



Talking about HS: Your guide to better conversations

It's important to talk about your hidradenitis suppurativa (HS) with your friends, family, colleagues and doctors. But talking about your experience may be harder than it seems.

As HS affects one in every 100 people, it's not a rare condition,¹ yet it's often misunderstood. While the symptoms of HS mainly affect the skin, it can impact various aspects of daily life, with many people also having trouble sleeping.²

Just as your condition is unique to you, your conversations should be too! Alongside tips for getting the most out of your appointment, you'll find a symptom checker section for you to personalise to make your conversations easier and help prepare you for your medical appointments.



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How can you get the most out of your appointment?



Bring a friend or family member with you

If you can, try to have a trusted friend or family member accompany you to your appointment; not only will they be able to provide support but they'll also help you remember important information.



Be open and honest

HS is more than the physical symptoms. For some, HS can have a detrimental effect on social and/or work life, as well as on their ability to carry out day-to-day activities.³ As HS can impact everyone differently, it's important to tell your doctor how you are really feeling. We've included a section below for you to personalise to help you better understand how your HS may be affecting your wellbeing.



Think ahead and write down any questions you have

Whether it's about your treatment or anything else, don't hesitate to ask any questions or express any concerns you may have – it will allow you to have an honest conversation with your doctor. The box on the right includes examples of questions you may want to ask. You'll also find a notes section at the end of this guide in case you have any others.

You may want to ask:

- What causes HS?
- How do you treat HS?
- Will my HS get better with time?
- Am I at risk for other conditions if I have HS?

My skin symptoms over the past 3 months

Symptoms are as individual as you are, and it may be difficult to remember them accurately. Complete this guide to help you and your doctor better track your symptoms.

Have you experienced the following symptoms?^{4,5}

Please tick all that apply:

Change in skin tone, swollen lumps,
some may be filled with pus

Itching

Odour

Discharge of liquid and/or blood

Where on your body
have you experienced
these symptoms?

Have you experienced
any other conditions or
symptoms that may be
linked to your HS?

My skin symptoms continued...

Think about any feelings of pain you've been experiencing recently:

How would you rank your pain? (0 being no pain and 10 being unbearable pain)

No pain

0 1 2 3 4 5 6 7 8 9 10

Unbearable pain

Have you noticed any changes in the duration or frequency of pain episodes?

Has your pain been preventing you from carrying out any daily activities?

Have you been doing anything to manage your pain?

How would you rank the overall effect of your symptoms? (0 being none and 10 being unbearable)

None

0 1 2 3 4 5 6 7 8 9 10

Unbearable

How long has it been since your last HS flare?

(A flare is when your symptoms get worse for a period of time)

How long did your symptoms last for during your last flare?

Is there anything that makes your symptoms worse and/or unmanageable?

Is there anything else about your symptoms that you would like to talk about?



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My wellbeing over the past 3 months

We understand that HS affects everyone differently. Many people will only experience mild symptoms, and while not all of the below may apply to you, be sure to tick those that do.

Has HS caused you to:⁵

Please tick all that apply

- Miss a day or more from work or school
- Cancel social plans
- Struggle with day-to-day activities, such as cooking, cleaning, watching TV, or childcare
- Have difficulty sleeping
- Have impaired sexual activity
- Spend 2 or more days in bed
- No change in my daily life
- Other

Has HS caused you to feel:⁵

Please tick all that apply

- Low or depressed
- Annoyed or frustrated
- More detached in my relationships (including friends, family and colleagues)
- Ashamed, self-conscious or low self-esteem
- Anxious or worried
- So hopeless that I've considered taking my own life
- Other

Any more questions?

Your HS is unique to you

By completing this guide, you should now have the information you need to discuss your symptoms. We recommend taking this guide to your appointments to make the most out of the time with your doctor.

When it comes to talking about and sharing your personal experience with HS with those around you, be it friends, family or colleagues, it may help to explain that while the symptoms come and go, it can be very difficult to manage during a flare up. You shouldn't feel bad about cancelling plans, discussing your options with your manager or colleagues, or bringing it up in a new relationship. But above all, whatever information you choose to share about your HS is completely up to you.

To read more about HS, visit

[local UCBCares website link and QR code]



References

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GL-DA-2400280 | Date of preparation: May 2024