Call to action: Improving the lives of people with hidradenitis suppurativa (HS) in Germany

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About this report

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Call to action: improving the lives of people with hidradenitis suppurativa (HS) in Germany

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What is hidradenitis suppurativa?

What is hidradenitis suppurativa?

Hidradenitis suppurativa (HS) is a chronic and painful skin condition that can be debilitating. HS, also known as acne inversa, is a skin condition that is thought to affect around 1 in 100 people across the world.[1]* It can cause significant physical challenges and lead to severe psychological distress.[2-4] It is an autoinflammatory condition that contributes to inflammation below the surface of the skin.[5 6] The condition often starts in a person's teenage years and is characterised by recurrent flare-ups of painful nodules which can become abscesses that look like lumps or boils.[7 8] These abscesses can rupture, resulting in a discharge that may have an unpleasant smell and stain clothing, and can cause scarring on the body, all of which can lead people to feel embarrassed or ashamed.[3 9 10] Over time, inflammation can progress and lead to irreversible damage to the skin.[11 12] People living with HS may also develop draining tunnels under their skin that can connect between nodules, producing blood and discharge.[13] HS is associated with a range of other conditions such as depression, spondyloarthritis (painful chronic arthritis that mainly affects joints in the spine), diabetes and inflammatory bowel disease, meaning that HS can require multidisciplinary care.[14-18]

HS has a significant impact on people's lives. HS has one of the highest impacts on quality of life among all dermatological conditions.[19] A key driver of the challenges of HS is pain, which is reported by almost all people living with the condition and can make it difficult to carry out everyday activities.[20 21] HS can have a major effect on almost every part of a person's life, including their personal relationships, work and social life; this ultimately contributes to the condition being highly distressing and affecting mental wellbeing.[22-24]

HS can result in considerable system costs through the loss of productivity and frequent use of high-cost services. The condition often affects people during their most productive years, and can mean people living with HS are more likely than the general population to miss days of work, be unwell at work or be unemployed.[23 25] This means the productivity of the HS population is significantly reduced. Additionally, high-cost settings such as emergency departments and inpatient care around surgery are used more frequently by people living with HS.[26 27] This combination of factors means that HS can lead to significant costs to the health system and wider economy. In Germany, the estimated cost of HS-related loss of productivity alone is approximately €12.6 billion per year.[23]

*Prevalence estimates can vary depending on the methodology used

HS in Germany

HS in Germany

In Germany, HS is estimated to affect 0.06–0.30% of the population.[28 29] One study looking at the prevalence of HS in Germany found that slightly more men than women were affected. This contrasts with findings in other European countries (where the condition is more prevalent in women) and may be a consequence of the study's methodology.[28]

A number of centres deliver care for HS, with dermatologists playing a central role. Dermatologists diagnose almost 80% of HS cases, followed by primary care physicians and surgeons.[30] People living with HS also primarily see dermatologists for their care but, again, primary care physicians and surgeons can be involved.[31] According to an HS expert interviewed for this report, dermatologists in Germany are trained in surgery and are therefore capable of managing the majority of cases.[32] Treatment for HS depends on how much the condition has progressed, and may include both medical and surgical interventions.[33] There are a number of centres across Germany involved in the diagnosis, treatment and management of HS, although it is difficult to estimate the exact number providing care.[34] Healthcare professionals in these centres deliver care in line with German and European guidelines.[2 35] Data on HS are currently being collected through the German Hidradenitis Suppurativa Registry.[36]

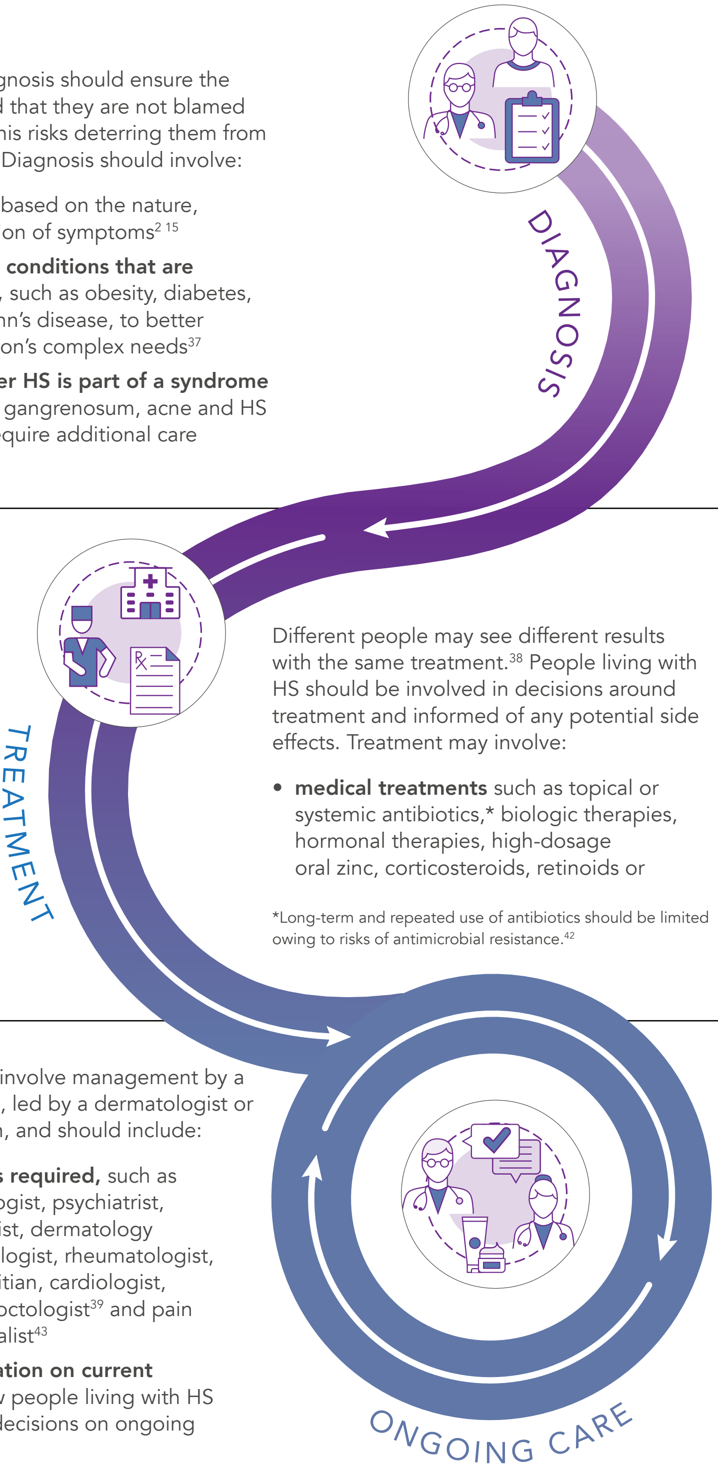
There is no active national patient association with a specific focus on HS. This may mean people living with the condition in Germany lack access to appropriate support and information.

What does best-practice care for HS look like?

What does best-practice care for HS look like?

HS can be a frustrating condition to manage, both for people living with the condition and for the healthcare professionals treating it. While there is currently no cure for HS, its impact can be reduced if people receive best-practice care at every stage (*Figure 1*).

Figure 1. Best-practice HS patient pathway



The process of HS diagnosis should ensure the person feels heard and that they are not blamed for their condition as this risks deterring them from seeking care in future. Diagnosis should involve:

- **clinical assessment** based on the nature, frequency and location of symptoms[2,15]
- **screening for other conditions that are associated with HS,** such as obesity, diabetes, depression and Crohn's disease, to better understand the person's complex needs[37]
- **establishing whether HS is part of a syndrome** – such as pyoderma gangrenosum, acne and HS (PASH) – that may require additional care
- **a quality-of-life assessment** using the Dermatology Life Quality Index (DLQI) to help establish severity (a flare-up may not be at its worst during a clinical assessment; therefore understanding the impact of HS separately from clinical presentation can provide a more accurate picture of severity)
- **a healthcare professional with specialist HS knowledge,** such as a dermatologist, to reduce the risk of misdiagnosis. Primary care physicians, surgeons, gynaecologists and emergency care clinicians with specialist HS knowledge may also be capable of diagnosing.

Different people may see different results with the same treatment.[38] People living with HS should be involved in decisions around treatment and informed of any potential side effects. Treatment may involve:

- **medical treatments** such as topical or systemic antibiotics,* biologic therapies, hormonal therapies, high-dosage oral zinc, corticosteroids, retinoids or immunosuppressors;[39,40] pain may also be managed using medical treatments such as non-steroidal anti-inflammatory drugs and opioids[2]
- **surgical interventions,**[41] depending on the location and severity of the condition[2,33]
- **laser procedures.**[39]

*Long-term and repeated use of antibiotics should be limited owing to risks of antimicrobial resistance.[42]

Ongoing care should involve management by a multidisciplinary team, led by a dermatologist or primary care physician, and should include:

- **other specialists as required,** such as a surgeon, psychologist, psychiatrist, wound care specialist, dermatology nurse, gastroenterologist, rheumatologist, gynaecologist, dietitian, cardiologist, endocrinologist, proctologist[39] and pain management specialist[43]
- **up-to-date information on current treatments** to allow people living with HS to make informed decisions on ongoing treatment
- **rapid access to a dermatologist for acute flare-ups** that require urgent care
- **empowering people to report side effects and concerns** from treatment
- **clinically validated self-care** to manage pain
- **a standardised at-home 'rescue pack'** that includes corticosteroids (to treat early flare-ups) and is accompanied by clear guidance on how to use them safely
- **support from an HS patient organisation.**

How does HS impact people's lives?

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Pain has a major effect on people's lives

Pain is very common for people living with HS and presents many challenges. According to a large study in Germany, most people living with HS (83.6%) reported pain.[44] More than a third of people in this study said HS had a very large effect on their quality of life and that this was linked to the intensity of the pain, indicating the significant impact pain has on people's lives.[44]

People living with HS often struggle with mental health issues

HS is a distressing condition, and people living with HS often experience mental health issues. Symptoms of HS can have an extensive negative impact on people's lives, leading to significantly higher rates of a range of mental health issues.[33 45 46] Studies have found that between 19.3% and 38.6% of people living with HS in Germany experienced depression,[47 48] compared with 10% of the general population.[49] One person interviewed for this report said the feeling of not having control of their symptoms contributed to a depressive period.[50]

Social life can be affected by HS

Symptoms of HS can cause people to withdraw from social situations. HS can make people feel self-conscious and embarrassed about their bodies.[46 50] This, in addition to the social stigma experienced,[51] can lead people to withdraw from socialising and become isolated, resulting in a significant impact on quality of life.[52]

People living with HS may find intimacy distressing, exacerbating quality-of-life challenges. Symptoms of HS are likely to have a negative impact on a person's sexual relations, leading to significantly worse quality of life.[46 52 53] One person interviewed for this report said their HS led to intimacy becoming problematic, and this had contributed to conflict in a previous relationship.[50]

HS can affect people's ability to work

HS-related pain and depression can result in illness at, or absence from, work – or even unemployment. Working with HS can be challenging and it is common for people to need time off work owing to their symptoms.[23 54] Pain and depression from HS can make people feel unable to go to work, or may impair them when they work.[23] People living with HS have been found to miss more than three times as many days of work per year than the average German employee.[23] The unemployment rate among people living with HS is approximately two times higher than among the rest of the German population, indicating the extent to which HS can affect people's ability to work.[23] This is likely to lead to financial distress, impact self-worth and ultimately exacerbate mental health challenges. One person interviewed for this report said they had to take five weeks off work to recover from surgery, leading to a backlog of work, which induced a great deal of stress when they returned.[50]

Living with HS can result in personal financial costs

People living with HS face a range of financial pressures. HS-related employment issues may contribute to financial challenges through the loss or reduction of income. Additionally, people living with HS may need to pay for medicines as well as daily wound care.[55] One person interviewed for this report said that they needed to change their dressings, which they buy themselves, every two hours when they had a flare-up.[50] An international study found that one in six people needed five or more changes to their dressing every day, highlighting the potential financial burden of wound care on people living with HS.[56]

Mona's story

Mona was 26 when she first noticed what she thought were pimples in her groin. After a few years they had grown and become very painful, to the point where they were preventing her from being able to sit. This led her to seek emergency care. During this visit, she was told she had HS and required immediate surgery.

'I went to the theatre one evening and just couldn't sit. The next day, I went to the doctor and he said, "You have to go to the emergency room to get surgery, because you could get blood poisoning." This was the first time someone had said it was HS, but they didn't give me any more information or tell me to see a dermatologist.'

Mona struggled to find a doctor who knew how to treat her condition. After searching online she found an HS specialist in Germany, but they were far away from her home.

'The doctors around me just told me I had to use a cream. When they see my scars they just look at them and see that they need to do more, but they don't have any ideas. I feel very alone – I just have contact with the clinic in Berlin and it's so far away from me.'

Mona feels restricted by HS because it affects what she can do and even the clothes she wears.

'It's stressful because you can't do what you want. You have to think about what you wear, and I don't like the clothes that I feel I have to wear.'

She has found it difficult to accept her diagnosis. Despite having symptoms since 2012, she found out only in 2022 that the condition is chronic. This had a significant impact on her mental health.

'I can't accept that I have it. Nobody told me that it was incurable… I searched online and found out it was a chronic condition. It was a shock. I felt like I was in the middle of a hole.'

Mona would like there to be more awareness of HS so people can have better access to care.

'It's very important that HS gets more publicity. There are people with HS who don't know they have it yet.'

What are the policy and system barriers to best-practice care?

What are the policy and system barriers to best-practice care?

Low awareness among healthcare professionals is contributing to delays in diagnosis and poor-quality care

> There is still a lot of work to do on raising awareness. We aren't seeing every patient and we aren't diagnosing them all correctly.
>
> FALK G. BECHARA
> INTERNATIONAL CENTRE FOR HIDRADENITIS SUPPURATIVA/ACNE INVERSA (ICH), RUHR-UNIVERSITY BOCHUM, GERMANY

Low awareness among primary care physicians contributes to unacceptable delays to diagnosis of HS. An HS expert interviewed for this report indicated that, although awareness of HS appears reasonable among dermatologists, awareness among primary care physicians and emergency care clinicians is too low.[32] This leads to slow referral rates as well as long delays in diagnosis.[32] In Germany, it takes an average of 10 years from onset of symptoms for people to receive an HS diagnosis, and people with late diagnosis (over 15 years) experience an average of five misdiagnoses.[30] One person interviewed for this report said her local doctor did not know about HS or how to treat her appropriately.[50] Earlier diagnosis and access to treatment – driven by bolstering awareness among dermatologists, primary care physicians and emergency care clinicians – may prevent disease progression.[31] This could lead to less costly management of the condition and improvements in the quality of life of people living with HS.[31]

People living with HS may not have access to the treatment that is most appropriate for them

> There's a huge need for more effective medicines.
>
> FALK G. BECHARA

Many people are dissatisfied with current HS treatments, owing to side effects and low effectiveness. There are still limited treatment options for HS and no treatment is considered uniformly effective or without side effects.[32 57] In a global study, which included German healthcare centres, 45% of people living with HS said they were either dissatisfied or very dissatisfied with current treatment options.[57] Low effectiveness and side effects were the key drivers of dissatisfaction.[57] Additionally, insurance policies may not allow people to access the treatment they feel could work for them. One person interviewed for this report wanted to receive laser hair removal to help their HS, but it was not covered by their insurance and they could not afford to pay for it themselves.[50]

Access to specialist care is inequitable

Specialist care for HS is available, but may not be accessible to everyone who needs it. While there are a number of centres listed as specialists in HS care, they are not evenly distributed across Germany, which may cause inequitable access to high-quality care.[34] Additionally, an expert interviewed for this report said that while these centres may be able to deliver HS care, they are not necessarily specialist centres, and there are only a few centres in the country that have a specific focus on HS.[32] It is also not clear whether multidisciplinary care is offered through these centres. A government-funded initiative, the EsmAiL project, is seeking to improve care for HS through the establishment of 'acne inversa centers' (AiZs), which have a specific focus on providing multidisciplinary care and patient education.[58] As part of the EsmAiL project, an evaluation of current care was conducted, which found that only 1.9% of people with HS were very satisfied with the care they were receiving.[59] The evaluation also found that, when compared with standard care, care delivered through AiZs led to better health outcomes, improved quality of life and increased patient satisfaction.[58] This highlights the potential impact of multidisciplinary care and emphasises the need for equitable access across Germany, which could be achieved through the continued roll-out of AiZs throughout the country.

A lack of data on HS in Germany may affect health outcomes

There are limited data available on HS in Germany, but a new registry is likely to improve the situation. There is currently a need for comprehensive data on HS in Germany to inform treatment decisions and improve care.[36] The German Hidradenitis Suppurativa Registry was created with the aim of bolstering HS data.[36] This is a promising but recent initiative that currently only involves 11 centres.[60] To ensure that its potential benefit is maximised, the registry should consider an expansion of the number of centres involved.

There is currently no patient organisation in Germany to support people living with HS

There is no patient organisation for HS in Germany. Patient organisations are crucial for providing support for people living with a condition, along with sharing personal experiences and tips – in the case of HS, this may be particularly beneficial for pain management and wound care. Although some self-help groups exist online, the absence of an official patient organisation for HS in Germany may mean people are less supported. One person interviewed for this report said they feel very alone with their HS.[50] There is a national organisation that supports people living with chronic skin conditions, which may be an option for people living with HS to access support.

Recommendations for policymakers

Recommendations for policymakers

People living with HS in Germany are significantly affected by their condition, with policy barriers preventing them from accessing high-quality care.

To improve the lives of people with HS, policymakers in Germany should consider the following recommendations:

- **Roll out HS educational programmes for healthcare professionals** – focusing on those working in dermatology, primary care and emergency services – to increase understanding of the condition, and improve the speed of diagnosis and quality of care.
- **Improve access to high-quality HS care through the continued roll-out of AiZs,** which focus on delivering multidisciplinary care and patient education.
- **Support the effective use of data collected through the German Hidradenitis Suppurativa Registry** to improve care and health outcomes.

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