS information card

The HS information card provides a quick explanation of HS without needing to speak. It is downloadable and printable so that you can carry it with you and show it to whoever you need. Download yours from UCBCares® today!

Please read

I have a long-term skin condition called **hidradenitis suppurativa (HS).**

- It is caused by an overactive immune system producing inflammation in my hair follicles and it is not contagious.
- HS comes and goes and can be unpredictable.
- It can be very painful and can affect my ability to do everyday activities.

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My medications:

Talking to your healthcare provider

Sharing your experiences of HS with your healthcare provider can be very valuable for both of you.

Your healthcare provider will know about the symptoms of HS they can see, but they may not know the effect HS has on your daily life as they only see a snapshot of you in the clinic.

Your healthcare provider may ask you 'How does HS affect you?' or 'Does HS stop you from doing anything?'. When answering these questions, try to be as open and honest as possible so they can understand all your experiences. It can also help to keep track of your HS symptoms and how these affect you in a diary, so that you cover everything you want to in your appointment.[2]

If your healthcare provider doesn't ask how HS affects you, feel free to raise anything that is bothering you about your HS. It doesn't just have to be your skin symptoms. It is your appointment so use the time to cover what is important to you.

When your healthcare provider knows the full picture of your HS, you can work together to build a management plan that works for you.

For more tips on how to talk to your healthcare provider, see Chapter 5.

Talking to other people with HS

You may wish to share your experiences and learn from others with HS. There are many HS groups and forums available, both in-person and online. Search online or talk to your healthcare provider to find an HS group near you. If there aren't any HS groups near you or you don't find one you like, why not consider starting a group yourself? You can ask your healthcare provider for resources on how to get started with this.

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Chapter 3

Living well with HS

This chapter describes the common triggers of HS flares and how you can take action to identify and avoid them. It also provides tips for effective skincare so that you can confidently manage your HS, and discusses the different medicines and surgical options that are available.

Managing HS

We are learning more and more about HS every day through research and many possible medicines are being tested all the time. Once scientists understand what causes HS, new treatments can be developed to stop HS at the source.[1] There is hope for a cure in the future, but in the meantime, there are a range of options that can help to manage your HS symptoms, including medicines, surgery, and lifestyle changes.[2]

Finding your triggers[3]

There are certain situations that have been identified as triggers for HS flares in some people. Each person will have their own trigger(s) or may experience flares without any obvious trigger at all.

Knowing what triggers your HS is a great starting point to be able to avoid or minimise starting or worsening a flare. Keeping a diary to record the situations in your life leading up to the flare can be very useful to pull out any common factors.

> Don't worry if you can't identify a trigger, everyone is different, and many people do not have obvious triggers.

Common triggers for HS flares and suggestions for avoiding them[3,4]

Shaving

- Avoid shaving on or near HS lumps
- Explore laser hair removal to see if it is a suitable alternative option for you

Smoking

If you smoke, talk to your doctor about support to stop; there are lots of useful resources and support services to help

Exercise/sweating

- Choose low-intensity, low-impact exercise, such as yoga or pilates – you will still be working your muscles but minimising overheating and sweating
- Talk to your healthcare provider about the appropriate level of exercise for you, including what clothing to wear and how to manage sweating and chafing

Menstrual cycle

- You may find it more comfortable to use tampons rather than sanitary towels to reduce the friction in your groin area
- If your HS flares around the time of your period, talk to your healthcare provider or sexual health clinician about the different forms of hormonal contraception available to regulate your hormones

Stress

Try to identify what causes you stress and practice stress management and mindfulness techniques[5]

Obesity

Talk to your doctor for support to help lose weight (if appropriate) through diet modification and a suitable level of exercise for you

Friction

Try wearing loose-fitting, breathable clothing made of cotton, rayon, or bamboo fibres, sports bras or camisoles with built-in wireless bras, and women’s briefs or boy shorts

Pregnancy

- HS activity can change during pregnancy. Some women report improvements in their HS, while others report worsening
- Talk to your gynaecologist/obstetrician for tips on how to navigate HS during pregnancy

Diet

- Certain foods, such as dairy and brewer’s yeast (most commonly found in bread, beer, and wine),[6] may worsen HS symptoms for some people
- If you think a certain food may be a trigger for you, try keeping a diary to see if it affects your symptoms and try cutting it out of your diet to see if this helps. Make sure to tell your healthcare provider if you are avoiding any foods to ensure you are getting a balanced diet
- See if your doctor can refer you to a dietitian to design and agree on a dietary plan

Keeping your skin clean and protected[7,8]

Throughout all stages of HS, the affected skin can release pus; this forms an opening in the skin, through which bacteria can enter. Most people with HS therefore need to use some kind of dressing to absorb any pus and prevent infection.

There are many different cleansers, ointments, and dressings available to keep your skin clean and protected; there is even an HS-specific dressing system available.

Keeping your skin clean and protected

Two key principles of caring for your skin:[7]

1. Keep the affected skin as clean as possible
2. Choose a dressing that is right for you

Dressings[8]

When it comes to dressings, everyone is different, although there are a few ideal characteristics to look out for:

Kind to skin
Does not damage the skin

Highly absorbent and deodorising
Can contain large amounts of pus and prevent odour

Easy to use
Easy to apply, adjust, and remove

Antimicrobial
To avoid infection

Adhesive-free
Non-adhesive or gentle adhesion

Secure
Reduces slippage, chafing, and leaks

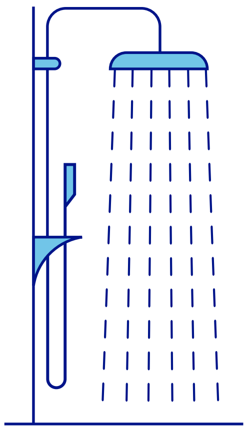
Try a few different types of dressing to find what works for you

! We recommend avoiding woven gauze – it can stick to the skin and be painful to change[7]

Changing your dressings[7]

Change your dressing as often as you need – everyone will be different

1. Gently remove the dressing – avoid dressings held in place with strong adhesives to help with this
2. Clean the skin using water or a cleanser recommended by your doctor, and dab dry with a clean towel. You may not need to clean the skin every time you change the dressing, see what works for you
3. Gently reapply a new dressing – there is no 'best dressing' in HS, see what works for you but keep in mind the ideal characteristics listed above



Generally, you should try to remove your dressings before showering. After showering, dab the wound dry with a clean towel before reapplying a new dressing. You can also keep your dressing in place by using a waterproof covering if you prefer[7]

Changing your dressing is a good opportunity to check your skin for any signs of infection[7]

Everyone is different, talk to your healthcare provider about the right skin care for you or ask for referral to a wound care specialist for more support

[UK, Ireland, Germany guides only]
See here for more information on an HS-specific dressing for use in the armpit, buttocks and groin.

Medicine

Medicine is a key way to manage the symptoms of HS, and there are many different types of medicine available.[2]

The medicine that is right for you depends on your IHS4 score and Hurley stage and what you would like to achieve from your treatment.[2]

Your healthcare provider may ask you 'What is the key part of your HS that you would like to improve?' or 'What would you like to achieve from your HS treatment?'. It is worth taking a moment to think how you would answer these questions before your appointment – you might like to note a few ideas down here.

Your healthcare provider may have a completely different aim in mind, so these questions are particularly useful to help you and your healthcare provider explore what you want to achieve from your treatment; you can then find the right treatment for your needs together.

When it comes to choosing a treatment, your healthcare provider may ask if you prefer to choose a medicine on your own, with your healthcare provider, or based on their recommendation alone. Have a think before you go into your appointment which you prefer – you can always change your mind in future.

You have a right to be involved in choosing your treatment. If you would like to be involved, you can ask your healthcare provider three questions so that you can make an informed decision:

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

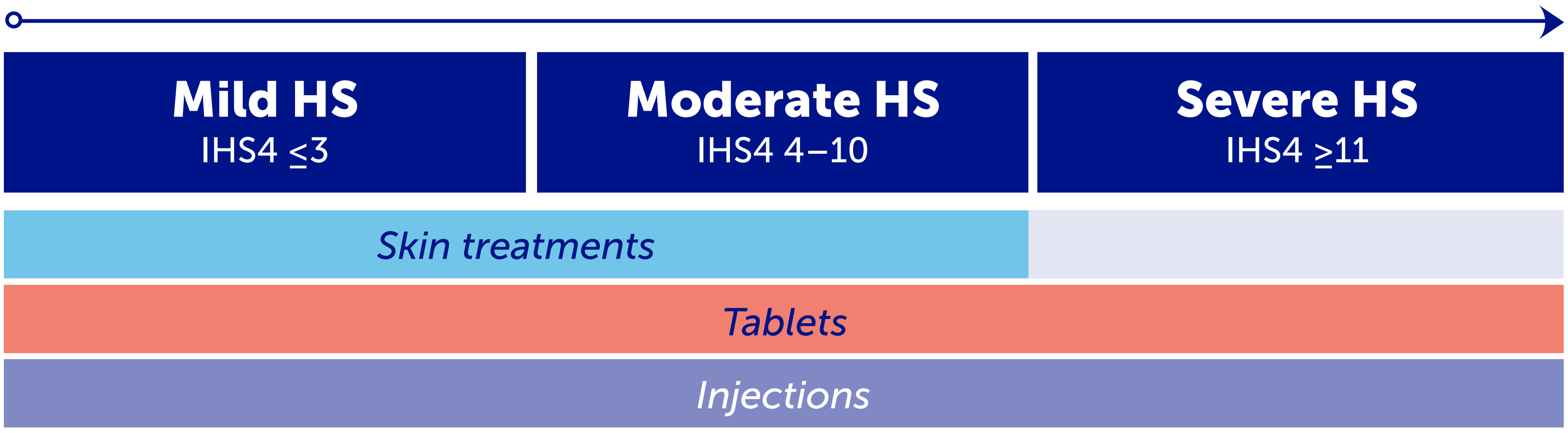
The HS Patient Decision Aid can help you get a head start on choosing a treatment that fits your needs. It contains background information on the treatments available, asks what is important to you, and uses a comparison tool to easily visualise which treatments match your needs.

Medicines available for HS[2]

[Section to be localised]

In the image below, you will find the treatment options that are currently recommended for HS by the European HS guidelines. Talk to your healthcare provider about the treatments that are available and suitable for you.[2]

Treatments for active (inflammatory) HS*



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Skin treatments

Resorcinol

Removes dead skin cells and bacteria that could clog hair follicles; eases itching and reduces inflammation[2]

❗ Potential for skin irritation[9]

Antibiotic cream

Kills bacteria and reduces inflammation[9]

❗ May cause stinging and skin irritation[9]

Tablets

Oral antibiotics

Kills bacteria and reduces inflammation[9]

❗ A range of side effects, particularly tummy problems.[9] Long-term use can lead to the antibiotic not working as well (antibiotic resistance)[2]

Zinc gluconate

Regulates the immune system and shields cells from damage[2]

❗ Side effects include tummy problems[2]

Injections

Biologics

(For use if antibiotics do not sufficiently control your HS)

Target specific parts of the immune system to stop inflammation at the source[2]

❗ Increased risk of infections[9]

Steroids

Reduces inflammation[9]

❗ Skin may become thinner and lose its colour[9]

continued on next page...

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*The figure only includes first- and second-line treatment options.

Other treatments that can be used with those on the previous page

Are you...

Flaring?

Steroids (tablets and injections)
Reduce inflammation

❗ The flare may return after stopping treatment

A female

who flares around the time of periods or has signs of high levels of male hormones (e.g. polycystic ovary syndrome)?

Hormonal contraception
Reduces the levels of male hormones to prevent triggering of a flare

❗ Talk to your dermatologist, doctor or sexual health clinician about the specific risks associated with the treatment chosen

Managing other symptoms of HS

Pain[10]

Over-the-counter pain relief

Cool compress
Make sure it does not come into direct contact with the skin

Talk to your healthcare provider
They may be able to prescribe stronger pain medications. Ask for referral to a pain specialist for further support

Itch[11]

Talk to your healthcare provider who may be able to prescribe a numbing cream or tablets to reduce the itchy feeling

Future treatments[1] ››

- The exact cause of HS is still unknown, but scientists are learning more about HS through research
- Many potential treatments for HS are currently going through rigorous testing so that more treatment options should become available in the near future

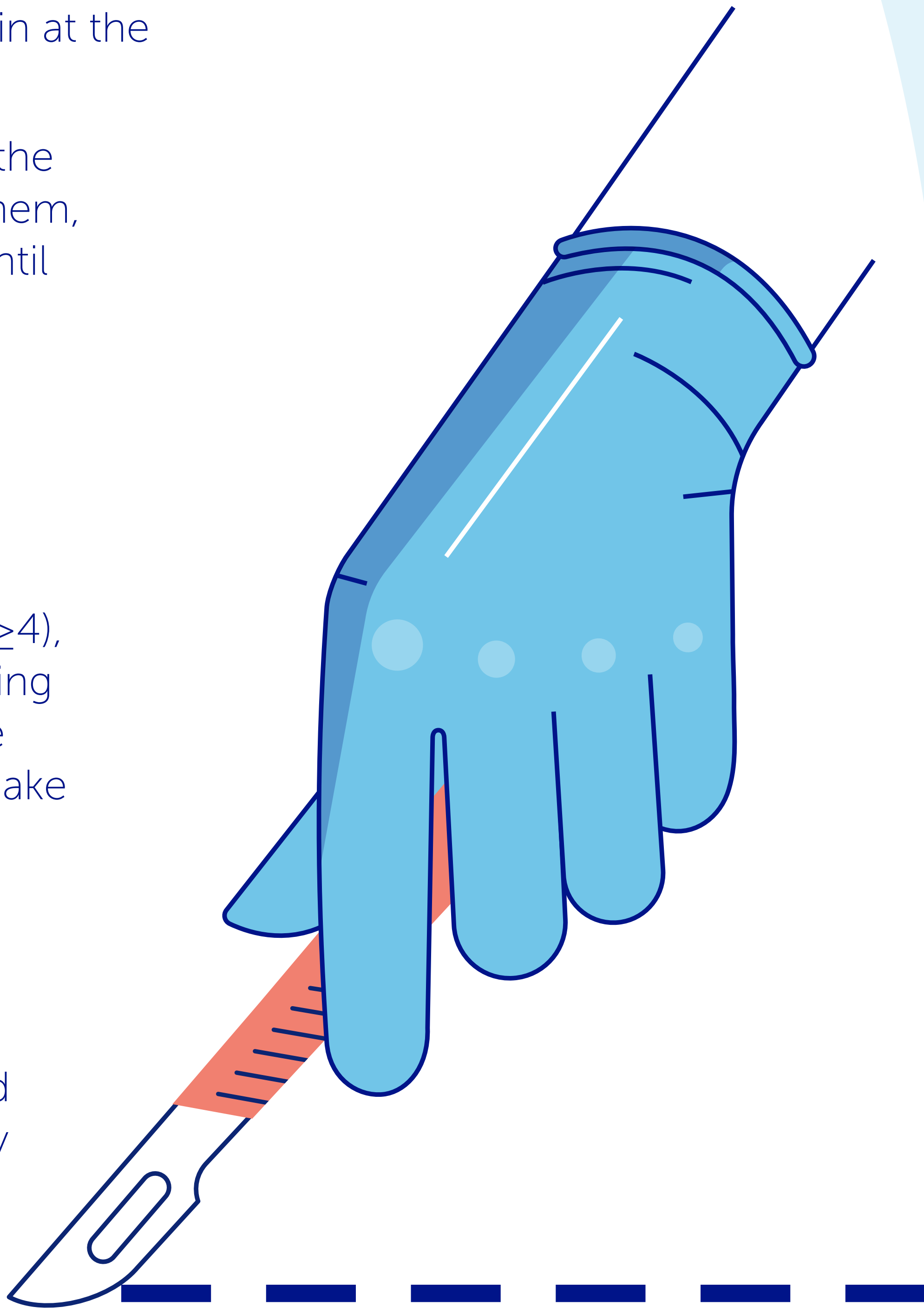
Surgery

Surgery is another option for managing HS that may be suitable for you. Surgery physically removes the HS lumps, abscesses and tunnels, leaving healthy skin behind.[2,9] Combining medical treatments with surgery may be an effective way to manage your HS.[2]

There are many different methods of surgery – some are more invasive than others:

- **Incision and drainage** – a cut is made in a lump or abscess to drain the pus, this can provide pain relief but the lumps often return[8,12]
- **Deroofing** – this involves cutting off the skin that is on top of a tunnel or abscess and removing the skin at the bottom of the tunnel/abscess[2]
- **Lasers** – a laser of carbon dioxide is pointed at the lumps, abscesses, and tunnels, and vaporises them, starting at the middle and moving further out until reaching healthy skin[2]
- **Cutting out lesions (excision)**:
  - In moderate HS (stage II, IHS4 4–10), single lumps or abscesses can be cut out – the wounds heal on their own[2,9]
  - In moderate-to-severe HS (stage II–III, IHS4 ≥4), a large area of skin may be cut away, removing the lumps and tunnels; the underlying tissue and surrounding skin are also cut away to make sure all the affected skin has been removed. The remaining wound is large and deep and plastic surgery to add a skin graft may be needed to help the wound heal[2,9]

The type of surgery that is right for you will depend on the areas of your body affected and the severity of your HS.[2] Talk to your healthcare provider to see if they think surgery can help you.



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Chapter 4

People involved in your care

This chapter covers the different specialists involved in managing HS and their roles.

People involved in your care

Your dermatologist, dermatology nurse, or family doctor is likely to be your main point of contact for HS, but other specialists may also be involved in your care depending on your symptoms and your treatment goals.[1]

Here are some of the people you may meet:[1]

Family doctor
Sees the first symptoms of HS and is available throughout your treatment to answer any questions

Dermatologist
Diagnoses HS

HS specialist
Confirms HS and starts appropriate treatment

Dermatologist and dermatology nurse
Holds regular appointments to check how you are doing

Wound care nurse
Provides tips on how best to care for your skin

Surgeon
Performs surgery to manage the skin symptoms
(see Chapter 3 for surgical options)

Depending on your symptoms, you may also see:[1]

- **Pain specialist**[2] – to provide pain relief
- **Rheumatologist** – to diagnose and manage joint issues that can occur with HS, i.e. arthritis
- **Gastroenterologist** – to diagnose and manage tummy issues that can occur with HS, i.e. inflammatory bowel disease
- **Endocrinologist** – to help women with polycystic ovary syndrome/flares around periods, and to support people with diabetes
- **Cardiologist** – to measure and manage your risk of heart problems
- **Obstetrician/gynaecologist** – to support you through pregnancy or manage symptoms of HS around the genitals
- **Proctologist** – to manage symptoms of HS around the anus
- **Psychologist** – to help with mental health
- **Physiotherapist**[3] – to create an exercise plan that is an appropriate level for you
- **Nutritionist/dietician** – to review your diet and provide tips on weight loss
- **Smoking advisor**[3] – to help stop smoking

For more information on the other conditions associated with HS, see Chapter 1.

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Chapter 5

Talking to your healthcare provider

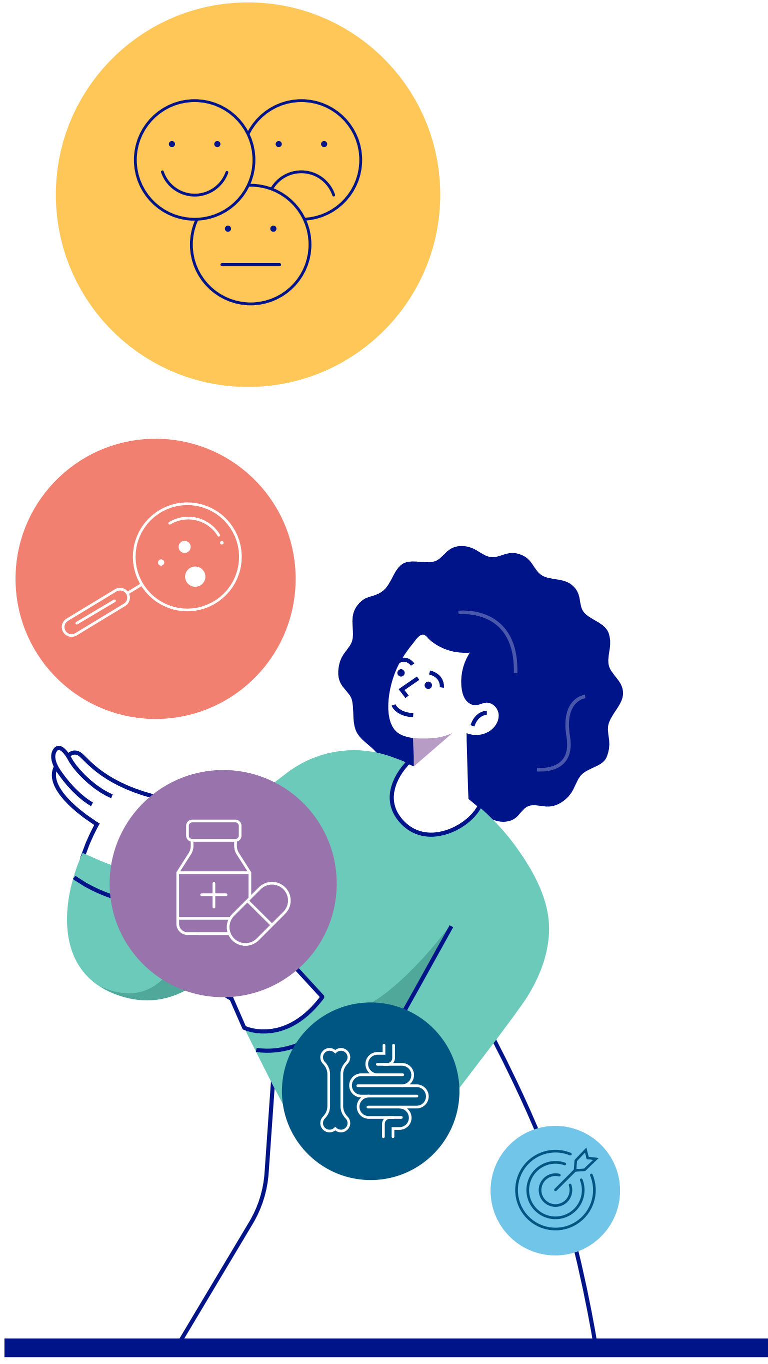
This chapter provides helpful tips on how to confidently talk about HS with your healthcare provider

Painting the full picture of HS[1]

To make sure you get the best care, your healthcare provider needs to understand everything you experience.

You should tell your healthcare provider about all aspects of HS, including:

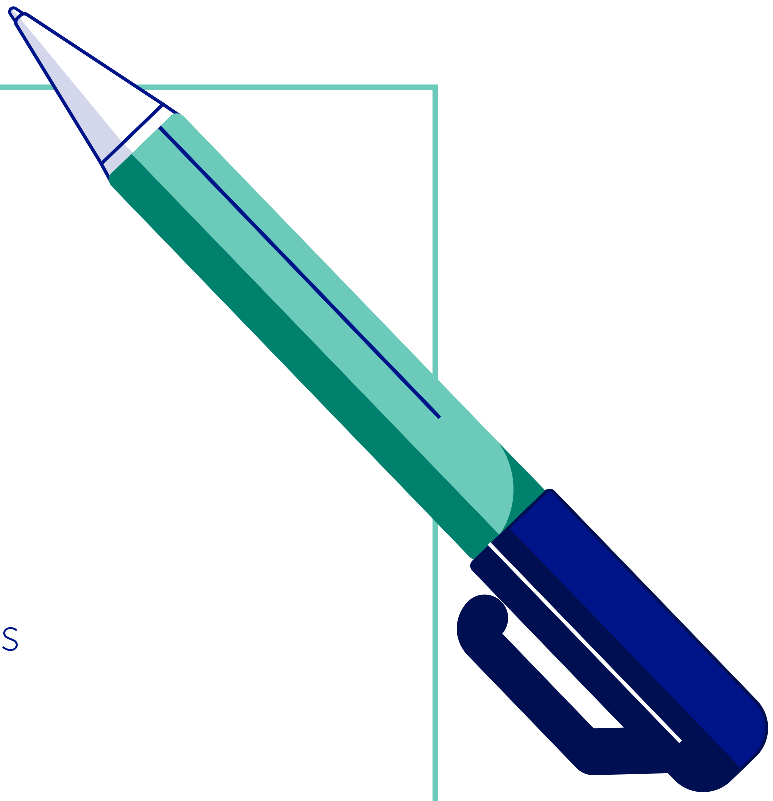
- Your skin symptoms (including what they are, where they appear, how often they happen, how long they last, and if they have changed)
- How HS makes you feel
- How HS affects your life
- If you have any symptoms of other conditions associated with HS
- How you feel about your treatment
- What is important for you to achieve from your treatment
- Your future plans, such as if you would like to have children or go to university
- If you have any concerns or questions about any aspect of HS



Your healthcare provider should make you feel at ease; they should focus on you, give you time to say everything you want to, answer any questions, and make a plan with you to address anything you raise. You should feel as though your thoughts and feelings are being heard and validated and they should be supportive and understanding.

It can take time to build a relationship with your healthcare provider, but eventually you should be able to trust them and feel comfortable opening up about anything that is bothering you. Rarely, healthcare providers can be dismissive of what you have to say; however, if this is the case, then seek care from a provider who specialises in HS.[1]

Top tips for appointments with your healthcare provider[1]



Top Tips

- **Be open and direct** – put aside any feelings of embarrassment; HS is nothing to be embarrassed about and healthcare providers have heard and seen it all before!
- **Go prepared** – keep a diary of your symptoms and any triggers, you can also write notes about what you want to say and questions you want to ask during the appointment
- To make the most of your appointment time, you could work through the HS Patient Decision Aid before your appointment to find which treatment options suit your needs and take your results to your healthcare provider
- Consider bringing a family member or friend to the appointment to be a second set of ears
- Take notes during the appointment if your healthcare provider isn't writing information down for you

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Chapter 6

Appendix

FAQs

Q: Is there a cure for HS?

A: There is no cure for HS at the moment, but there are a range of options that can help to manage your HS symptoms, including medicines, surgery, and lifestyle changes.[1]

Q: How do people get HS?

A: The exact cause of HS is unknown, and anyone can get HS. The chance of getting HS is thought to be due to a mixture of genetics and environmental factors.[2]

Q: Does HS always get worse over time?

A: Each person's HS is unique. Getting the right treatment as soon as possible is important to minimise the chance of disease progression.[3]

Q: What causes the lumps in HS?

A: In HS, the immune system is overactive and generates inflammation in the body's hair follicles, which causes swollen, red lumps to appear that can fill with pus.
For more information on the steps leading up to this process, see here.[4]

Q: What causes flares?

A: HS is caused by an overactive immune system targeting the body's hair follicles,[4] but there are certain factors that can make symptoms worse, causing a 'flare'. These factors are called 'triggers'. Each person will have their own trigger(s) or may experience flares without any obvious trigger at all. For more information on triggers, see here.[5]

Q: Can changing diet help manage symptoms?

A: Certain foods, such as dairy and brewer's yeast (most commonly found in bread, beer, and wine)[6] have been reported to worsen HS symptoms for some people. Obesity can also exacerbate symptoms so a change in diet may be beneficial. Talk to your healthcare provider to see if a change in diet would work for you.[5]

Q: Does HS affect my employability?

A: Your employer cannot discriminate against you for having HS. However, the symptoms of HS may affect your ability to work at times.[7] You may want to speak to your Human resources team, occupational health, colleagues or manager to help them understand what HS is, how it affects you, and to support you with your work. See here for tips on how to talk about HS with your colleagues.

Q: What role do associated conditions play in HS and will I be screened for these at the time of diagnosis?

A: Many people can experience other conditions at the same time as HS, such as arthritis, inflammatory bowel disease, and polycystic ovary syndrome. These associated conditions may influence your treatment. Your dermatologist should screen you for some associated conditions once a year, but make sure to tell your healthcare provider if you experience any new symptoms (not just skin symptoms) as soon as possible so that they can get the right treatment for you.[7,8]

Q: How can I cope if I am feeling low because of HS?

A: Caring for your mental health and physical health are equally as important. The first step is to identify what you are feeling and why, and then you can take action. You may want to try writing your thoughts and feelings down in a journal or talking to friends, family, or your healthcare provider about how you are feeling. You could also search online or ask your healthcare provider for local HS groups where you can share your experiences with other people with HS. You could also seek a referral to a therapist to talk through how you are feeling, and they may be able to provide some coping techniques.[9]

Q: When there isn't enough support from healthcare providers, what information do I need to best manage my HS?

A: Identifying your triggers is a key way that you can regain some control over HS, see here for more information.[5] Keeping your skin clean and protected is also an important way that you can manage your HS, there are some tips on how to do this here.[10] If you feel you aren't getting enough support from your healthcare provider, try using the tips in Chapter 2 to help with getting the most out of your appointments. If you still feel dismissed by your healthcare provider, seek care from a provider who specialises in HS.

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HS glossary

Abscess – A swollen red lump filled with pus[1]

Acne inversa – Another name for hidradenitis suppurativa[2]

Anaemia – Low levels of red blood cells which can lead to fatigue and easily becoming out of breath[3]

Arthritis – A long-term inflammatory disease causing painful and stiff joints[4]

Biologic – A medicine, usually given by injection, which has been produced by a living organism, rather than being made by mixing chemicals in a lab.[5] Examples include live vaccines, blood transfusions, and particularly in HS, natural proteins that are changed so that they stop a specific reaction from happening in the immune system[5,6]

Cutaneous squamous cell carcinoma – An aggressive skin cancer that can spread to other parts of the body and be life-threatening. It is rare but most commonly affects white men, who are smokers, with long-term HS affecting the buttocks[7]

Flare – A period of time when HS symptoms appear or get worse[8]

Follicle – A tiny hole in the skin that a hair grows from[9]

Hidradenitis suppurativa – A long-term, non-contagious skin condition, caused by an overactive immune system targeting the hair follicles[10,11]

Hurley stage – The measurement of the severity of HS based on the amount and spread of the lumps. Stage I is mild disease, stage II is moderate, and stage III is severe[12]

IHS4 – The measurement of the severity of HS based on the number of nodules, abscesses and draining tunnels. A total score of ≤3 signifies mild, 4–10 signifies moderate and ≥11 signifies severe disease.[12]

Immune system – The body's defence system[13]

Inflammatory/Inflammation – Part of the immune system response to defend the body against infection. It involves swelling, redness, heat, pain, and can produce pus[14]

Inflammatory bowel disease (Crohn's disease and ulcerative colitis) – A long-term inflammatory disease causing severe tummy pain and diarrhoea or constipation[15]

Keratin – A naturally occurring protein that makes up hair, skin, and nails[16]

Lymphatic system – A network of channels and glands in the body that help fight infection and remove excess fluid[17]

Polycystic ovary syndrome – A condition affecting a woman's ovaries. Symptoms include irregular periods, weight gain, and a high level of male hormones resulting in excessive facial or body hair[18]

Psoriasis – A long-term inflammatory disease causing red, itchy, scaly patches of skin[19]

Pus – A thick, opaque, usually yellowish-white liquid produced from inflammation[20]

Resorcinol – A cream that helps to break down rough, scaly, or hard skin and disinfects the skin[21]

Retinoid – A class of medicine derived from vitamin A used to treat skin conditions[22]

Skin graft – A piece of healthy skin taken from an unaffected area of the body and used to cover a wound to help it heal[23]

Steroid – A type of medicine that reduces inflammation[2]

Trigger – A factor that causes or worsens a flare[24]

Tunnels – A hollow passage under the skin with at least one open end at the surface of the skin[25]

Verneuil's disease – Another name for hidradenitis suppurativa[26]

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Further information

Your healthcare provider is a great source of information, but you can also check out:

- European Hidradenitis Suppurativa Foundation
  https://ehsf.eu/patients/information-for-patients/
- [Local HS group to be added per country]