

How do hidradenitis suppurativa (HS) symptoms affect the day-to-day life of patients with HS?



Inspired by patients.
Driven by science.

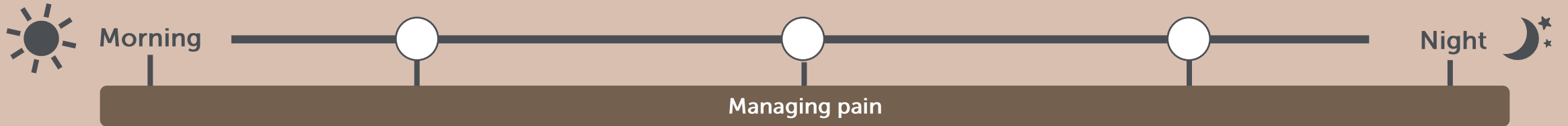
This resource is aimed at healthcare professionals, produced and funded by UCB.

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Objectives

- Understand the impact of pain on patients living with HS
- Recognise how HS affects patients including:
 - Quality of life
 - Work
 - Relationships and social interactions

Pain is a debilitating symptom for many patients, particularly those with severe HS^{1,2}



Patients with HS experience pain throughout their day, including general pain, pain on sitting and painful movement of limbs¹

In the HS Global VOICE study (N=1,299):^{2*}

9/10

Of patients described recent pain associated with their disease

6/10

Of patients described their recent pain as moderate to worst possible

“I would be in my room crying and rocking back and forth because the pain was so bad”

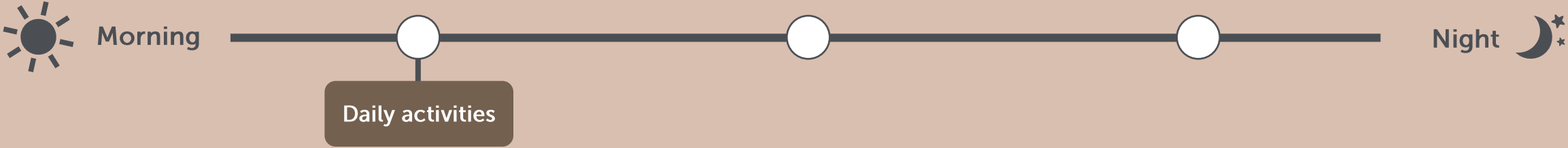
– A patient with HS³

*Prospective multinational survey of patients with HS between October 2017 and July 2018 (N=1,299).

HS, hidradenitis suppurativa.

1. Ingram JR, et al. J Eur Acad Dermatol Venereol. 2022;36:1597–605. 2. Garg A, et al. J Am Acad Dermatol. 2020;82:366-76. 3. Patel SZ, et al. Curr Pain Headache Rep. 2017;21:49.

Patients report significant impact to their quality of life and daily activities^{1,2}



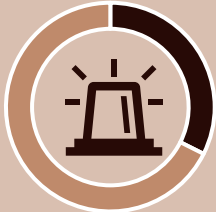
Patients with HS often report a **very large impact on their quality of life** that is higher than other dermatological conditions such as psoriasis³

In the HS Global VOICE study (N=1,299):^{2*}

>70%

of patients reported that HS **impacted their lives** moderately or greater in the last week

...and over a quarter reported their HS lesion **very much/extremely** caused them to feel:²



Angry



Depressed



Withdrawn

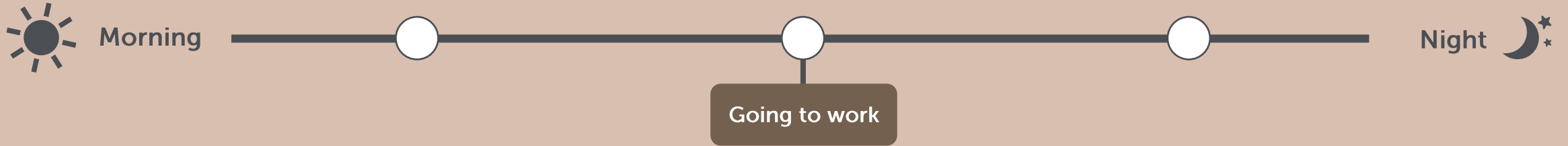
“There are days when I can’t hold up my arm to tie up my hair...
it’s little things like that or even climbing the stairs.”
– A patient with HS¹

*Prospective multinational survey of patients with HS between October 2017 and July 2018 (N=1,299).

HS, hidradenitis suppurativa.

1. Howells L, et al. Br J Dermatol. 2021;185:921-34. 2. Garg A, et al. J Am Acad Dermatol. 2020;82:366-76. 3. Matusiak L, et al. Acta Derm Venereol. 2010;90:264–8.

High levels of working disability may have a major impact on patients with HS¹⁻³



HS can have a profound impact on the working lives of patients, from absence to unemployment¹⁻⁴

Work productivity

- **WPAI scores were lower** for patients with HS compared with patients with moderate to severe psoriasis³
- A study in Germany reported productivity **loss of 25.2%** while at work⁵

Promotion

- A **lower rate of promotion** has been reported by patients with HS²
- 23.3% of patients believe that **HS interfered** with promotion^{2*}

“I no longer work, I stay at home.

Explaining the disease to employers is almost impossible.”

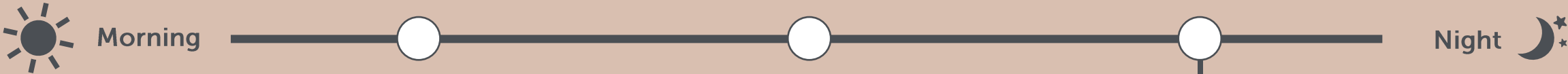
– A patient with HS⁶

*In a study of 54 Polish patients with HS, 7 reported that HS interfered with promotion and 3 patients reported being dismissed from work due to absences and inability to perform work duties. WPAI, Work Productivity and Activity Impairment.

HS, hidradenitis suppurativa.

1. Dufour DN, et al. Postgrad Med J. 2014;90:216–21. 2. Matusiak L, et al. J Am Acad Dermatol. 2010;62:706–8. 3. Mac Mahon J, et al. Patient Relat Outcome Meas. 2020;11:21–6. 4. Delany E, et al. J Eur Acad Dermatol Venereol. 2018;32:467–73. 5. Schneider-Burrus S, et al. Br J Dermatol. 2023;188:122–30. 6. Canadian Skin Patient Alliance. Scarred for Life. 2017. Available at: https://www.canadianskin.ca/images/Documents/CSPA_Report_March_22_2017_website_final.pdf [Accessed April 2024].


Many patients with HS report impacted relationships and social interactions due to their disease¹⁻³





The symptoms of HS can often affect **sexual intimacy, relationships and social interactions** for patients¹

Many patients cope through **avoiding situations**, which can have **negative psychological consequences**¹

In an online survey of people with HS:^{2*}

 **47.9% reported a fear of rejection or feared the reaction of their sexual partner**

 **61.9% reported pain interfered with sexual relations**



Many patients with HS feel **reluctant to discuss HS with their spouse/significant other**^{3†}

“I don’t really go out as much because I am typically in pain...
I’m not really interested in socialising with friends and family as much”
– A patient with HS¹

*In an online cross-sectional survey (N=386), 47.9% (185/386) of participants experienced fear of rejection or feared the reaction and 61.9% (239/386) reported that pain interfered with sexual relations. †In an online survey across North America, 43.0% (320/873) reported they felt reluctant to discuss HS with their spouse/significant other. HS, hidradenitis suppurativa.
1. Howells L, et al. Br J Dermatol. 2021;185:921-34. 2. Cuenca-Barrales C, Molina-Leyva A. Int J Environ Res Public Health. 2020;17:8808. 3. Thompson AM, et al. Skin Appendage Disord. 2022;8:448-53.

Summary

- Patients with HS may often experience pain throughout the day
- HS has a severe impact on patients' lives including pain, their ability to work, quality of life, and relationships
 - Patients with HS report a moderate or significant impact on their lives
 - Absence and unemployment contribute to the high levels of working disability in patients with HS
 - Patients may avoid social situations, and report that pain can interfere with sexual relationships