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

Supporting people with hidradenitis suppurativa to embrace life with confidence

An HS smart guide for healthcare professionals

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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.

Contents

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How to use this guide

This guide has been produced as part of **HIDRACENSUS 7.3**, a Europe-wide, UCB-sponsored initiative, led by a steering committee of HS experts.

HIDRACENSUS 7.3 aims to improve the standard of care for people living with hidradenitis suppurativa (HS) by educating everyone involved in HS and sharing best practice management.

This guide provides key practical information to successfully recognise, manage, and communicate with people living with HS.

This guide is part of a pair; there is one for you and one for your patient, and they should be used together to support and guide consultations. You can download the patient version via MedHub. Your patients should be able to access their version of the guide at home as a resource to digest and recap the information in their own time. The guides have twinned chapters so you can direct patients to the corresponding chapter in their guide (indicated throughout) for further information on a topic. Communication essentials are featured at the end of the chapters to provide best practice examples of communicating with patients.

Please feel free to share this guide with your colleagues from other specialities to optimise disease management throughout the HS journey; Chapter 4 explores more about the importance of multidisciplinary care in managing HS.

Twinned chapters

This guide		Chapter in the patient guide
Chapter 1	**What is hidradenitis suppurativa (HS)?**	What is hidradenitis suppurativa (HS)?
Chapter 2	**Lifting the burden of HS**	Sharing your experiences
Chapter 3	**Managing HS**	Living well with HS
Chapter 4	**Collaborating with your colleagues**	People involved in your care
Chapter 5	**Resources for healthcare professionals**	Talking to your healthcare provider
Chapter 6	**Appendix**	Appendix

Note that Chapters 2 and 5 in the two guides cover different information.

The information provided in this guide is correct as of May 2024. This guide will be reviewed and updated as understanding and management of HS advances.

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Chapter 1

What is hidradenitis suppurativa (HS)?

This chapter provides you with an overview of HS. However, when explaining HS to patients, please refer to Chapter 1: What is HS? in the patient guide.

Definition of hidradenitis suppurativa

HS is a chronic, inflammatory, recurrent, debilitating skin disease of the hair follicle that usually presents after puberty with painful deep-seated, inflamed lesions in the intertriginous, apocrine gland-bearing areas of the body, most commonly, the axillae, inguinal, anogenital, and inframammary regions.[1,2] HS is also called acne inversa or Verneuil's disease.[3]

Presentation

HS is characterised by recurrent inflammation occurring more than twice in 6 months in intertriginous areas possessing apocrine glands. HS presents with painful nodules, tunnels, and abscesses, often accompanied by chronic drainage, and scarring.[1,2]

Chronicity is the hallmark of HS[4]

The Hurley staging system is used to assess the severity of HS:[5]

Stage I

single or multiple abscesses without tunnels or scarring

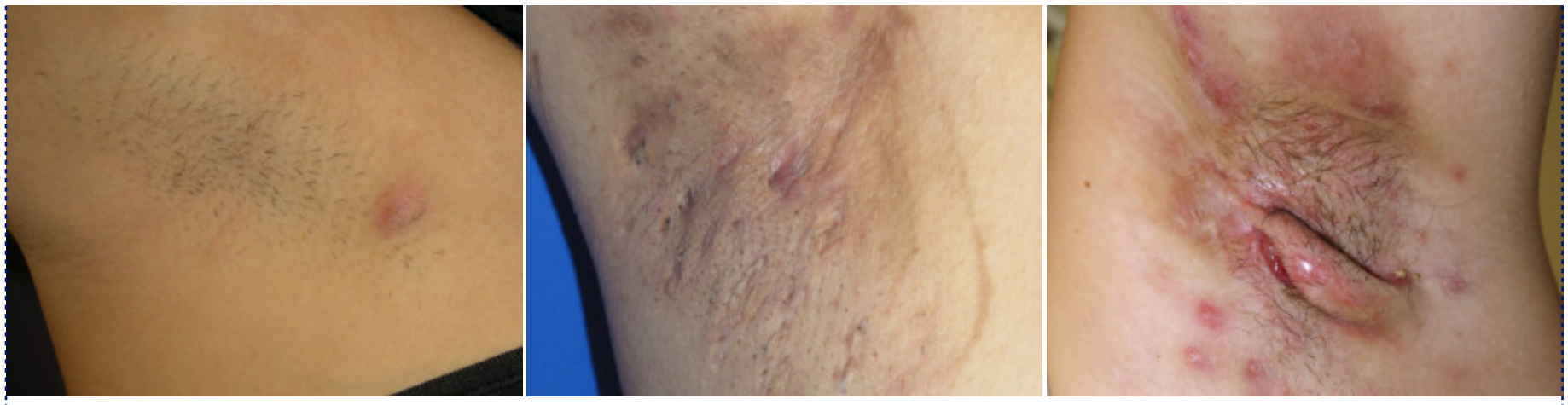
Stage II

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

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

General practitioners should promptly refer patients to a dermatologist when patients present with severe disease (Hurley stage III), or when mild to moderate disease has not responded to first-line treatment.[6] A referral template is available via MedHub

Phenotypes

At least four phenotype classifications have been proposed for HS. Here we focus on the most recent recognised classification by Martorell A, et al., published in 2015. This classification is founded on the type of primary lesions present and relates phenotype to prognostic outcomes, thus having applications to clinical practice.[7] For more information on the other phenotype classifications see here.

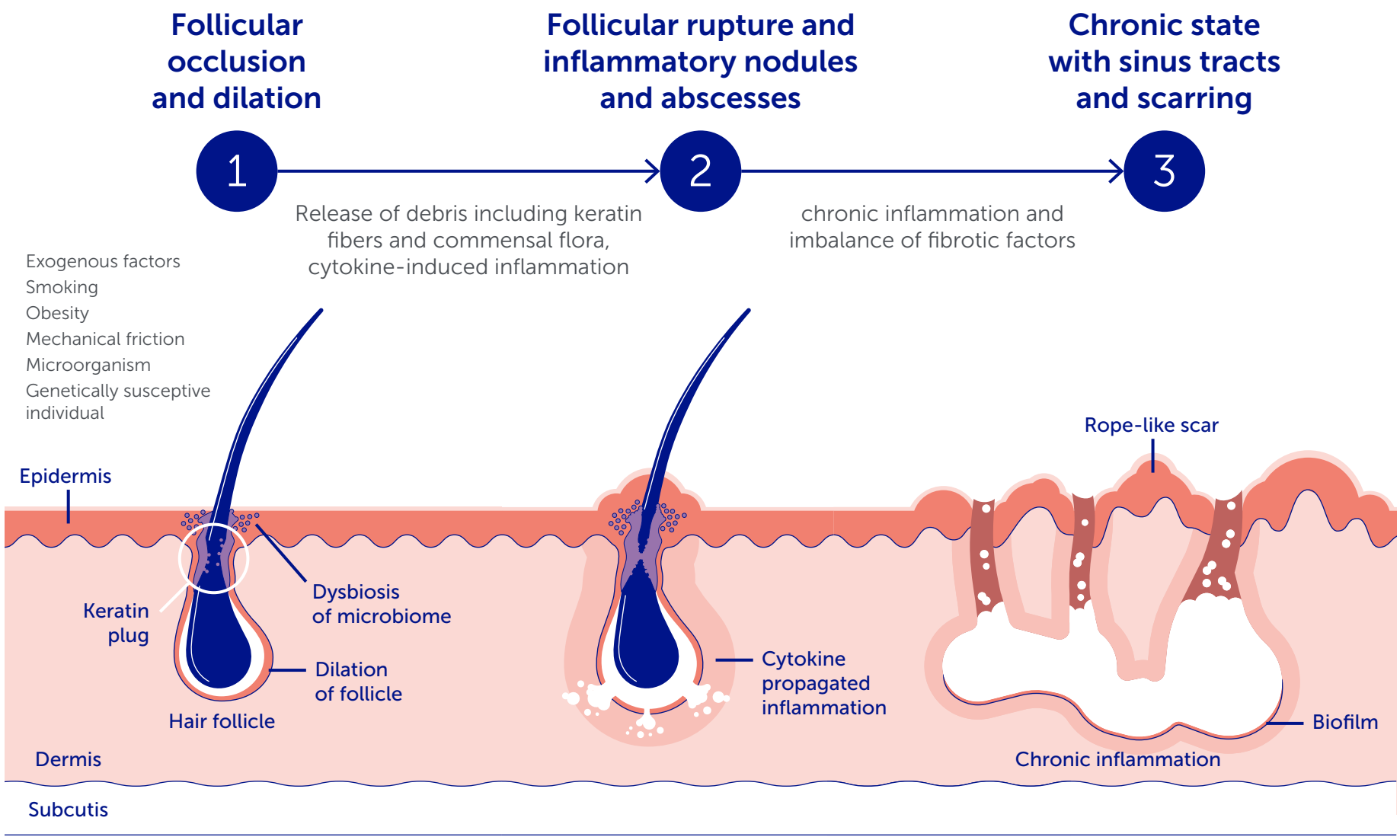
Martorell A, et al. Phenotype Classification[7]

Phenotype	Follicular	Inflammatory
Prevalence	~70% of patients	~30% of patients
Presentation	• Follicular lesions on a background of comedones and nodules with occasional abscesses • Non-coalescent • Tunnel formation is uncommon	• Predominately abscesses with occasional nodules in the absence of comedones • Severe disease with frequent flares, tunnels*, and scarring
Differentiation of lesion location†	Thighs	Groins, buttocks, and face
Key patient-reported symptoms	Pruritus	Pain and odour
Populations most at risk	• Females • Earlier age of onset • Family history of HS • History of mild acne (popular and nodular)	• Males • Later age of onset • History of acne conglobata and fulminans
Risk of disease progression	Not progressive	Progressive

*Advancing knowledge has identified four key endotypes of HS tunnels which may inform further about HS phenotypes and individualised treatment in future.[8]
†Lesions present on the armpits and breasts with similar frequency between phenotypes.

HS pathogenesis

HS is a multifactorial, polygenic, autoinflammatory disease. The exact underlying cause of HS remains to be elucidated, but many genetic and environmental factors, such as mutations in genes involved in the γ-secretase complex and keratinisation pathway, and nicotine, mechanical stress, hormones, and skin microbiome alterations, have all been implicated.[9]



HS is initiated by hyperkeratinisation and follicular occlusion, followed by follicle rupture and a subsequent inflammatory cascade with cytokine-driven positive feedback propagating and sustaining chronic inflammation, resulting in the formation of inflammatory nodules, abscesses, and eventually tunnels and scar tissue.[10]

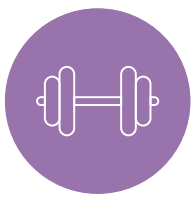
Image adapted from Goldburg SR, et al. J Am Acad Dermatol. 2020[10]

Triggering factors

HS has a relapsing and remitting course.[11] Some patients may have recognised triggers for their flares, while others may have no obvious cause. You may like to recommend a symptom tracker for your patients to help identify potential triggers.

Common triggering factors for HS include:[12]

Shaving



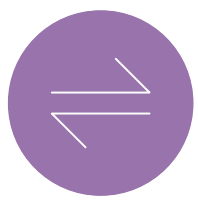
Exercise/sweating

Diet (e.g. dairy and brewer's yeast)

Stress

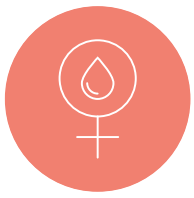
Pregnancy

Smoking



Friction from tight clothing or skin

Obesity



Menstrual cycle

For more information on lifestyle modifications to avoid triggering factors, see Chapter 3.

Populations affected by HS

The prevalence of HS in Europe is estimated to be at least 1%, suggesting it is a common condition.[13]

HS can occur at any age but generally presents after puberty and prevalence gradually decreases after menopause; however, cases of developing HS pre-puberty and post-menopause have been reported.[2,13,14] There is a clear female predominance in Europe, with approximately three times as many females affected by HS than men.[13] Other factors associated with HS are: smoking, obesity, metabolic syndrome, a family history of HS, and other inflammatory diseases;[10,13,15] however, many patients with HS may not have any of these factors.[10,16]

Diagnosis

HS is a chronic and progressive disease with varying evolution between patients. By identifying patients with HS early, you can initiate treatment and optimise patient outcomes.[1,17]

7.3 years is too long to be without a diagnosis[18]

7.3 yrs

The average **time** from **symptom onset to diagnosis**[18,19]

≥12 yrs

The delay in diagnosis due to misdiagnosis[2]

5

The average number of **HCPs visited before diagnosis**[2]

Diagnosis of HS is made by clinical observation and symptom history – a biopsy is rarely needed.[4]

Examine all areas in which HS can occur with the naked eye; it is not enough to just ask the patient about their skin lesions.[1] Keep in mind that the patient may have lesions in sensitive areas that you may need to proactively ask about.

See the **resources** section for more information on diagnosing HS.

Use the three key questions to identify patients with HS. If your patient answers yes to all three questions, **suspect HS!**[1,20]

1. Have you had more than two boils?
2. In the past 6 months?
3. In one of the following locations: armpits, groin, genitals, under the breasts or other locations, e.g. perianal, neck, and abdomen?

Differentiating HS

HS is commonly misdiagnosed, causing patient distress, lack of trust in the healthcare system, and an increased likelihood of disease progression.[21] This does not need to be the case. With knowledge of how and when the disease presents, HS can be differentiated relatively easily from other skin conditions to get patients on the right track to treatment.[2]

HS can be differentiated from other diseases by:

Appearance and chronicity of the lesions[1,2,4]

Recurrent flares of painful or purulent lesions (more than twice in 6 months)

Nodules, papules, abscesses, tunnels, scars, or open comedones

Location of the lesions in intertriginous areas possessing apocrine glands[1,2]

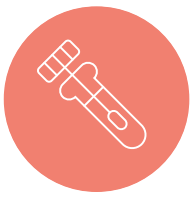
Armpits, groin, perineum, buttocks, perianal region, breasts

Age of onset[1,2,4,6,14]

Generally occurs at or soon after puberty and prevalence often reduces after menopause

(Note: isolated cases of HS have been reported before puberty and after menopause)

A family history of the disease[1,2]



Negative bacterial swabs[1]

A rare, but life-threatening complication of HS is cutaneous squamous cell carcinoma (cSCC). This aggressive skin cancer mainly affects men who smoke and have long-term, severe HS affecting the gluteal and perianal area. Rapid identification and treatment of cSCC is critical for positive patient outcomes.[22]

HS summary grid for communication with patients[10,17,23–26]

HS is...

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

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

Potentially disruptive to daily life

See Chapter 2 for the far-reaching effects of HS on patients' quality of life, and refer your patient to Chapter 2 in their guide for tips on how to communicate effectively about HS with those around them, to raise understanding of the disease and gain a support network

Manageable with appropriate treatment or surgery and multiple specialists working together

See Chapter 4 for more information on the importance of collaborating with your multidisciplinary team, and refer your patient to Chapters 3 and 4 in their guide for more information on the management of HS and the specialists involved

HS is NOT...

Contagious

A sexually transmitted infection

Acne

A cyst

An ingrown hair

Caused by an infection

A simple boil

Caused by poor personal hygiene

Curable

The patient's fault

References

1. Zouboulis CC, et al. Dermatology. 2015;231:184–90.
2. Anduquia-Garay F, et al. Ann Med Surg (Lond). 2021;68:102679.
3. Martora F, et al. Medicina (Kaunas). 2023;59:801.
4. Napolitano M, et al. Clin Cosmet Investig Dermatol. 2017;10:105–15.
5. Zouboulis CC, et al. J Eur Acad Dermatol Venereol. 2015;29:619–44.
6. Ingram JR, et al. Br J Dermatol. 2019;180:1009–17.
7. Martorell A, et al. J Eur Acad Dermatol Venereol. 2020;34:1309–18.
8. Martorell A, et al. Dermatol Surg. 2019;45:1237–44.
9. Zouboulis CC, et al. Exp Dermatol. 2020;29:1154–70.
10. Goldburg SR, et al. J Am Acad Dermatol. 2020;82:1045–58.
11. Jiang SW, et al. JID Innov. 2021;1:100001.
12. Collier E, et al. Int J Womens Dermatol. 2020;6:85–8.
13. Ingram JR. Br J Dermatol. 2020;183:990–8.
14. Cucu CI, et al. Acta Endocrinol (Buchar). 2021;17:274–7.
15. Diaz MJ, et al. Curr Issues Mol Biol. 2023;45:4400–15.
16. Rosi E, et al. Biomedicines. 2021;9:1168.
17. Sayed CJ, et al. Obstet Gynecol. 2021;137:731–46.
18. Barmatz S, et al. Dermatology. 2022;238:772–84.
19. Nguyen TV, et al. J Eur Acad Dermatol Venereol. 2021;35:50–61.
20. Esmann S, et al. Br J Dermatol. 2010;163:102–6.
21. Howells L, et al. Br J Dermatol. 2021;185:921–34.
22. Racanelli E, et al. Cancers (Basel). 2021;13:1153.
23. National Institute of Arthritis and Musculoskeletal and Skin Diseases. Hidradenitis suppurativa (HS). https://www.niams.nih.gov/health-topics/hidradenitis-suppurativa-hs. Accessed May 2024.
24. Hidradenitis Suppurativa Foundation. HS causes. https://www.hs-foundation.org/hs-causes. Accessed May 2024.
25. HSDisease.com. Common misdiagnoses of hidradenitis suppurativa. https://hsdisease.com/misdiagnosis. Accessed May 2024.
26. HSDisease.com. How is hidradenitis suppurativa treated? https://hsdisease.com/treatment. Accessed May 2024.

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Chapter 2

Lifting the burden of HS

This chapter discusses the far-reaching and debilitating effects that HS can have on patients' lives. Your role in establishing the full burden of HS for each patient, and providing holistic management based on individual treatment priorities, is key to improving overall quality of life.

The impact of HS

HS is a debilitating and relentless disease, profoundly affecting all aspects of a person's life and the lives of those around them.[1] The majority of patients with HS report a very much or extremely impaired quality of life.[2]

Patients live daily with unbearable pain, disfigurement and dressing of their wounds to prevent leaking malodourous pus.[1,3] The skin symptoms, fatigue, and high comorbidity burden coupled with the isolating and stigmatising nature of the disease dramatically affect patients' quality of life.[1,4,5] HS negatively affects patients' personal and work life to a greater extent than psoriasis, atopic dermatitis, alopecia, acne, vitiligo, urticaria, and rosacea.[2]

HS is ranked in the top five skin diseases with the most negative impact on patients' quality of life.[6]

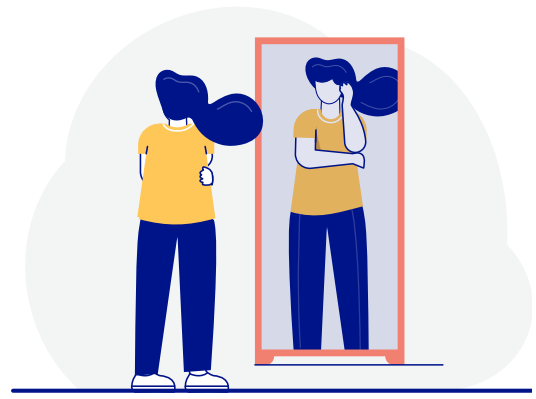
Depression and anxiety are common in HS and patients have a significantly increased risk of completed suicide compared with the general population; this significant risk is not present in patients with psoriasis, acne, or atopic dermatitis.[7]

Formally assess all patients with HS for anxiety and depression and offer referral to psychological support at the earliest opportunity, if appropriate[7]

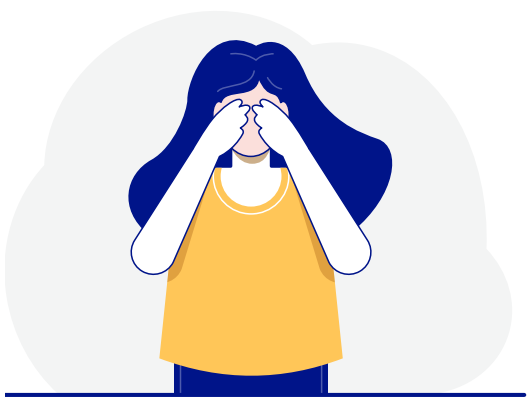
The impact of HS on a patient's life

Isolation

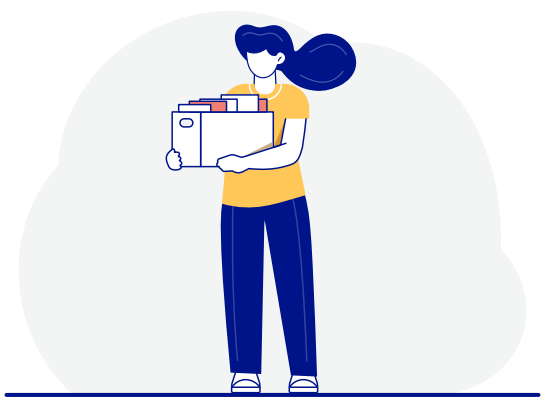
Stigma



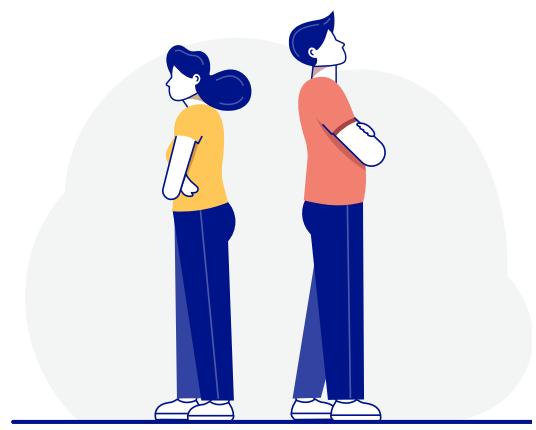
Self-conscious



Embarrassment



Unemployment



Lack of intimacy

Burdensome

Sleep disturbance

Pain

Patient quotes[1]

I have a party tonight. I bought a new dress and have waited so long for this event. But two ugly abscesses have appeared under my chest and armpit, and I can't lift my arm or wear the dress. This disease won again, one–nil HS. I don't want to go. All I want to do is stay home in bed and cry.

I am not going to marry anyone, and, in any case, I am not going to have children.

I just didn't want anyone to see me, so I just isolated myself rather than having to explain it I guess.

What happens is the pain increases and then you get to the point where it's the most unbearable thing you could imagine.

I feel no hope with HS. It isolates me from everything. I deal only with it all the time, and I am so tired.

I'm to the point right now where my marriage is falling apart… My husband has just had enough.

Pain

Pain is often the greatest factor negatively affecting patients' lives; it can be debilitating, unbearable, relentless, and extreme.[1,3]

Pain can occur at all stages of disease, and acute pain, often associated with flares, and chronic pain can occur simultaneously.[3,8]

> Patients describe HS pain as: hot, burning, stinging, shooting, stabbing, pressure, stretching, cutting, sharp, taut, splitting, gnawing, pressing, sore, throbbing, and aching.[3,5,8]

The chronic pain and inflammation associated with HS results in approximately 40% of patients experiencing clinically significant fatigue (<30 points on the Functional Assessment of Chronic Illness Therapy – Fatigue [FACIT-F] questionnaire), which greatly affects their quality of life and ability to carry out daily activities. The level of fatigue in HS has been reported as relatively high, making HS a leader among severe dermatoses.[9]

To alleviate the pain your patient is experiencing, you first need to understand the severity, type, and duration of pain; this should be assessed at regular intervals throughout the HS journey using a numeric rating scale or visual analogue scale and by asking the patient to describe their pain.[8]

You could also recommend that your patient tracks their pain in a symptom diary and reserve time to talk through the notes during appointments.

Management options depend on the type of pain (acute or chronic) and include analgesics, referral to a pain specialist, or collaborating with the multidisciplinary team to provide physical therapy, wound care, and behavioural health techniques.[8] For more information on pain management, see Chapter 3.

Getting beneath the surface of HS may take time and requires a trusting HCP–patient relationship.[10] Ascertaining the extent of the impact of HS and establishing priorities for treatment allows holistic care of HS to improve overall quality of life.[11]

> The patient you see in the clinic is only a snapshot of their life. They may not immediately disclose all the ways that HS affects them, especially if HS affects intimate parts of their body or their life. It is important to remember the person behind the disease.[12]

Communication essentials

For general tips on communicating with patients, please see Patient communication – top tips.

Reframing HS

As mentioned above, HS negatively affects all aspects of patients' lives.[1] The way that you communicate about HS is of utmost importance to instil hope and empowerment in patients.[1,13] HS can be managed with appropriate treatment or surgery and does not have to feel like a prison sentence for patients.[5]

Avoid catastrophising the disease, using phrases such as 'I'm sorry you have HS', or vivid descriptions of the disease such as 'disfiguring', 'oozing', and 'debilitating'. Avoid telling patients 'don't look HS up online' as this only stirs fear and curiosity; you should strive to equip patients with sufficient knowledge about the disease so that they feel empowered rather than fearful.[13] 'Incurable' can be used but should immediately be followed up by stating that there are effective treatments available to manage symptoms,[5] and research is ongoing to find more treatments that target the source of the disease.[14]

Consultation questions to ascertain the burden of HS[11]

Every patient will experience and perceive HS differently. It is important to establish the full extent of the burden that each patient is feeling, as they may not proactively volunteer this information.

Listed below are example questions that you may wish to ask patients to ascertain the extent of their disease burden:

- Would you be willing to share your experience of receiving your HS diagnosis?
- How does HS affect you?
- Does HS stop you from doing anything?

By answering these questions, it is likely that your patients will be sharing personal and sensitive information with you; to build trust in the HCP–patient relationship, it is good practice to validate their emotions and show empathy for their experiences – the following phrases could be used to do this:

- I'm hearing how hard this has been for you
- I can see how big an impact HS is having on your life
- I want to acknowledge the strength you have shown living with this

Once the extent of the HS burden has been established, you can then align and prioritise treatment goals to ensure the chosen management option suits the patient's individual needs. See Chapter 3 for tips on shared decision-making.

References

1. Howells L, et al. Br J Dermatol. 2021;185:921–34.
2. Gisondi P, et al. J Eur Acad Dermatol Venereol. 2023;37(Suppl 7):6–14.
3. Huang CM, Kirchhof MG. J Cutan Med Surg. 2021;25:591–7.
4. Goldburg SR, et al. J Am Acad Dermatol. 2020;82:1045–58.
5. Zouboulis CC, et al. J Eur Acad Dermatol Venereol. 2015;29:619–44.
6. Tzellos T, Zouboulis CC. Exp Dermatol. 2022;31(Suppl 1):29–32.
7. Thorlacius L, et al. J Invest Dermatol. 2018;138:52–7.
8. Savage KT, et al. J Am Acad Dermatol. 2021;85:187–99.
9. Matusiak L, et al. Acta Derm Venereol. 2010;90:264–8.
10. Green M, et al. BMJ. 2012;344:e357.
11. Shih T, et al. Int J Womens Dermatol. 2022;8:e063.
12. HS Foundation. Talking about HS. https://www.hs-foundation.org/talking-about-hs. Accessed May 2024.
13. Aslani P. Int J Pharm Pract. 2013;21:347–8.
14. Mansilla-Polo M, et al. Actas Dermosifiliogr. 2023;114:T772–83.

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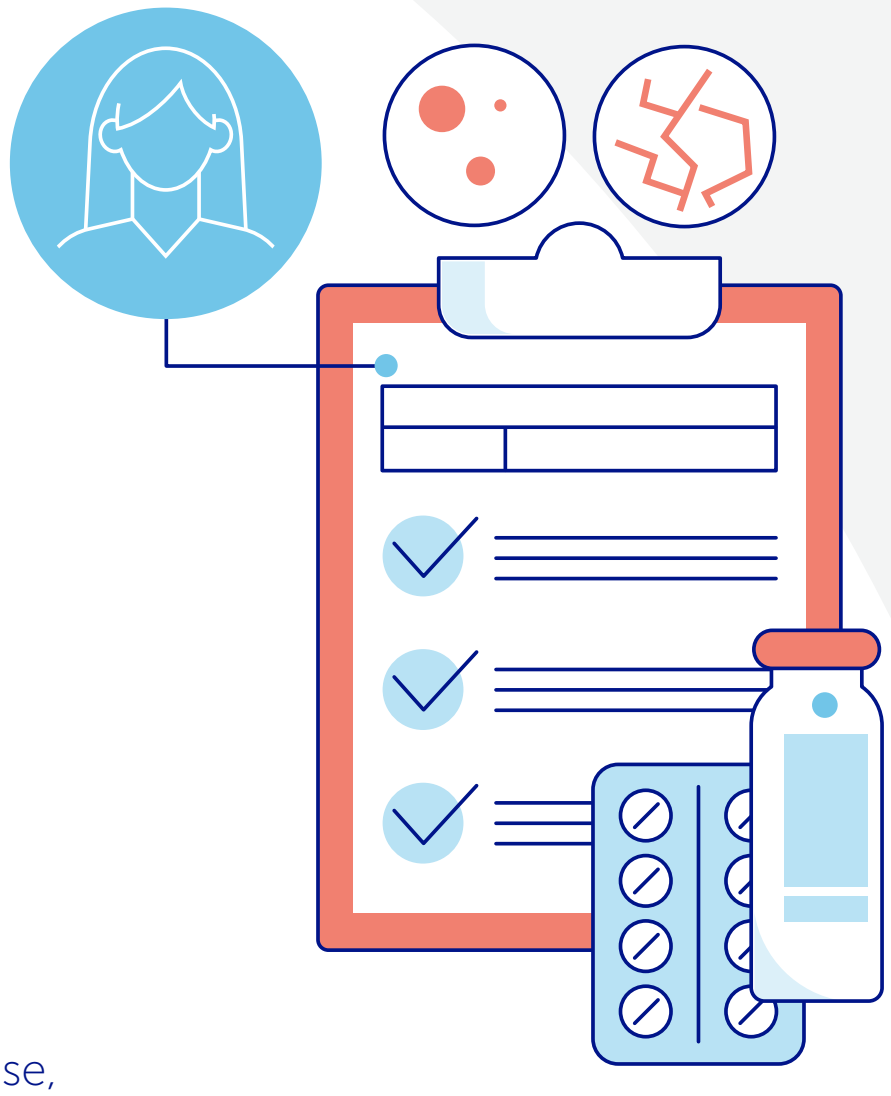
Chapter 3

Managing HS

This chapter provides an overview of the management options available for HS. When communicating HS management options to patients, please refer to Chapter 3: Living well with HS in the patient guide.



Management options

HS is an incurable, chronic inflammatory disease, but symptoms can be managed with pharmaceutical treatments and surgery.[1] Some patients may also benefit from lifestyle changes to ease their symptoms and reduce the risk of comorbidities such as metabolic syndrome and cardiovascular disease.[1,2] The treatment of HS should be individualised and based on the subjective impact and objective severity (Hurley stage) of the disease.[1]

HS is a progressive disease. It is important to initiate timely appropriate treatment to optimise patient outcomes[3]

Pharmaceutical options for the treatment of HS

Pharmaceutical options are the mainstay of HS management and are prescribed according to Hurley stage.[1] Below, you will find the latest recommendations from the current European guidelines for the management of HS, which were published in 2015. With recent advances in disease knowledge and the development of new treatment approaches, the European guidelines for the management of HS are under revision. The treatment options herein will be updated upon the imminent release of the revised guidelines.

> Many of the treatment options recommended in the European guidelines are not indicated in HS and have limited evidence supporting their use, reflecting the sparsity of knowledge of HS when published in 2015.

Please note that the following treatment options may not be available in your country; consult your local Prescribing Information for more details.

[Treatment options listed below to be localised per country]

[Call-out below for German use only]

Hot off the press! The S2k guideline for the treatment of hidradenitis suppurativa/acne inversa (ICD-10 code: L73.2) was published in February 2024.

Read the latest German-specific guidelines **for the treatment of HS.**

Topical treatment

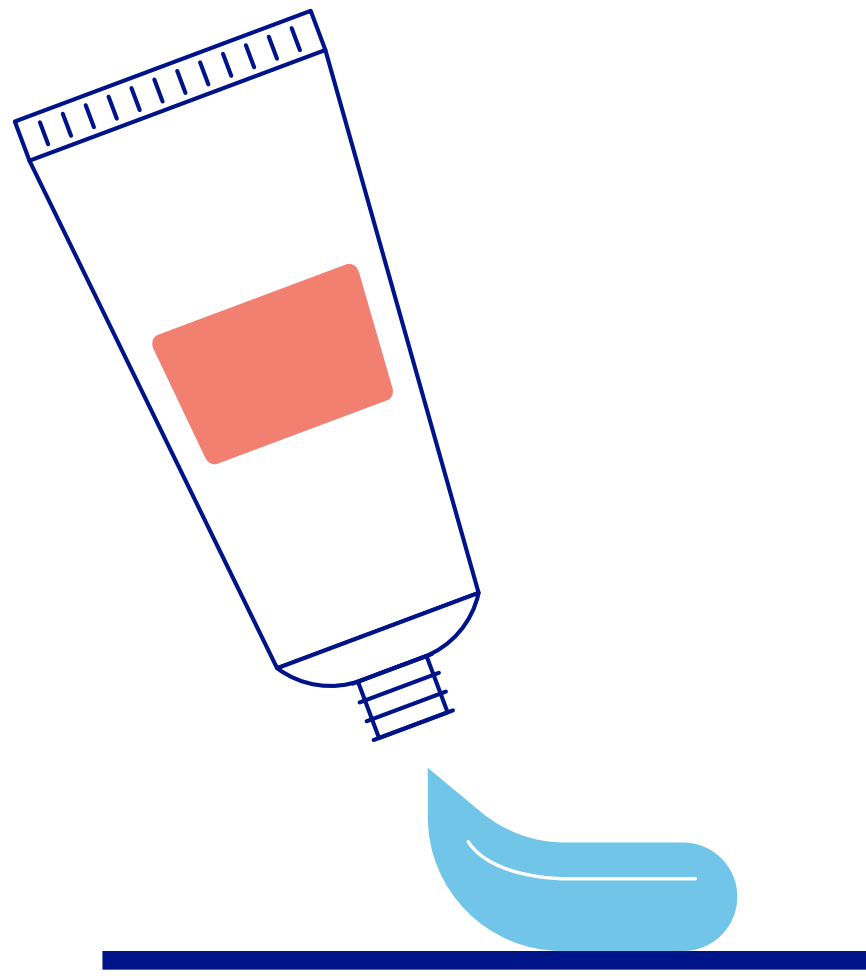
Keratolytics[1]

Agents with keratolytic properties promote separation and shedding of the hyperkeratinised epithelium, unblocking occluded follicles, and preventing future occlusion.[4] The current European guidelines recommend resorcinol for patients with Hurley stage I or II HS, based on a case review of 12 women. In addition to exerting a keratolytic effect, resorcinol also has antipruritic and antiseptic properties. Safety concerns include onset of contact dermatitis.

Antibiotics

The role of bacteria in the pathogenesis of HS is controversial. A wide range of bacteria have been isolated from HS lesions indicating a potential inflammatory trigger,[5] but no antibiotics have been approved for use in HS to date. However, expert opinion supports the use of antibiotics in mild to moderate HS as first-line treatment.[1]

Off-label clindamycin is the only topical antibiotic agent recommended for use in Hurley stage I and mild stage II HS, based on the results of a randomised controlled trial of 27 patients.[1] Clindamycin exerts antibacterial and anti-inflammatory effects.[1,6] Safety concerns include stinging, skin irritation, and microbial resistance.[1]



Systemic treatment

Systemic treatment is indicated for more severe or widespread lesions.[1]

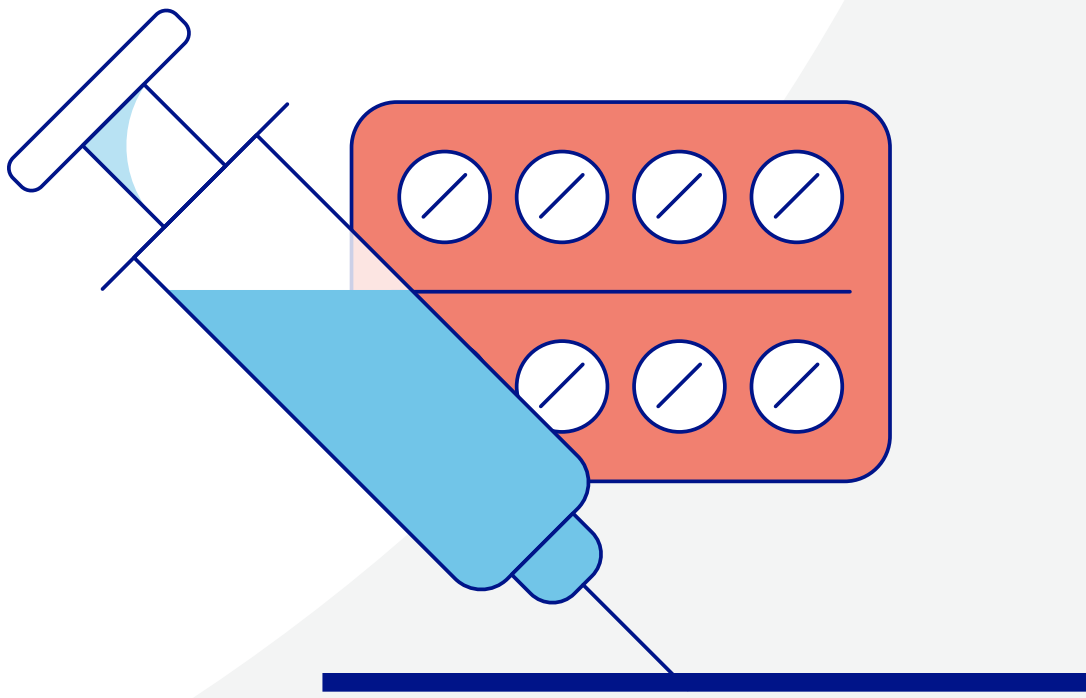
Antibiotics

- Off-label oral tetracycline is recommended for widespread Hurley stage I or mild stage II disease based on one small randomised controlled trial.[1] It is thought to exert antibacterial and anti-inflammatory effects.[1,6] Safety concerns include teratogenicity, microbial resistance, and concomitant use of oral contraceptives[1]

- Off-label clindamycin–rifampicin is recommended for any Hurley stage active inflammatory HS, based on three open case series involving 114 patients. Safety concerns include gastrointestinal adverse effects[1]

- Off-label rifampicin–moxifloxacin–metronidazole (either alone or preceded by systemic ceftriaxone) is recommended for treatment-resistant Hurley stage II and III disease, based on a retrospective study of 28 patients. Safety concerns include gastrointestinal disturbances and vulvovaginal candidiasis[1]

- Dapsone is recommended for Hurley stage I and II HS as a second- or third-line treatment.[1] It exerts antibacterial and anti-inflammatory effects.[1,6] Safety concerns include haemolysis, haemolytic anaemia, methaemoglobinaemia, hypersensitivity syndrome, agranulocytosis, and peripheral neuropathy[1]



Retinoids

Acitretin is the only retinoid recommended and indicated across all Hurley stages of HS. Acitretin exerts anti-inflammatory, keratinolytic, and antiproliferative properties. Safety concerns include dermatitis and teratogenicity.[1,6]

Flare management

Intralesional corticosteroids are recommended for the rapid reduction in inflammation associated with acute flares and for the management of recalcitrant nodules and tunnels. Safety concerns include atrophy, pigmentary change, and telangiectasia. Oral corticosteroids are also recommended for the management of acute flares; however, these must be used short-term and rapidly tapered to avoid rebound disease flare on withdrawal.[1]

Hormonal treatments

Antiandrogens are recommended to manage HS symptoms in females with menstrual abnormalities, flares around menstruation, signs of hyperandrogenism, or upper normal or high serum levels of dehydroepiandrosterone, androstenedione and/or sexual hormone-binding protein. Safety concerns include mild headache, breast pain, nausea, dysmenorrhoea, neurosity, weight gain, sinusitis, influenza-like symptoms, and abdominal pain.[1]

Biologics

There are currently three biologics approved for the treatment of active moderate-to-severe HS with an inadequate response to conventional systemic HS therapy. Adalimumab, a tumour necrosis factor (TNF) inhibitor, is approved in patients aged 12 years and older; secukinumab, an interleukin (IL)-17A inhibitor and bimekizumab▼, an IL-17A and IL-17F inhibitor, are approved in adult patients.[7–9] These biologics demonstrated a significant reduction in the number of abscesses and inflammatory lesions, compared with placebo, in Phase 3, multicentre, randomised controlled trials.[9–11] The current European guidelines also recommend off-licence use of TNF inhibitor infliximab for moderate-to-severe disease. Safety concerns of these biologics include injection-site reaction and infection.[1,9]

Future treatments

Recent research has provided insights into the pivotal role of cytokines in the pathogenesis of HS, but the sequence of release and the key initiators of the inflammatory cascade are yet to be elucidated.[3] Nevertheless, the inhibition of TNF, IL-17A and IL-17F has been validated in clinical trials as relevant and led to the approval of adalimumab, secukinumab and bimekizumab for the treatment of HS.[5,7–11] An arsenal of biologics targeting various cytokines is currently under investigation for the treatment of HS, and promising results have been demonstrated – **the therapeutic future of HS is encouraging.[12]**

▼ This medicinal product is subject to additional monitoring. Healthcare professionals are asked to report any suspected adverse reactions.

Surgical options

Surgery plays a common and accepted role in the management of HS because pharmaceutical treatments rarely result in a lasting cure; however, recurrence is common (~33%) even with the most radical surgery. There are several types of surgery, which are listed below; the appropriate type of surgery is selected based on the body region affected and severity of disease.[1]

Incision and drainage

An incision is made into localised lesions to drain pus; this provides pain relief but is of limited value for clearing lesions and recurrence rate is high[13]

Deroofing

Removal of the roof of a tunnel and raking of the tunnel floor to remove all tunnel contents, leaving healthy skin behind; this option is appropriate for recurrent, draining tunnels at fixed locations in Hurley stage I or II areas[1]

Excision

Removal of isolated areas of active disease[1]

- Partial excision removes individual lesions, and the wound heals without intervention; patients with Hurley stage I–II are likely to benefit from this procedure[1]
- Radical excision may be appropriate for more severe cases and involves removing an entire affected skin area and the underlying tissue and can require reconstruction to aid healing[1]

Lasers

- Scanner-assisted CO_2 laser: focal radical vaporisation of all nodules, abscesses, and fistulas from the inside out until surrounding healthy tissues is reached[1]
- Neodymium-doped yttrium aluminium garnet laser (Nd:YAG): targets and reduces the number of hair follicles and sebaceous glands[13]

Complications of surgery include post-operative bleeding, long healing times, infection, and scarring.[1]

Adjuvant therapy

Despite a lack of evidence, it is well established that holistic care is an essential factor to improve patients' quality of life.[1,14,15]

Pain management

Pain is the most burdensome symptom of HS, and accounts for a greater impairment in HS-related quality of life than disease severity.[14] Addressing HS pain is critical to improve quality of life and reduce morbidity from opioid and other substance use. However, current HS therapies often provide inadequate pain relief, and studies of HS pain-directed therapies are sparse.[15]

A pain management algorithm for HS has been proposed, based on the chronicity and type of pain (nociceptive or neuropathic), with multidisciplinary involvement to manage the associated psychological distress.[15]

For chronic pain

(nociceptive or neuropathic, e.g. widespread burning, itching, pricking, shock-like, shooting, or tingling)[15]

In order of increasing refractoriness:

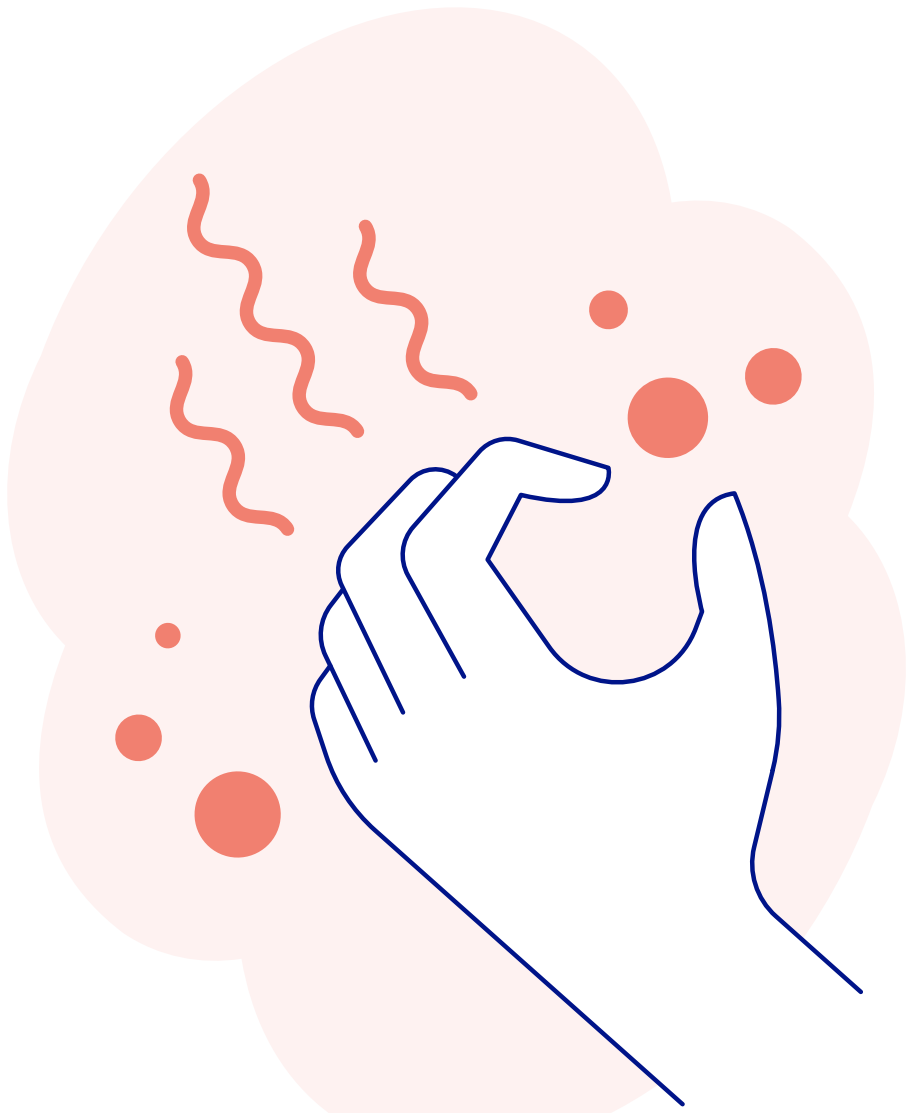
1. HS disease-directed therapy **PLUS** screening for pain severity and psychological comorbidities
2. Referral to physical therapy, wound care, and behavioural health specialists
3. Pharmaceutical analgesia based on the type of pain
    a. Nociceptive pain: NSAID (**PLUS** paracetamol), **THEN** a serotonin–norepinephrine reuptake inhibitor (e.g. duloxetine) or a tricyclic antidepressant (e.g. nortriptyline), **OR**
    b. Neuropathic pain: anticonvulsants (e.g. gabapentin, pregabalin), **OR** a serotonin-norepinephrine reuptake inhibitor (e.g. duloxetine, venlafaxine), **OR** a tricyclic antidepressant (e.g. nortriptyline), **PLUS**
    c. Adjunctive topical NSAIDs and topical lidocaine
4. Refer to a pain specialist if: failed ≥2 pharmacological agents, have medically refractory HS with debilitating pain, or ongoing chronic opioid use

For acute pain

(largely nociceptive, e.g. aching, gnawing, pressure-like, stabbing, squeezing, or throbbing at lesions)[15]

In order of increasing severity/ refractoriness:

1. Cold compress[16] **PLUS** paracetamol **PLUS** topical NSAID, **PLUS**
2. Oral NSAIDs **PLUS** intralesional corticosteroid **PLUS** incision and drainage, **PLUS**
3. Refer to a pain specialist before initiating a first-line opioid (e.g. tramadol) **OR** other short acting, second-line opioid for breakthrough pain



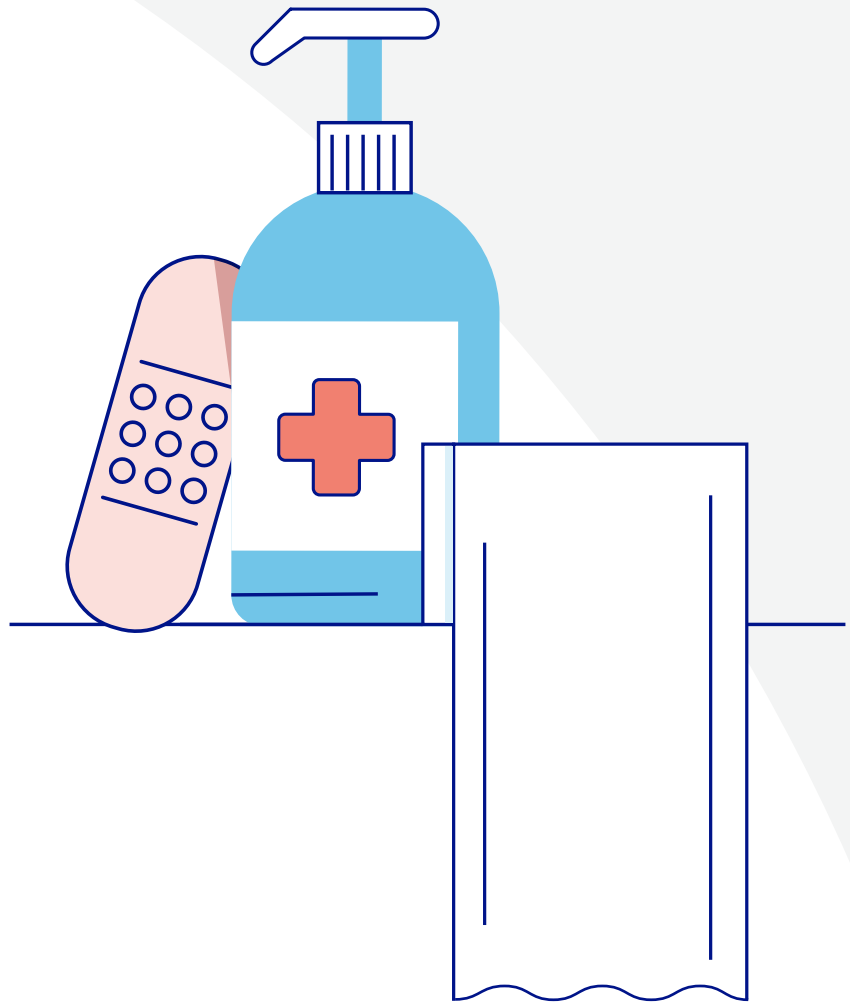
Managing itch

Pruritus is another symptom commonly experienced by patients with HS and contributes to disability and poor health-related quality of life.[14] Similar to pain, the disease mechanisms that lead to pruritus in HS are complex and may involve both inflammatory and neuropathic components.

Due to a lack of data, recommendations for the management of pruritus are based on professional experience and evidence from other pruritic diseases.[14]

Proposed treatment algorithm for pruritus, in order of increasing severity and refractoriness:[14]

1. Topical therapies (e.g. lidocaine)
2. Systemic therapies (e.g. anticonvulsants, antidepressants)
3. Invasive or experimental therapies (e.g. psychological interventions, surgery)



Wound care

Wound management inflicts a lifelong burden on patients, negatively impacting their quality of life and contributing to out-of-pocket expenses.[17]

Patients face a daily battle to keep their wounds clean and to contain the malodourous discharge using dressings that are not designed for intertriginous body areas. Inappropriate adhesives also cause pain with each dressing change.[17]

> Most patients with Hurley stage I and II disease change their dressings 1–3 times per day, and those with severe disease have reported changing their dressings more than five times a day, amounting to almost 1 day per month managing wounds. To put this into perspective, people with pressure ulcers change their dressings approximately three times per week.[17]

Patients may be confused on how to care for their wounds. Although there are no recommendations for a gold-standard dressing in HS, you can provide advice on what to look for when choosing a dressing and provide best practice tips on how to change dressings. If applicable to your clinic, referral to a wound care nurse would also be beneficial.

Direct your patient to the wound care infographic in Chapter 3 of their guide for more information on how to keep their skin clean and protected and to find out the ideal characteristics of HS dressings.

Do lifestyle modifications play a role in HS?

A change in lifestyle may help some patients relieve their symptoms; however, it is often a sensitive topic to raise and cannot replace effective pharmaceutical and surgical treatments.

Ask your patient if they have identified any triggers for their flares, such as shaving, exercise/sweating, tight clothing, stress, or their menstrual cycle, and suggest appropriate lifestyle modifications to help counter these (see the next page and refer your patient to Chapter 3 in their handbook). If your patient is not aware of any triggers, recommend using a symptom tracker to record situations and flares that can be retrospectively analysed.[18]

Smoking and obesity can exacerbate HS and further add to the risk of cardiovascular events due to chronic inflammation.[18,19] Smoking cessation and weight loss via dietary modifications and a suitable level of exercise are therefore beneficial lifestyle changes, but they may not be achievable by all. Lifestyle advice regarding smoking and weight may be withheld until a trusting relationship has been established to avoid 'blaming' the patient.[18]

The concept of losing weight and stopping smoking may be difficult to comprehend for some patients who already face a great burden due to their disease. The dedication and upheaval required to make these lifestyle changes may also not be worth the uncertain and potentially minor benefits to HS symptoms; however, these changes are beneficial to reduce the risk of cardiovascular events.[2] Assess whether posing the concept of lifestyle modifications may be beneficial for each patient and withhold such information if necessary.

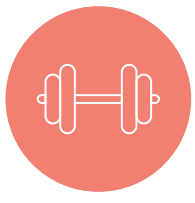
Common triggers for HS flares and suggested lifestyle modifications[18]

Shaving

- Advise against shaving in areas of active lesions
- Assess if laser hair removal is an option

Smoking

Provide resources and referral to smoking cessation programmes



Exercise/sweating

- Recommend low-intensity, low-impact exercise, e.g. yoga or pilates
- Recommend loose-fitting, moisture-wicking clothing, and applying a barrier cream or sweat-absorbing powder prior to exercise to reduce friction
- Refer to a physiotherapist to design an exercise regimen of the appropriate level with minimal friction in areas of active HS lesions

Menstrual cycle

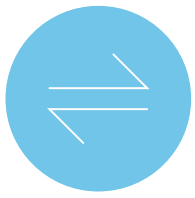
- Recommend tampons rather than sanitary towels to reduce friction in the groin
- Consider oestrogen and antiandrogenic progesterone-containing oral contraceptives in patients prone to premenstrual HS flares

Stress

Recommend stress management and mindfulness techniques

Obesity

Implement a weight loss plan via diet modification and exercise, if appropriate



Friction

Recommend loose-fitting, breathable clothing made of cotton, rayon, or bamboo fibres

Diet

- Test the elimination of dairy or brewer's yeast, if suspected as a trigger
- Refer to a nutritionist to design and agree on a dietary plan

Pregnancy

- There are mixed reports on the effect of pregnancy on HS, some patients experience remission while others experience worsening
- Discuss the optimal method of delivery with obstetrics–gynaecology specialists when needed; severe genital HS lesions may influence choice of delivery method or caesarean section scar placement
- Recommend patients with gestational diabetes consider consultation with maternal–foetal medicine for evaluation of need for insulin

Summary of management options for HS[1,14,15]

[Figure of available treatments to be localised per country – see below]

	Mild HS (Hurley stage I)	Moderate HS (Hurley stage II)	Severe HS (Hurley stage III)
Pharmaceutical treatments	Resorcinol Clindamycin Tetracycline Dapsone *(second/third line)*		
		Rifampicin-moxifloxacin-metronidazole	
		Biologics *(second/third line)*	
	Clindamycin-rifampicin Acitretin		
Surgery	I&D (for pain relief only) Individual excision Deroofing CO_2/Nd:YAG laser		Radical excision with skin graft
Adjuvant therapies	Pain management Pruritus management Wound care Corticosteroids (oral or intralesional) Hormonal contraception Lifestyle modfications (if appropriate) Smoking cessation Weight loss		

For more information on the current European guidelines for the treatment of hidradenitis suppurativa/acne inversa, see **here**

I&D, incision and drainage; Nd:YAG, neodymium-doped yttrium aluminium garnet.

Shared decision-making

Involving patients in treatment decisions is a great way to increase patient empowerment, strengthen the HCP–patient relationship, improve patient satisfaction with their care, and ensure adherence to the chosen interventions to improve patient outcomes overall.[20,21]

The HS Decision aid is a useful resource to facilitate shared decision-making. It contains information on the treatments available for HS, captures patients' treatment goals, and visually compares the treatments that meet their needs. You may wish to refer your patients to this tool so that they can arrive at appointments knowledgeable and ready to participate in decision-making.

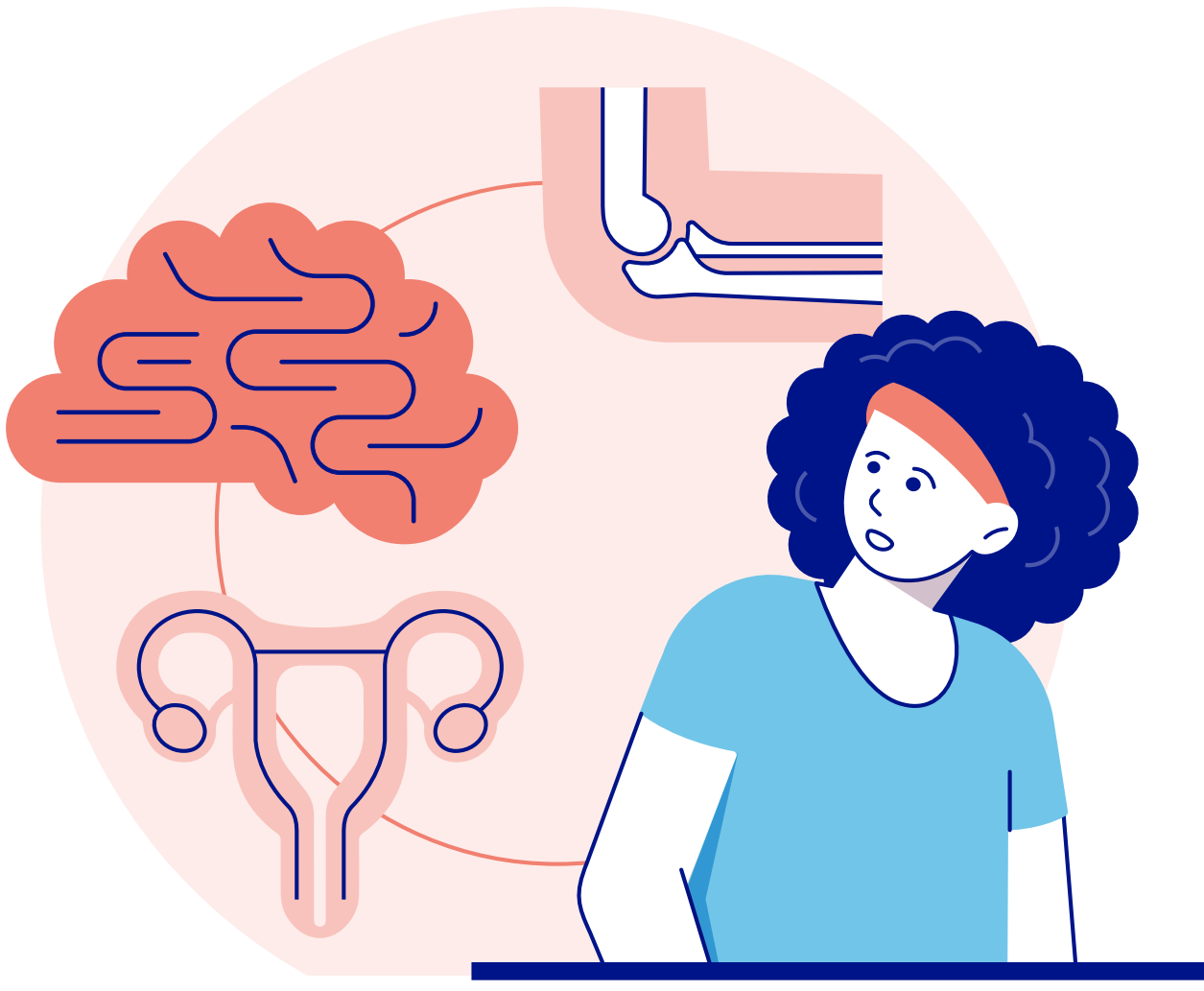
To establish treatment goals and inform shared decision-making, you may wish to ask:[22]

- When making medical decisions, some people like to decide on their own, some like to decide with me, and some like to know my recommendations. What is best for you?
- What is the key part of your HS that you would like to improve?
- What would you like to achieve from your HS treatment?

Management of comorbidities

Patients with HS have an incredibly high comorbidity burden,[23] due to the chronic inflammatory nature, shared risk factors, and impact of the disease.[23,24] Holistic care from multiple specialists is required for optimal patient outcomes.[24]

See Chapter 4 for more information on the comorbidities associated with HS and how to effectively collaborate with your multidisciplinary team to ensure patients have access to the care they need.



Communication essentials

For general tips on communicating with patients, please see Patient communication – top tips.

Explaining Hurley stage

HS can be categorised into three stages depending on the number and spread of your skin symptoms. Stage I is the mildest form, progressing to stage III which is the most severe.

After examining your skin, I can see that you have stage I disease.

Even though your skin symptoms are classed as mild, I recognise that HS has a great impact on you. The good news is that there are many treatments available to manage your symptoms.

See the resources section for more tips on how to communicate the results of scoring tools to patients.

Communication essentials

For general tips on communicating with patients, please see Patient communication – top tips.

Discussing treatment options/ shared decision-making

What is the key part of your HS that you would like to improve?

The pain. I would like to be able to have a full night's sleep without waking up in pain.

Thank you for sharing that. Let's focus on reducing your pain as a treatment priority and then we can look to manage other aspects of HS once that is under control.

How would you rate the level of pain you have experienced over the past 3 months from 0–10, 0 being none and 10 being the worst pain imaginable?

It comes and goes with flares, when I flare it is a 9 or a 10 and it often lasts for a week at a time.

Discussing treatment options/ shared decision-making (cont.)

Thank you, we must certainly do something to manage this pain as that sounds very difficult to live with.

How would you describe the pain you feel?

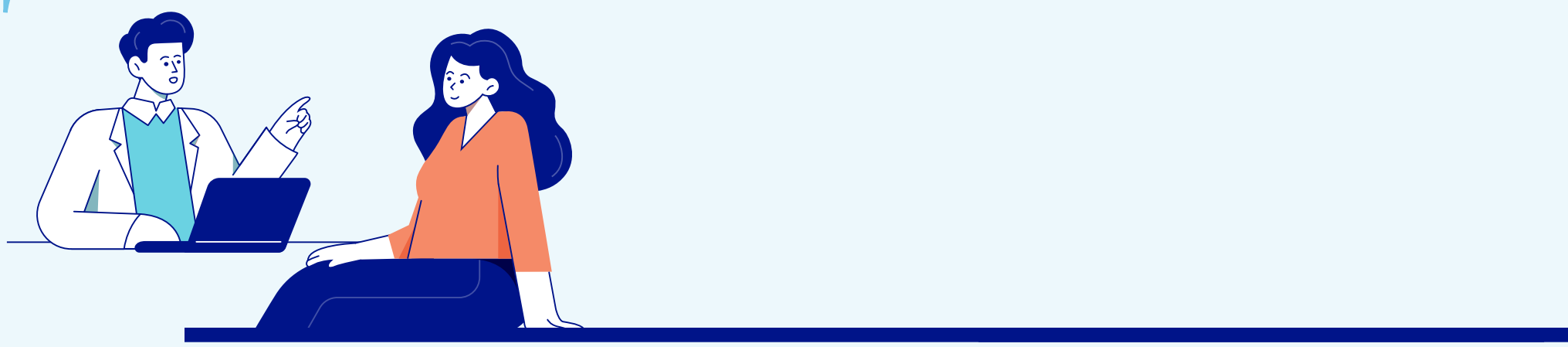
It feels like I am being stabbed where all the lumps are.

Ok, there are a few ways we can relieve your pain. Have you tried any techniques so far, like a cold compress or paracetamol?

Yes, I have tried paracetamol, but it doesn't have any effect on me.

Ok, there are a few options I would like to get your thoughts on. We could try a cream that you apply to reduce the inflammation and pain at the affected skin, or a tablet to reduce inflammation, but it can give some people tummy problems. There is also a more invasive option to inject the lumps with a steroid to reduce inflammation, or we could make a cut into the lumps and drain the pus to relieve some of the pressure and pain – the last option can provide temporary relief, but the lumps will refill with pus in time.

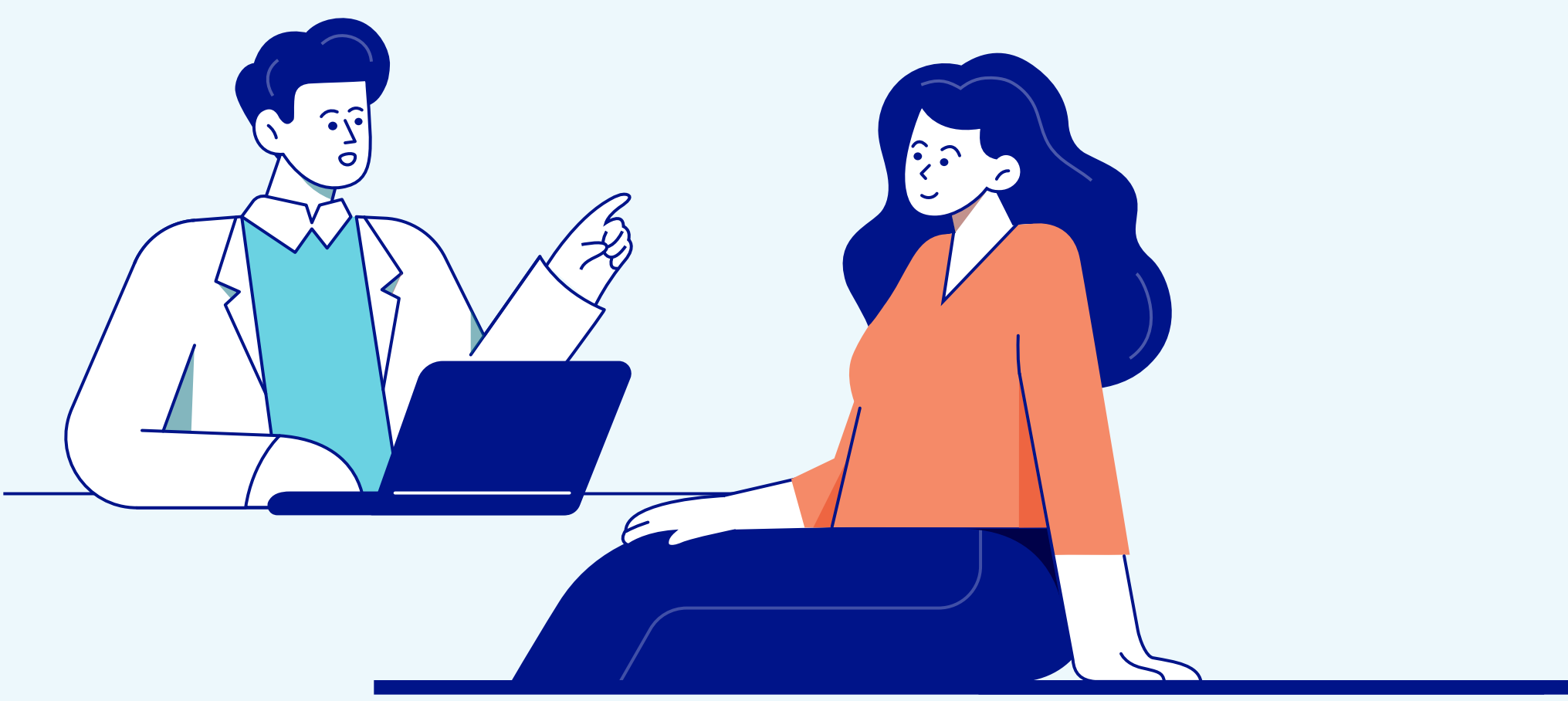
Which one of those sounds best to you or would you like to know my recommendation?



Discussing treatment options/ shared decision-making (cont.)

I think I would like to try the tablet to start with please, as applying cream is very painful. Do you think that is a good option?

Yes, I think that is a good option for you. I will write you a prescription for the anti-inflammatory tablet and I will see how you are getting on in 3 weeks' time. If you experience any side effects such as tummy problems, you should stop taking the tablet and ring me or your dermatology nurse to change your treatment.



References

1. Zouboulis CC, et al. J Eur Acad Dermatol Venereol. 2015;29:619–44.
2. Tzellos T, Zouboulis CC. Dermatol Ther (Heidelb). 2020;10:63–71.
3. Sayed CJ, et al. Obstet Gynecol. 2021;137:731–46.
4. Wohlrab J. J Dtsch Dermatol Ges. 2021;19:554–61.
5. Zouboulis CC, et al. Exp Dermatol. 2020;29:1154–70.
6. Nesbitt E, et al. Int J Womens Dermatol. 2019;6:80–4.
7. EMA. HUMIRA® (adalimumab). Product information. https://www.ema.europa.eu/en/documents/product-information/humira-epar-product-information_en.pdf. Accessed May 2024.
8. EMA. COSENTYX® (secukinumab). Product Information. https://www.ema.europa.eu/en/documents/product-information/cosentyx-epar-product-information_en.pdf. Accessed May 2024.
9. EMA. Bimzelx® (bimekizumab). Product Information. https://www.ema.europa.eu/en/documents/product-information/bimzelx-epar-product-information_en.pdf. Accessed May 2024.
10. Kimball AB, et al. N Engl J Med. 2016;375:422–34.
11. Kimball AB, et al. Lancet. 2023;401:747–61.
12. Mansilla-Polo M, et al. Actas Dermosifiliogr. 2023;114:T772–83.
13. Anduquia-Garay F, et al. Ann Med Surg (Lond). 2021;68:102679.
14. Cole EF, et al. Chapter 19: Pain and itch control. In: Shi VY, et al., editors. A Comprehensive Guide to Hidradenitis Suppurativa, 1st ed. Philadelphia, PA, Elsevier, Inc.; 2022.
15. Savage KT, et al. J Am Acad Dermatol. 2021;85:187–99.
16. Horváth B, et al. J Am Acad Dermatol. 2015;73(Suppl 1):S47–51.
17. Moloney S, et al. Dermatology. 2022;238:762–71.
18. Collier E, et al. Int J Womens Dermatol. 2020;6:85–8.
19. Tzellos T, Zouboulis CC. Exp Dermatol. 2022;31(Suppl 1):29–32.
20. Krist AH, et al. Stud Health Technol Inform. 2017;240:284–302.
21. Aslani P. Int J Pharm Pract. 2013;21:347–8.
22. Shih T, et al. Int J Womens Dermatol. 2022;8:e063.
23. Goldburg SR, et al. J Am Acad Dermatol. 2020;82:1045–58.
24. Garg A, et al. J Am Acad Dermatol. 2022;86:1092–101.

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Chapter 4

Collaborating with your colleagues

This chapter discusses the need for effective multidisciplinary care when managing HS and the roles involved in the HS multidisciplinary team. When talking with patients about multidisciplinary care, refer to Chapter 4: People involved in your care in the patient guide.

The need for multidisciplinary care

The nature and burden of HS requires management from different specialities such as wound care nurses/ experts, surgeons, and psychologists.[1,2] Chronic inflammation and the risk factors for HS also predispose patients to multiple systemic comorbidities, such as arthritis, inflammatory bowel disease, and metabolic syndrome, which require multidisciplinary care.[1,3,4]

> Comorbidities must be identified early and treated appropriately to avoid adding a significant burden to patients and society[5]

Dermatologists have overarching responsibility of the HS multidisciplinary team; effective collaboration and communication with your colleagues are key to deliver optimal holistic care.[2]

Comorbidities associated with HS and the roles required for holistic care[1,2,5,6]

COMORBIDITIES

Alopecia areata
Rheumatoid arthritis
Spondyloarthropathy
Metabolic syndrome
Pyoderma gangrenosum
Non-melanoma skin cancer
Depression and anxiety
Schizophrenia
Cardiovascular disease
Diabetes
Sexual dysfunction
PCOS
Psoriasis
Vitiligo
IBD

MDT

Nutritionist/dietician
Psychologist
Smoking cessation specialist
Cardiologist
Endocrinologist
Obstetrician/ gynaecologist
Pain specialist
Proctologist
Physiotherapist
Gastroenterologist
Rheumatologist

CORE TEAM

Dermatology nurse
Surgeon
Family doctor
HS specialist
Wound care nurse

Dermatologist

Effective comorbidity management:

- **Screen for comorbidities**
- **Consider comorbidities when deciding on a treatment strategy**
- **Employ a multidisciplinary team**

Communication essentials

For general tips on communicating with patients, please see Patient communication – top tips.

To identify comorbidities, perform physical examinations where possible and ask the patient screening questions about their symptoms:[4]

IBD

Have you had abdominal pain at least 3 times a week for at least 4 weeks, bloody stools, diarrhoea (>3 bowel movements daily) for 7 consecutive days, or been awoken from sleep because of abdominal pain or diarrhoea?

Spondyloarthritis

Do you have any joint pain or stiffness that is worse first thing in the morning or after a period of inactivity and gets better as the day goes on?

Sexual dysfunction

Have you been sexually active in the past 6 months? Do you or your partner have any sexual difficulties, such as your interest level or intercourse-related pain?

Smoking

Do you, or have you ever smoked? In the past year, how often have you used tobacco products?

Depression

Ask questions from the Patient Health Questionnaire (PHQ)-2 and PHQ-9

If a comorbidity is suspected, refer the patient to the appropriate specialist for confirmation of diagnosis and management.[4]

References

1. Timila Touhouche A, et al. Int J Womens Dermatol. 2020;6:164–8.
2. Chiricozzi A, et al. J Eur Acad Dermatol Venereol. 2019:33(Suppl 6):15–20.
3. Goldburg SR, et al. J Am Acad Dermatol. 2020;82:1045–58.
4. Garg A, et al. J Am Acad Dermatol. 2022;86:1092–101.
5. Tzellos T, Zouboulis CC. Exp Dermatol. 2022;31(Suppl 1):29–32.
6. Nguyen TV, et al. J Eur Acad Dermatol Venereol. 2021;35:50–61.

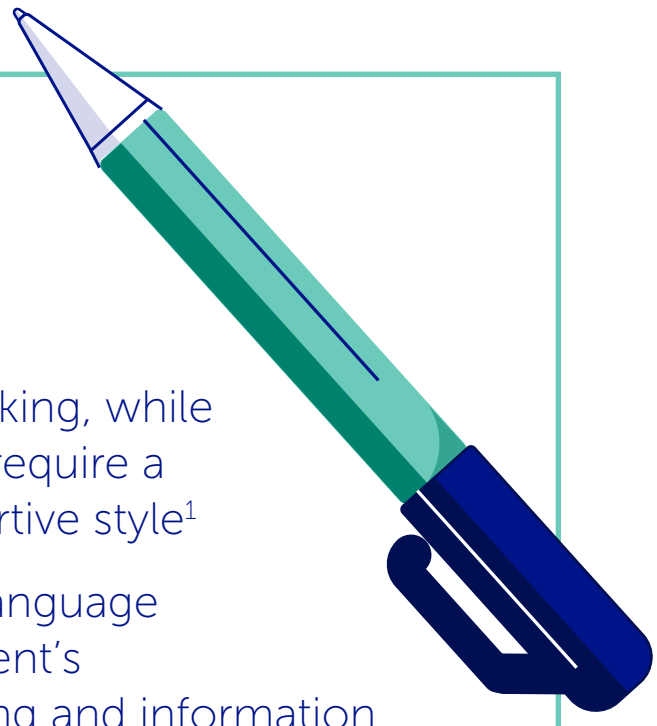
Chapter 5

Resources for healthcare professionals

This chapter provides helpful resources to support you to diagnose, manage, and communicate about HS.

Patient communication

Top Tips



- Negotiate a shared agenda for appointments; ask patients what they need from the appointment to set a purpose and explain what can be covered in the time available[1,2]
- Ask open questions – start with an open question to invite patients to talk about what is at the front of their mind; when this is addressed, they are able to relax and be receptive to other topics[3]
- Build rapport with the patient by listening attentively, recognising and acknowledging their thoughts and feelings, and responding with empathy and validation[1–3]
- Maintain eye contact and convey an approachable manner through body language[1,3]
- Dedicate your attention solely to the patient – avoid reading notes or looking at the computer screen while they are talking[1]
- Tailor your communication style – some patients may appreciate a more direct approach if they do not want to be involved in shared decision-making, while others may require a more supportive style[1]
- Tailor your language to each patient's understanding and information needs, e.g. give analogies or graphical representations that may be relevant to their life to explain concepts[1,3]
- Be aware of how HS affects their whole life – holistic assessment may affect how you communicate with them[3]
- Maintain curiosity about your patient and understand they may be holding some information back[3]
- Provide the information patients want, e.g. avoid talking too much about pharmaceutical treatments if the patient has not expressed an interest in this, instead provide information that patients have asked for, such as the causes of HS, likely prognosis, side effects, and advice on how to relieve pain and emotional distress[1]

- Ask what they already know about a topic and ask for permission before sharing medical information or providing recommendations[2]
- Enquire about the patient's preferred role in decision-making. You could say 'When making medical decisions, some people like to decide on their own, some like to decide with me, and some like to know my recommendations. What is best for you?'[2]
- Employ shared decision-making: align on treatment goals, discuss the treatment options available to fulfil the goals, and establish a dialogue to reach a shared treatment decision[3]
- Involve friends and family in consultations to avoid misinterpretation or forgetting of information[3]
- Be aware of your biases, acknowledge them, and do not let them affect how you care for or communicate with patients[3]
- Apologise when mistakes occur or for the suffering experienced by your patient[1]
- Introduce the patient to the HS multidisciplinary team to overcome communication barriers[3]
- Summarise throughout the consultation – ask the patient if you have correctly understood the key points of their story to show that you are listening and that you care you have got it right[3]
- Share your notes with patients; you may write things down for patients, refer them to their HS guide or send the consultation notes out afterwards[3]

HS scoring tools

Listed below are common HS-specific tools for assessing the severity of disease and treatment response. Patients will generally not be aware of these tools, so it is important to convey what their result means so that patients know where they lie on the scale of severity and response.

Severity of disease

Hurley staging system[4]

Purpose	To assess the severity of HS, which in turn guides management.
Scale	Stage I through to III (mild to severe).
Tool	• **Stage I** – single or multiple abscesses without tunnels or scarring • **Stage II** – recurrent abscesses, single or multiple widely separated lesions, with tunnels and scarring • **Stage III** – diffuse or broad involvement, or multiple interconnected tunnels and abscesses across the entire area

For more information on how Hurley stage informs treatment decisions, see: Zouboulis CC, et al. J Eur Acad Dermatol Venereol. 2015;29:619–44.

Communicating the score to patients

The Hurley staging system measures the severity of HS using the amount and spread of lumps, tunnels, and scars. Your Hurley stage determines which treatment options are suitable for you. There are three possible stages: stage I is mild disease, stage II is moderate, and stage III is severe. Stage I disease is the most common, then stage II, then stage III. Your Hurley stage can change, it can increase if your disease progresses, or it can decrease if your condition improves.

Dermatology Life Quality Index (DLQI)[5]

Purpose	To assess the impact of dermatological conditions on patients' quality of life. *Note: The DLQI is not HS-specific but can be applied to patients with HS to determine quality of life.*
Scale	0–30 0–1: no effect at all on patient's life; 2–5: small effect on patient's life; 6–10: moderate effect on patient's life; 11–20: very large effect on patient's life; 21–30: extremely large effect on patient's life.
Tool	10 questions completed by the patient. The downloadable questionnaire is available here in several languages.

Communicating the score to patients

The DLQI questionnaire measures how much HS has affected your daily life in the past week, including the level of pain and number of flares you have experienced. It gives dermatologists a good idea of how troublesome HS is for you so that they can start you on the right treatment to manage your priorities.

Treatment response

International Hidradenitis Suppurativa Severity Score System (IHS4)[6]

Purpose	To assess the severity of HS and identify treatment response.
Scale	0–>11 0–3: mild; 4–10: moderate; ≥11: severe.
Tool	***IHS4 = Nodules + 2(abscesses) + 4(draining tunnels)*** Patients with ≥55% reduction in their IHS4 score between two visits are responders.

For more information on the background and application of the IHS4, see: Zouboulis CC, et al. Br J Dermatol. 2017;177:1401–9.

Communicating the score to patients

The International Hidradenitis Suppurativa Severity Score System (IHS4) is used to measure the severity of your disease and if a treatment has worked for you. If you achieve the IHS4, it means that your symptoms have improved, as more than half of your lumps, abscesses, and tunnels have gone.

Hidradenitis Suppurativa Clinical Response (HiSCR)[7]

Purpose	To identify treatment response.
Scale	HiSCR is achieved if there is a ≥50% reduction in inflammatory lesion count (abscesses plus inflammatory nodules), and no increase in abscesses and draining tunnels when compared with baseline.
Tool	***Current lesion count* – Baseline lesion count = x*** $\frac{x}{\textbf{Baseline lesion count}} \times 100 = \%\ \textbf{reduction}$ If the % reduction is ≥50, the first requirement for response has been achieved. **Lesion count = abscesses + inflammatory nodules.* *Note: A positive result indicates an increase in lesions and thus does not fulfil response criteria.* **AND** ***Current abscesses and tunnels – Baseline abscesses and tunnels*** A result of ≤0 indicates no increase in abscesses or tunnels and thus fulfils the second requirement for response.

For more information on the background and application of HiSCR, see:
Kimball AB, et al. Br J Dermatol. 2014;171:1434–42.

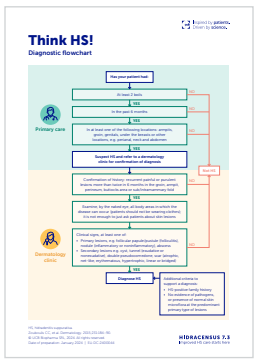
Communicating the score to patients

The Hidradenitis Suppurativa Clinical Response (HiSCR) is used to measure if a treatment has worked for you. If you achieve the HiSCR, it means that your symptoms have improved, as at least half of your lumps and abscesses have gone, and no more abscesses or tunnels have appeared.

Further resources

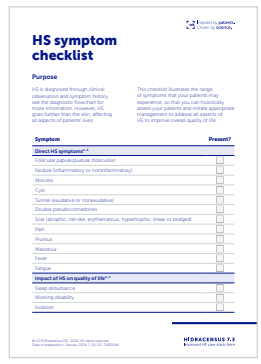
Access all resources now via MedHub

Diagnostic resources



Think HS! Diagnostic flowchart

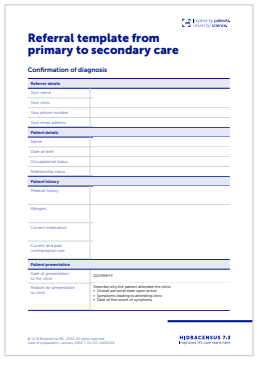
An algorithm to aid diagnosis of HS



HS symptom checklist

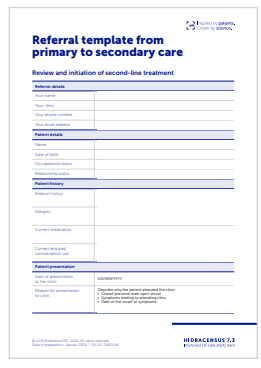
A list of all the symptoms patients with HS may experience, to capture the full burden of disease and facilitate holistic care

Referral resources



Referral template from primary to secondary care: Confirmation of diagnosis

General practitioners can use this template to facilitate the referral of patients with suspected or severe HS to dermatologists in secondary care



Referral template from primary to secondary care: Review and initiation of second-line treatment

General practitioners can use this template to facilitate the referral of patients with HS to dermatologists in secondary care when mild to moderate disease has not responded to first-line treatment

Management resources

Management options

See the European guidelines for more information on the management options available for HS

For local recommendations on HS management, see **here**

[Link to local HS guidelines]

References

1. Green M, et al. BMJ. 2012;344:e357.
2. Shih T, et al. Int J Womens Dermatol. 2022;8:e063.
3. British Heart Foundation. 16 ways to improve your communication skills with patients. https://www.bhf.org.uk/for-professionals/healthcare-professionals/blog/16-ways-to-improve-your-communication-skills-with-patients. Accessed May 2024.
4. Zouboulis CC, et al. J Eur Acad Dermatol Venereol. 2015;29:619–44.
5. DermNet. Hidradenitis suppurativa: severity assessment. https://dermnetnz.org/topics/hidradenitis-suppurativa-severity-assessment. Accessed May 2024.
6. Zouboulis CC, et al. Br J Dermatol. 2017;177:1401–9.
7. Kimball AB, et al. Br J Dermatol. 2014;171:1434–42.

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

Chapter 6

Appendix

FAQs

Listed below are the top 10 most frequently asked questions by patients and suggested responses on how to answer these questions.

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 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 Hurley stage I always progress to stage III?

A: Not everyone with HS will progress to Hurley stage III disease. 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 Chapter 1 in your HS Smart guide.[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 Chapter 3 in your HS Smart guide.[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), have been reported to worsen HS symptoms for some people. Obesity can also exacerbate symptoms so a change in diet may be beneficial. I can refer you to a dietician to assess your diet if you would like?[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.[6] Talking to your boss and colleagues is key for them to understand what HS is, how it affects you, and to support you with your work. See Chapter 2 in your HS Smart guide 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. I [will] screen you for some associated conditions each year, but make sure to tell me if you experience any new symptoms (not just skin symptoms) as soon as possible so that I can get the right treatment for you.[6,7]

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. If you feel uncomfortable talking to me about how you are feeling, you may want to try writing your thoughts and feelings down in a journal or talking to friends, family, or your partner. There are also some local HS groups you could try, where you can share your experiences with other people with HS. I can also refer you to a psychologist or a therapist if you would like to talk through how you are feeling, and they may be able to provide you with some coping techniques.[8]

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

This question is in the top 10 asked by patients on social media. Please consult Patient communication – top tips to ensure that your patients feel supported.

HS patient glossary

Use these descriptions to clarify HS terminology with patients.

Abscess – A swollen red lump filled with pus[9]

Acne inversa – Another name for hidradenitis suppurativa[10]

Anaemia – Low levels of red blood cells which can lead to fatigue and easily becoming out of breath[11]

Arthritis – A long-term inflammatory disease causing painful and stiff joints[12]

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.[13] 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[13,14]

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[15]

Flare – A period of time when HS symptoms appear or get worse[16]

Follicle – A tiny hole in the skin that a hair grows from[17]

Hidradenitis suppurativa – A long-term, non-contagious skin condition caused by an overactive immune system targeting the hair follicles[18,19]

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[20]

Immune system – The body's defence system[21]

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Inflammatory/Inflammation – Part of the immune system response to defend the body against infection. It involves swelling, redness, heat, pain, and can produce pus[22]

Inflammatory bowel disease (Crohn's disease and ulcerative colitis) – A long-term inflammatory disease causing severe tummy pain and diarrhoea or constipation[23]

Keratin – A naturally occurring protein that makes up hair, skin, and nails[24]

Lymphatic system – A network of channels and glands in the body that help fight infection and remove excess fluid[25]

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[26]

Psoriasis – A long-term inflammatory disease causing red, itchy, scaly patches of skin[27]

Pus – A thick, opaque, usually yellowish-white liquid produced from inflammation[28]

Resorcinol – A cream that helps to break down rough, scaly, or hard skin and disinfects the skin[29]

Retinoid – A class of medicine derived from vitamin A used to treat skin conditions[30]

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[31]

Steroid – A type of medicine that reduces inflammation[14]

Trigger – A factor that causes or worsens a flare[31]

Tunnels – A hollow passage under the skin with at least one open end at the surface of the skin[33]

Verneuil's disease – Another name for hidradenitis suppurativa[34]

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Further information for patients

You may wish to direct your patients to reliable sources of further information, we recommend:

- European Hidradenitis Suppurativa Foundation
  https://ehsf.eu/patients/information-for-patients/
- [Local HS group to be added per country]
- UCBCares®
  https://ucbcares.co.uk/en/content/1189815343/patients

References

1. HSDisease.com. How is hidradenitis suppurativa treated? https://hsdisease.com/treatment. Accessed May 2024.
2. Rosi E, et al. Biomedicines. 2021;9:1168.
3. Vanlaerhoven AMJD, et al. Dermatology. 2018;234:232–3.
4. Goldburg SR, et al. J Am Acad Dermatol. 2020;82:1045–58.
5. Collier E, et al. Int J Womens Dermatol. 2020;6:85–8.
6. Tzellos T, Zouboulis CC. Exp Dermatol. 2022;31(Suppl 1):29–32.
7. Garg A, et al. J Am Acad Dermatol. 2022;86:1092–101.
8. ShareCare. Hidradenitis suppurativa: Mental and emotional health. https://www.sharecare.com/skin-health/hs-mental-emotional-health. Accessed May 2024.
9. NHS. Skin abscess. https://www.nhs.uk/conditions/skin-abscess/. Accessed May 2024.
10. HSDisease.com. What is hidradenitis suppurativa? https://hsdisease.com/basics. Accessed May 2024.
11. Merriam-Webster. Anemia. https://www.merriam-webster.com/dictionary/anemia. Accessed May 2024.
12. NHS. Arthritis overview. https://www.nhs.uk/conditions/arthritis/. Accessed May 2024.
13. MedicineNet. Biologics (Biologic Drug Class). https://www.medicinenet.com/biologics_biologic_drug_class/article.htm. Accessed May 2024.
14. HSDisease.com. What medications treat hidradenitis suppurativa? https://hsdisease.com/medication. Accessed May 2024.
15. Racanelli E, et al. Cancers (Basel). 2021;13:1153.
16. RxList. Definition of Flare. https://www.rxlist.com/flare/definition.htm. Accessed May 2024.
17. Cambridge Dictionary. Follicle. https://dictionary.cambridge.org/dictionary/english/follicle. Accessed May 2024.
18. National Institute of Arthritis and Musculoskeletal and Skin Diseases. Hidradenitis suppurativa (HS). https://www.niams.nih.gov/health-topics/hidradenitis-suppurativa-hs. Accessed May 2024.
19. Hidradenitis Suppurativa Foundation. HS causes. https://www.hs-foundation.org/hs-causes. Accessed May 2024.

20. Zouboulis CC, et al. J Eur Acad Dermatol Venereol. 2015;29:619–44.
21. Merriam-Webster. Immune system. https://www.merriam-webster.com/dictionary/immune%20system. Accessed May 2024.
22. Merriam-Webster. Inflammation. https://www.merriam-webster.com/dictionary/inflammation. Accessed May 2024.
23. Crohn's & Colitis UK. All about Crohn's and Colitis. https://crohnsandcolitis.org.uk/media/y42le4ua/all_about_ed_7c_2021_web.pdf. Accessed May 2024.
24. Merriam-Webster. Keratin. https://www.merriam-webster.com/dictionary/keratin. Accessed May 2024.
25. NHS. Lymphoedema. https://www.nhs.uk/conditions/lymphoedema/. Accessed May 2024.
26. WHO. Polycystic ovary syndrome. https://www.who.int/news-room/fact-sheets/detail/polycystic-ovary-syndrome. Accessed May 2024.
27. British Skin Foundation. Psoriasis. https://knowyourskin.britishskinfoundation.org.uk/condition/psoriasis/. Accessed May 2024.
28. Merriam-Webster. Pus. https://www.merriam-webster.com/dictionary/pus. Accessed May 2024.
29. Drugs.com. Resorcinol (topical). https://www.drugs.com/mtm/resorcinol-topical.html. Accessed May 2024.
30. Zasada M, Budzisz E. Postepy Dermatol Alergol. 2019;36:392–7.
31. Merriam-Webster. Skin graft. https://www.merriam-webster.com/dictionary/skin%20graft. Accessed May 2024.
32. RxList. Definition of a Trigger. https://www.rxlist.com/trigger/definition.htm. Accessed May 2024.
33. Wound Source. Tunnelling Wounds or Sinus Tracts. https://www.woundsource.com/patientcondition/tunneling-wounds-or-sinus-tracts. Accessed May 2024.
34. National Organization for Rare Disorders. Hidradenitis Suppurativa. https://web.archive.org/web/20170219163032/https://rarediseases.org/rare-diseases/hidradenitis-suppurativa/. Accessed May 2024.

HIDRACENSUS 7.3 pledge

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

The most important to sufferers. Because it takes on average 7.3 years to correctly diagnose HS.

Imagine – 7.3 years spent wondering if you are somehow to blame.

That you've not spoken to the right HCP.

That it'll just keep getting worse.

Seven-point-three is a number. But to patients, it's a prison sentence

So, from here on, we all work together; HCPs, patients, nurses and payors.

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