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

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The Health Policy Partnership

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About this report

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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 2] It can cause significant physical challenges and lead to severe psychological distress.[3-5] It is an autoinflammatory condition that contributes to inflammation below the surface of the skin.[6 7] 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.[8 9] 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.[4 10 11] Over time, inflammation can progress and lead to irreversible damage to the skin and scarring.[12 13] People living with HS may also develop draining tunnels under their skin that can connect between nodules, producing blood and discharge.[14] HS is also 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.[15-19]

HS has a significant impact on people's lives. HS has one of the highest impacts on quality of life among all dermatological conditions.[20] 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.[21 22] 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.[23-25]

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.[24 26] 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.[27 28] This combination of factors means that HS can lead to significant costs to the health system and wider economy.

HS in Denmark

HS in Denmark

In Denmark, around 1 in 100 people are thought to have HS.[2] Women are almost twice as likely as men to have HS. This is similar to trends seen in other Western countries.[2 20 29]

Several treatments for HS are available, but none are uniformly effective. Various treatments are used for HS, but none are effective for every person.[30] In general, topical treatments are used as first-line treatments, followed by prolonged antibiotics, with biologic therapy used if all previous options are ineffective.[30] Surgery is also used to treat tunnels and scarring[31] – interventions may involve excision or laser techniques.[9]

Dermatologists play a key role in the diagnosis and management of HS, but other healthcare professionals are involved too. Dermatologists are able to diagnose and manage the majority of people living with HS, but non-dermatologists also often encounter people with the condition.[26 30] Some dermatologists are able to perform surgical procedures, but surgeons and gynaecologists (depending on the location of symptoms) may also be involved if surgery is required.[30] Management of HS is guided by clinical guidelines from the Danish Dermatological Society.[32] There are at least six hospitals in Denmark that deliver specialist HS care.[33-38] Data on HS is currently being collected through the Clinical Scandinavian Registry for Hidradenitis Suppurativa, but in future this will be collected through the European Registry for Hidradenitis Suppurativa.[39 40]

People living with HS in Denmark can access support from a national patient organisation. Patientforeningen HS Danmark is the HS patient organisation in Denmark and provides support for people living with the condition. The organisation gives information on what HS is, how to get a diagnosis, potential treatments and wound care.[41] Patientforeningen HS Danmark also shares the experiences of people living with the condition and the impacts the condition has had on their social and work lives.[41]

Bente's story

Bente was 16 when she found her first abscess – she told her parents and was set to have surgery to remove it, but the abscess disappeared on its own. Over the next couple of years the disease came back and got worse. As a teenager she really wanted to look good but wasn't able to wear the clothes everyone else was wearing because the her abscesses made it too painful.

'I couldn't wear jeans like everyone did, so sometimes I made long skirts for myself that I would wear. I sewed special shorts with sanitary towels inside them, and I brought extra in my bag for if they were soaked.'

As the condition got worse, Bente found it hard to manage her symptoms and they would prevent her from doing things she loved, such as riding her bicycle. This had a significant impact on her mental health.

'It was really hard to manage on an everyday basis. Not being able to exercise is really bad for me and also for my mental health. Mental health is so bad among HS patients. I think the best question to ask an HS patient is "How are you?" It's very rare that someone does.'

As she grew older and her HS became more severe, the pain meant Bente struggled with intimacy and this had a serious impact on her quality of life.

'When my HS was at its worst, I had to talk to my husband about where he can touch me and how much he can touch me. I often refused sex because it was too bad. It was just so painful.'

Bente has had lots of sick leave because of surgeries and flare-ups. When she was 46, her primary care physician said they would support the option of Bente receiving her pension early, because of the impact of HS on her work. She refused because she loves her job and did not want her HS to restrict her life.

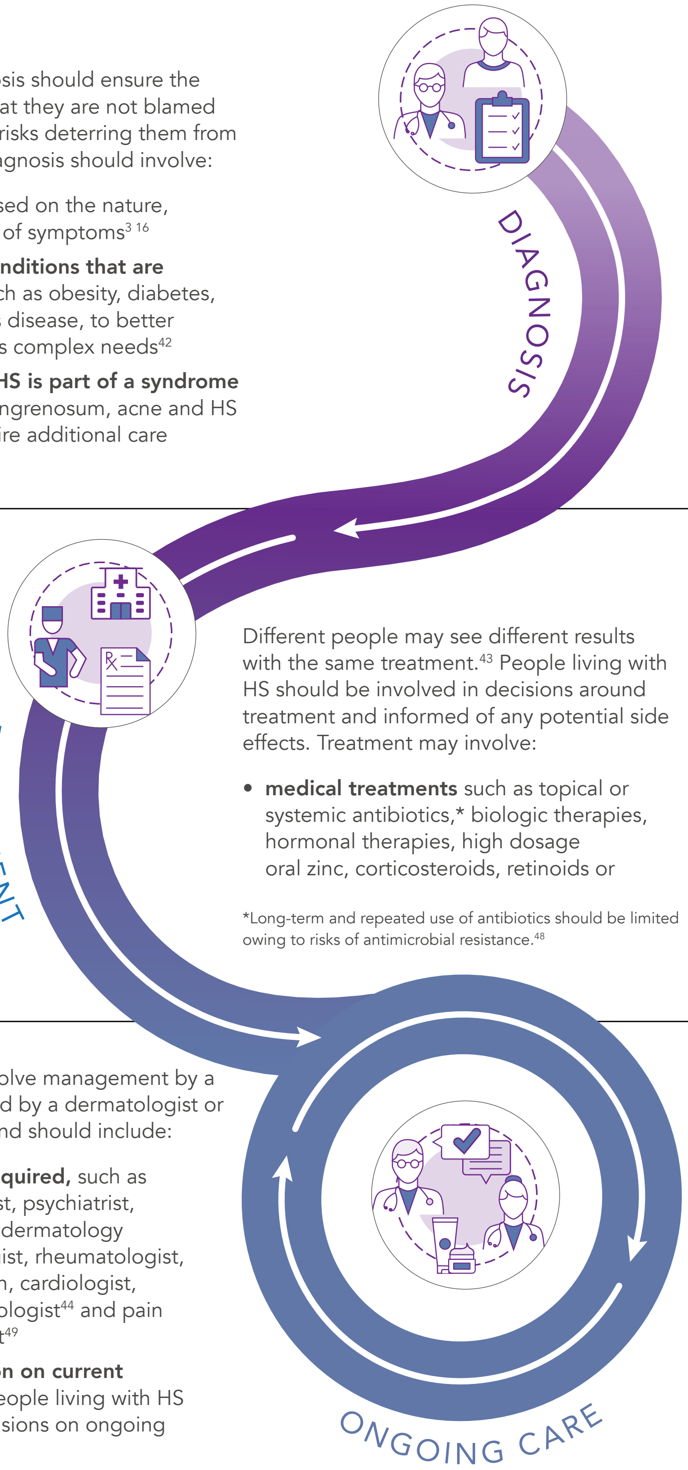
*'Sometimes it was very painful to go to work.
I really love my work [in the environmental sector].
I often say that I chose the environment, but HS has chosen me.'*

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[3,16]
- **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[42]
- **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.[43] 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;[44,45] pain may also be managed using medical treatments such as non-steroidal anti-inflammatory drugs and opioids[3]
- **surgical interventions,**[46] depending on the location and severity of the condition[3,47]
- **laser procedures.**[44]

*Long-term and repeated use of antibiotics should be limited owing to risks of antimicrobial resistance.[48]

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[44] and pain management specialist[49]
- **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?

How does HS impact people's lives?

Pain has a major effect on people's lives

Pain is very common for people living with HS and drives many of the challenges related to the condition. It is well understood that pain is experienced by almost all people living with HS and is a major, debilitating symptom.[21 25 50 51] People report pain as one of the worst symptoms of their condition.[52] The high intensity and frequency of pain is a persistent burden and has a huge impact on the quality of life of people living with HS.[50 53]

People living with HS often struggle with mental health issues

HS can cause significant mental health challenges, resulting in an increased risk of suicide. It is common for people living with HS to face mental health issues, with around one in five people struggling with depression as a result of their symptoms.[54] This is considered to be a consequence of the pain, smell and scarring caused by HS.[55] Symptoms can also appear randomly, leading people to feel that they lack control.[55] All of these factors contribute to people with HS being twice as likely to take their own lives than people without the condition.[56] There are also reports of some individuals with HS becoming dependent on drugs or alcohol as a result of the challenges they encounter.[55]

Social life can be affected by HS

Symptoms can make people feel embarrassed and lead to them becoming socially isolated. When abscesses rupture, it can result in discharge that smells and may visibly stain clothing; this can be a source of embarrassment and make people feel self-conscious, which may cause people to isolate themselves.[55]

People living with HS may experience challenges around intimacy

Pain and scarring can have an impact on intimacy. People may feel self-conscious about scarring on their bodies, which can affect how people feel about themselves and whether they want to be intimate or not.[55] A study in Denmark found that people living with HS have a worse perception of their own body compared to people with other skin conditions.[57] According to one person interviewed for this report, the intense pain from symptoms can make intimacy physically difficult and this has an enormous impact on quality of life.[58]

HS can affect people's ability to work

HS symptoms can lead to people missing work or being sick at work. HS symptoms can often affect people at their most productive time in life, hindering their ability to work.[26] A considerable number of people report feeling impaired by their HS at work, or that their condition forces them to miss work.[59] In Denmark, rates of unemployment are over four times higher among people living with HS than the national average.[60]

Living with HS can result in personal financial costs

People living with HS in Denmark face a range of financial pressures. HS-related employment issues may contribute to financial challenges. Additionally, people living with HS may face needing to pay for medicines as well as daily wound care.[55] A global study, which included participants from Denmark, found that one in six people needed five or more changes to their dressing a day.[61]

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

A lack of awareness among healthcare professionals encountering HS is resulting in unacceptably long delays in diagnosis. One global study, which included people from Danish centres, estimated it takes more than seven years from experiencing symptoms to receiving a diagnosis.[62] This delay may be a result of insufficient knowledge of HS, particularly among non-dermatologists who may encounter HS at an early stage.[26 31 62] Ensuring that these healthcare professionals are properly educated about HS could improve the speed of diagnosis.[9]

Insufficient management of symptoms is leading to risky self-treatment

A large number of people with HS self-treat pain, suggesting management of this symptom is poor. In one global study, which included participants from Denmark, almost half of people living with HS were dissatisfied or very dissatisfied with their current treatment.[63] Low effectiveness and unwanted side effects were cited as the most common reasons for dissatisfaction.[63] Additionally, a Danish study found that four in five people living with HS were self-treating nodules by squeezing them, or by cutting them open with needles or scalpels to relieve pain.[64] This suggests that the efficacy of current treatments for managing pain, in particular, is insufficient. Self-treatment using these techniques puts people at risk of infection.[65]

Access to multidisciplinary care may be limited

There are centres that offer specialist HS care in Denmark, but people living with HS may still have to travel to receive care from different healthcare professionals. While there are some centres around Denmark that provide specialist HS care, it is unclear which specialists people can access through these.[66] Unlike European guidelines, the Danish HS clinical guidelines do not clearly recommend management by a multidisciplinary team.[3 32] One person from Denmark who was interviewed for this report said they had to travel between centres to receive care from different specialists, suggesting that multidisciplinary care was not available to them.[58] Additionally, the individual felt they had to coordinate parts of their care by asking for referrals to certain specialists.[58] This placed further burden on the person living with HS, as they had to repeatedly explain their condition to convince healthcare professionals that they needed care – a tiring and frustrating experience.[58]

Emergency care is in need of improvement

Some people may seek emergency care for their HS, but this is considered to be suboptimal. A global survey, which included people living with HS in Denmark, found that around one in five people had visited the emergency department for their symptoms five or more times throughout their life.[67] According to one person interviewed for this report, the care received through emergency services can be inappropriate in Denmark.[58] The individual went on to call for improvements in emergency dermatological services to provide people living with HS in Denmark the option of rapid access to urgent care.[58]

Recommendations for policymakers

Recommendations for policymakers

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

To improve the lives of those living with HS, policymakers in Denmark should consider the following recommendations:

- **Roll out HS educational programmes for healthcare professionals** – with a focus on primary care physicians, surgeons and gynaecologists – to increase understanding of the condition and improve speed of diagnosis.
- **Introduce a guide on safe self-treatment of HS symptoms** to support people to better manage their own condition without risk.
- **Encourage the equitable implementation of multidisciplinary care** through HS specialist centres.
- **Consider the development and roll-out of emergency dermatology clinics** that are capable of providing rapid access to urgent care for people living with HS.

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