

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

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The  
**Health Policy Partnership**

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## About this report

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

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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.<sup>1,2</sup> It can cause significant physical challenges and lead to severe psychological distress.<sup>3-5</sup> It is an autoinflammatory condition that contributes to inflammation below the surface of the skin.<sup>6,7</sup> 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.<sup>8,9</sup> 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.<sup>4,10,11</sup> Over time, inflammation can progress and lead to irreversible damage to the skin and scarring.<sup>12,13</sup> People living with HS may also develop draining tunnels under their skin that can connect between nodules, producing blood and discharge.<sup>14</sup> 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.<sup>15-19</sup>

**HS has a significant impact on people's lives.** HS has one of the highest impacts on quality of life among all dermatological conditions.<sup>20</sup> 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.<sup>21,22</sup> 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.<sup>23-25</sup>

**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.<sup>24,26</sup> 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.<sup>27,28</sup> This combination of factors means that HS can lead to significant costs to the health system and wider economy.

HS in Sweden

## HS in Sweden

**In Sweden, HS is estimated to affect 1 in 700 people, with women more likely to be affected than men.** A large study using data from the national patient register found that 1 in 700 people in Sweden had a diagnosis of HS, which is considerably lower than the European average of 1 in 100.<sup>20</sup> This may be an underestimation as a consequence of underdiagnosis.<sup>20</sup> Women are three times as likely as men to have HS, which reflects trends in other Western countries.<sup>20</sup>

**Dermatologists play a key role in the management of HS, with treatments varying depending on disease severity.** In Sweden, dermatologists have a central role in managing HS, ideally in a multidisciplinary setting with support from other specialists.<sup>29</sup> Management of HS appears to follow European guidelines – there are currently no national HS guidelines in Sweden.<sup>3,30</sup> Treatment for HS varies on an individual basis, but can involve antibiotics, biologics and surgery, depending on the severity.<sup>29,31</sup> Data on HS is currently being collected through the Clinical Scandinavian Registry for Hidradenitis Suppurativa.<sup>32,33</sup>

**There is an active national association supporting people living with HS.** HS International Sweden provides people with information on HS and tips for accessing care, and also carries out surveys to establish the current level of care provision in each region of Sweden.<sup>34</sup>

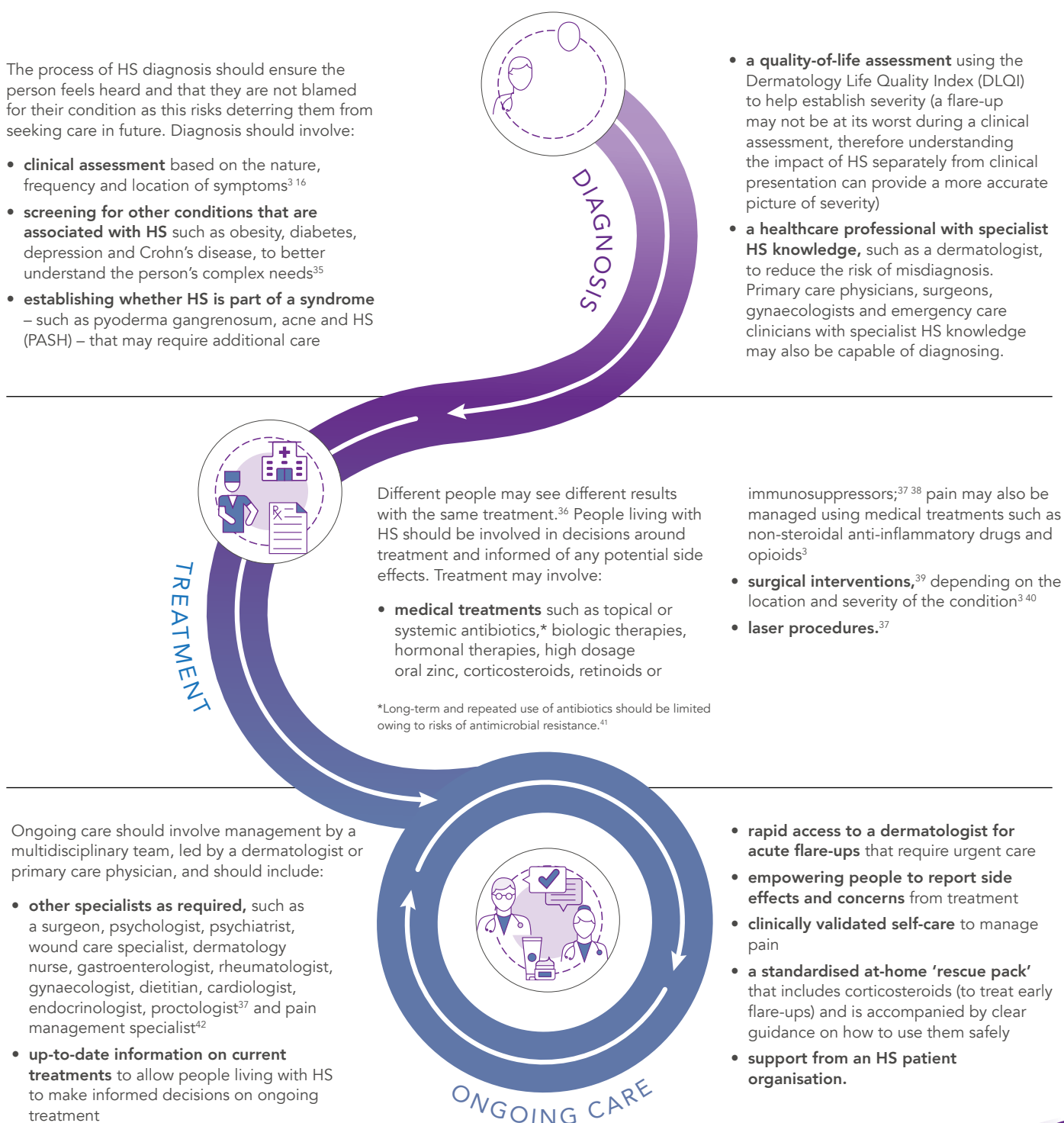
What does best-practice  
care for HS look like?



# 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



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.** Although there is no Swedish data available on pain, it is well understood that pain is experienced by almost all people living with HS, and is a major, debilitating symptom.<sup>21 25 43 44</sup> 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.<sup>43 45</sup>

## People living with HS often struggle with mental health issues

**HS can have an impact on the mental wellbeing of people living with the condition.** People with HS are at increased risk of depression and anxiety compared with people living with other conditions.<sup>31 46</sup> One person living with HS interviewed for this report said that her chronic pain, and the restrictions that the pain placed on her life, had led to her experiencing mental health challenges.<sup>47</sup>

## Social life can be affected by HS

**The range of HS symptoms can make socialising difficult.** Pain from HS can limit people's ability to be active.<sup>46</sup> One person interviewed for this report said that HS-related pain and fatigue can make seeing friends and family physically demanding, while unpredictable flare-ups (which may involve draining abscesses and tunnels) can interrupt social interactions.<sup>47</sup> This can contribute to feeling depressed and isolated.<sup>48</sup>

## People with HS may experience challenges around intimacy and personal relationships

**Pain and the location of symptoms can lead to issues around intimacy.** Although there is a lack of Swedish data on how HS affects intimacy, evidence from other countries has found that almost all people living with HS report a negative impact on intimacy.<sup>49 50</sup> One person interviewed for this report said that flare-ups of their HS made them avoid intimacy.<sup>47</sup> This can have a significant impact on a person's quality of life.

## HS can affect people's ability to work

**HS can force people to miss work, work while they are unwell and, in some cases, may lead to unemployment.** Currently, there is no published evidence on the impact of HS on employment in Sweden. However, there is evidence from other countries that indicates HS leads to people missing many days of work or working when they are not well enough.<sup>24 51</sup> It can also result in people losing their jobs or being unable to work – unemployment is between two and six times higher among people living with HS than the general population.<sup>24 51</sup>

## Living with HS can result in personal financial costs

**Wound care is a key part of managing HS symptoms, but this can place a financial burden on people living with HS.** Wound care is a daily part of managing HS, with one in six people needing five or more dressing changes a day, according to an international study that included people from Sweden.<sup>52</sup> The financial impact can vary widely depending on symptoms and healthcare costs, but almost half of people living with HS report that HS-related wound care negatively affects their financial wellbeing.<sup>52</sup>



### Annette's story

Annette was 16 when she found a small lump in her groin that disappeared after a few months. Nine years later she started to get a painful abscess on the inside of her thigh that hurt when she walked. Two years later (after losing 22kg) the symptoms had developed in her right armpit and she eventually had surgery to remove a sweat gland. Her eventual diagnosis of HS came from a dermatologist in 1998, 19 years after her initial symptoms. Annette's HS has become more severe in recent years as she has entered the menopause, with a diagnosis of Hurley stage 3 in 2018. This has led to more pain, more frequent flare-ups and a greater impact on her mental health.

*'The last ten years have affected my mental health because there have been more frequent flare-ups and chronic pain. It's difficult to always have chronic pain, but you somehow learn to live with it.'*

HS has made it difficult for Annette to be physically active and has led to issues around her weight.

*'I think most people can't do what they really want. You can't exercise, and by sitting too much you also put on a bit of weight, but also you can't lose any weight. I was told by a doctor I visited once that an HS patient can live on rice and water and still not lose weight.'*

Symptoms such as pain and fatigue have made it harder for Annette to socialise with friends in recent years.

*'Sometimes I don't really feel like going and seeing friends because I'm so tired from the pain. Your brain is tired and you have no energy.'*

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

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

## Low awareness of HS among healthcare professionals is contributing to delays in diagnosis

**Limited awareness of HS among healthcare professionals is contributing to long delays in diagnosis.** One global study, which included people from Swedish centres, estimated the average delay from people experiencing symptoms to receiving a diagnosis to be more than seven years.<sup>53</sup> A lack of awareness among non-dermatologists who are involved in referring people to dermatology has been suggested as a possible factor in the underdiagnosis of HS.<sup>20</sup> This may also be contributing to delays in diagnosis. One person with HS who was interviewed for this project said that they had experienced a delay of 19 years from their first symptoms to their HS diagnosis.<sup>47</sup> This highlights the need to educate healthcare professionals about HS, to speed up diagnosis.

## Access to multidisciplinary care is variable

**HS care should involve multidisciplinary care for people with complex symptoms, but this is not widely available in Sweden.** A survey carried out by HS International Sweden found that among 13 (out of 21) regions that provided data, seven appear to have no specific team for HS.<sup>54-60</sup> One person interviewed for this report said that they had not experienced multidisciplinary care for their HS.<sup>47</sup> More is needed to ensure that people living with HS in Sweden have access to the best care available.

# Recommendations for policymakers

## Recommendations for policymakers

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

To improve the lives of people living with HS, policymakers in Sweden should consider the following recommendations, which have been developed by the authors of this report:

- **Roll out HS educational programmes for healthcare professionals** – with a focus on non-dermatologists – to raise awareness, increase understanding of the condition and improve the speed of diagnosis.
- **Encourage the provision of multidisciplinary care** in centres providing HS care.



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