UNDERSTANDING
HIDRADENITIS SUPPURATIVA (HS)

Information to help you work with your doctor so you can better manage your HS

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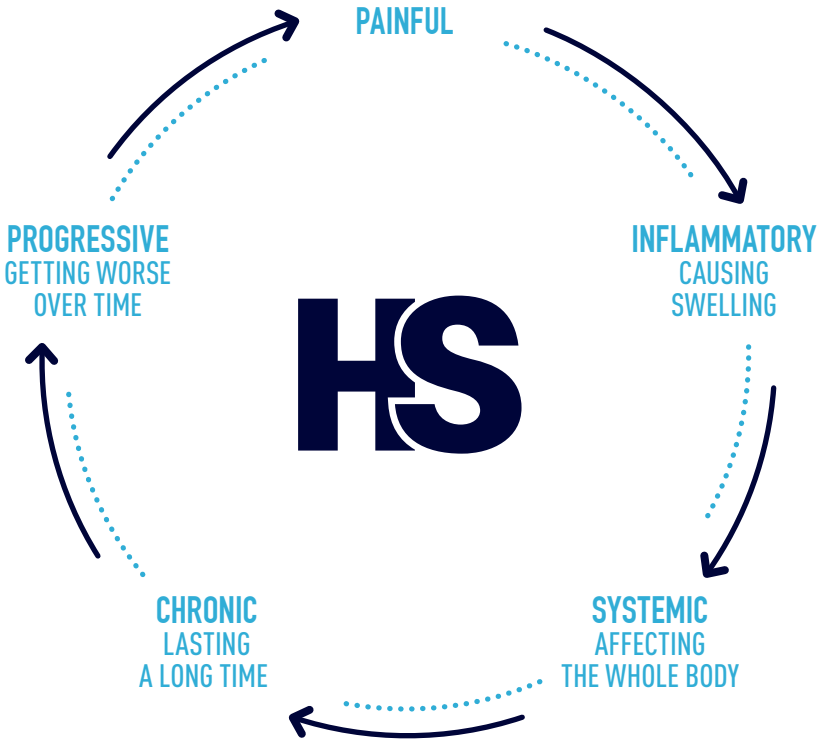
HIDRADENITIS SUPPURATIVA (HS) IN BRIEF

You have been diagnosed with HS, a disease which is:



HS is known to produce lesions in the skin that are inflamed (swollen), recurrent (reappearing after lesions disappear), and chronic (lasting a long period of time).

HS can have both a physical and psychological impact. The resulting pain and affected areas of your skin can restrict movement and your ability to do day-to-day tasks. Because of the areas of the body affected and how unsightly, smelly, and uncomfortable or painful HS may be, it can also lead to negative feelings such as embarrassment, stress and low mood.

While we understand this is how some people with HS may feel, it's important to remember that HS is a medical condition — its development is **not your fault**.

It's important to be able to manage the physical side of the condition while also trying to reduce any feelings of embarrassment you may feel. There is more information about addressing your thoughts and feelings on page 14.

Talk to your dermatologist or nurse if you have any questions or concerns about HS, or if you are having problems coping. We have tips on page 18 to help you make the most of your relationship with your doctor.

We hope this booklet will help you build meaningful discussions with your dermatologist so you can find solutions together to cope with this disease.

WHERE DOES THE NAME *HIDRADENITIS SUPPURATIVA* COME FROM?

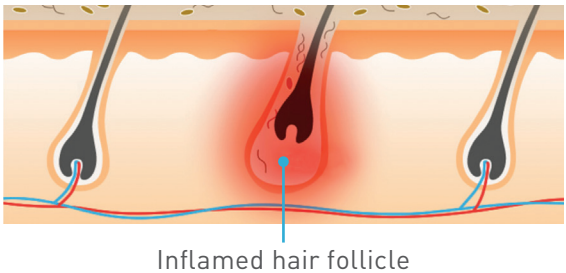
Hidradenitis: a Greek word that means "inflammation of the sweat glands"
Suppurativa: a word that means "producing pus", which is a symptom that may be present in more severe forms of HS

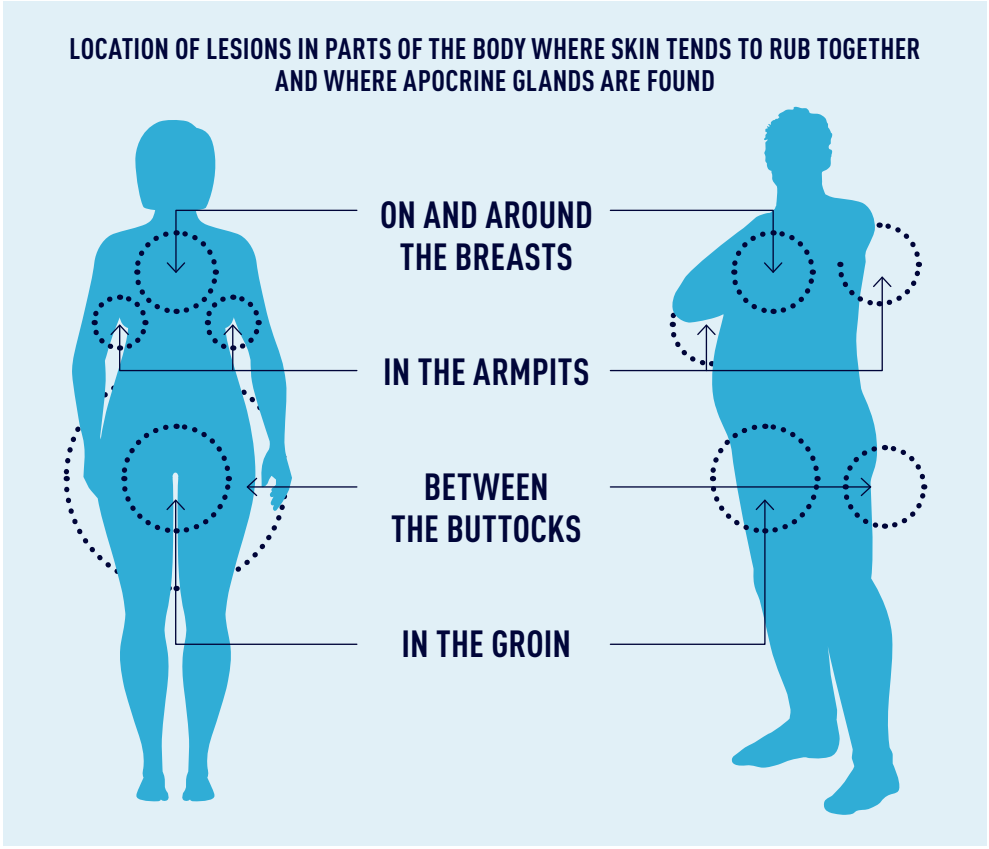
HS – THE FACTS

HS lumps are usually found in portions of the skin where there are special sweat glands called apocrine glands. Apocrine glands are located in parts of the body where hair is abundant, such as armpits, the groin, and the genital area. HS is thought to be a disease that involves the hair follicle, which means that HS lumps are especially likely to appear on the skin where hair is abundant. HS lumps also form under the breasts, on the buttocks and/or on the inner thighs, which are parts of the body where skin tends to crease or rub together.

HS may be due to defects within the hair follicle.

Hair follicle:
A cavity where hair grows out of the skin





What are the symptoms of HS?

Each person with HS is different. HS symptoms for one person may not be just like those for another person with HS. However, some signs of HS are more common, and will be present at one time or another for most people with this disorder.

Depending on the severity of your HS, you may experience some of the following signs and symptoms:

Blackheads

- Small blackheads are common in HS, and often appear in pairs in pitted skin.

Abscesses

- Often, these red and tender bumps enlarge and break open. Abscesses can burn, cause pain, and contain pus. They can create an unpleasant odour when they break open and release pus.

Nodules

- Nodules are hard lumps in the skin that may persist for years. They may get bigger and cause pain and swelling.

Fistulas and sinus tracts

- Fistulas are open wounds that heal very slowly, if at all. In many cases, this leads to the development of tunnels (sinus tracts) connecting the bumps in the skin.

Flares

- For some patients, HS lesions recur and resolve (come and go) at regular or irregular time intervals. When they recur, it is called a flare.

Pain

- Regardless of the type of lesion, many of them tend to be associated with pain.

HS severity

HS can vary greatly in severity, both between cases and over time for one individual with HS. Different classification systems exist to rank HS by degree of severity.

HS can be classed as Hurley Stage I, II or III:

HURLEY STAGE I	HURLEY STAGE II	HURLEY STAGE III
Single or multiple abscesses without sinus tracts or scarring	One or more widely separated and recurrent abscesses with tract formation and scarring	Multiple interconnected tracts and abscesses across an entire area

The images are from actual patients with HS and were adapted from an article written by Dr. Gregor Jemec (*N Engl J Med* 2012;366:158-64).

Sometimes HS is mistaken for other diseases, and it takes longer to get a correct diagnosis. Your dermatologist is trained to diagnose HS.

What causes HS?

Although the exact cause of HS is not known, we know that the condition could in part be the result of a problem in your immune system that leads to the blocked and inflamed hair follicles. Even though researchers don't know why this blockage occurs, they believe factors that may play a role in the development of HS include:

Age: HS can occur at any age, but is most common in people in their early 20s.

Hereditary factors: People may inherit genes that make it more likely for them to develop HS. For that reason, there is a tendency for HS to run in families: 30% to 40% of people with HS also have a family member living with HS.

Gender and hormones: There are three times more women than men diagnosed with HS. Sex hormones likely play a role.

HS is called an *immune-mediated disorder*, which means that HS develops when the immune (protective) system malfunctions and attacks healthy portions of the body. When painful symptoms of HS appear in the skin, researchers believe it is because the immune system overreacts to a blocked hair follicle.

How common is HS?

If you have been diagnosed with HS, you are not alone: at least 1% of adults are thought to be affected by HS.

WHAT HS IS NOT:

- It is not an infection, or caused by an infection.
- It is not a series of ordinary sores, cysts or boils.
- It is not a type of severe acne.
- It is not contagious.
- It is not caused by poor hygiene.

LIVING WITH HS

What living with HS feels like for Darlene and Nicholas

"I am depressed, irritable, very frustrated and in excruciating pain some days."

"I am missing work because there are days that I can't even get dressed."

"I certainly don't want to try and explain something that neither I nor the doctors are able to explain."

Darlene, HS patient

"Living in constant pain is a serious deterrent from social activities."

"I all but eliminate social interactions and semi-frequently require to stay home from work, whether due to pain or the location of lesions."

Nicholas, HS patient

Testimonials adapted from quotes from Nicholas and Darlene, actual patients living with HS.

COPING WITH HS

HS is a disease: it is not your fault that you have HS.

The inflammation and pain **may affect your ability to do routine tasks** at home or to go to work as normal, while the unpredictability of the condition may affect you in terms of making plans.

You may find it **stressful and emotionally challenging**, at times, to live with HS. Remember that **you are not alone** and that you can turn to your family and friends for help. It may help reduce the emotional impact and stress of your HS to have positive conversations with your loved ones.

Other coping methods may work well for you, too. You can find **HS support groups online** that provide a safe space to connect with other people touched by HS. It may be helpful just to know that there are people in a situation similar to yours; some of your peers with HS may also provide you with new approaches, empathy, and even a sympathetic ear when you need to vent about how you're feeling.

Being open and honest with your dermatologist may provide him or her with a better understanding of how you are doing. You can also consult a psychologist for help with finding new solutions to your stress, providing a new viewpoint that may help you to see issues more clearly, or working through the emotions that come with living with HS.

If you work, **you may want to discuss HS with your manager**: together, you can tackle any problems that come up, and decide on ways of easing the pressures of work. For example, your employer may agree to a more casual wardrobe for your workplace, or to minimizing your discomfort by allowing you to work from home some days.

TIPS AND TRICKS FOR LIVING WITH HS

Here are some ideas that your doctor may have discussed with you and that other people with HS have found helpful in reducing its day-to-day impact. Each patient with HS is different. Using these tips may help you live better with HS and regain ownership of your life.

Say YES to keeping your skin cool: Becoming overheated and sweaty may trigger a flare of your HS symptoms. Your dermatologist can also tell you which antiperspirants would be suitable for your skin.

- Avoid prolonged exposure to heat and humidity, if possible.
- Ask your health care team about antiperspirants that may help reduce sweating while also avoiding skin irritation. They may also be able to recommend perfumes/aftershaves that can be used on clear areas to help hide the smell.
- Avoid applying perfumes or deodorants directly onto the skin of affected areas.

Say YES to wearing HS-friendly clothing: You can help prevent friction and skin irritation by wearing loose clothes and underwear. Cotton, silk and other natural fibres are breathable fabrics that allow air to flow around your skin. Avoid synthetic fabrics and tight-fitting clothes and underwear, which may irritate affected areas.

Say YES to keeping affected areas clean: Use a gentle antibacterial soap to wash affected areas of your skin. Your health care team is a great resource for advice on caring for wounds, and managing any leakages.

Say YES to applying warm compresses to painful cysts and nodules: You can use a warm washcloth or compress to help reduce swelling. Start by running a clean washcloth under hot water, then place the hot compress on the affected area of your skin for 10 minutes. While the warmth won't get rid of the cyst or nodule, it will provide some pain relief.

- **Say YES to having a social life that suits your needs**: For days when meeting friends in public would feel more stressful than fun, invite them over to your house instead for a casual get-together. This way, if need be, everything will be within reach should you need to care for your skin.
- **Say YES to planning ahead before leaving the house**: When you go out, bring with you extra dressings, a change of clothing, and any medication your doctor has prescribed for the pain.
- **Say NO to smoking**: As you know, quitting smoking provides many health benefits; when it comes to HS, not only can smoking cessation help reduce flares, but it can also decrease the severity of your HS symptoms.
- **Say NO to shaving affected areas**: Avoid shaving, which can irritate the skin. Ask your dermatologist about hair removal methods that may be right for you.

HS can affect people differently – make sure to discuss these tips with your health care team.

ADDRESSING YOUR THOUGHTS AND FEELINGS

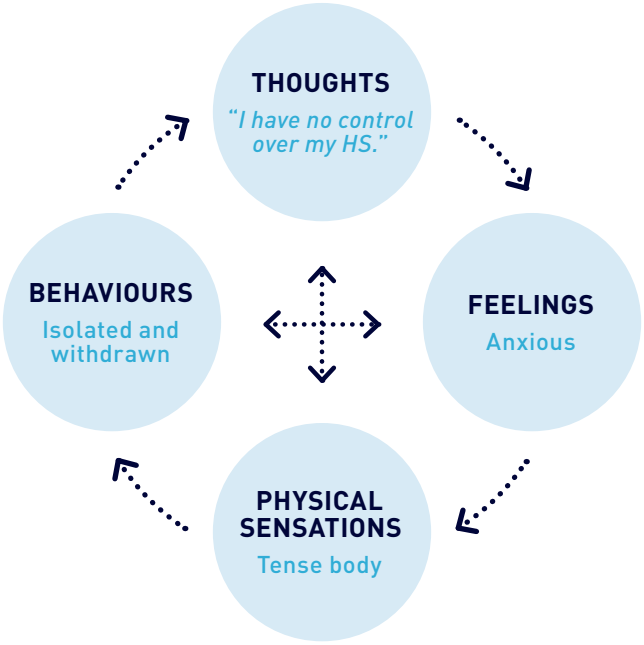
While it's important to try and manage the physical side of HS, looking after the way you feel is also important. **HS can have a big impact on your day-to-day life**, and some days are better than others.

Often if you feel that a situation is out of your control, it can make you feel self-conscious or anxious, and these feelings can build up to make you feel even worse. However, **there are some steps you can take to help manage the way you feel** and how you react to certain situations.

You don't have to face HS alone: We encourage you to ask for help early, when you first need it. **There are many resources available**, which you can find out about and make the most of throughout your journey with HS.

The way we think and feel can affect the way we behave, and the way we behave can in turn impact the way we think and feel. **Finding a new way of thinking** can make us feel better and can result in more positive thinking.

For instance, if you're reluctant to leave the house in case a lump bursts, or if you're worried about how HS might look to others, then it can be helpful to **be aware of these feelings** and work on ways to ease some of that anxiety.



Certain situations – or incidents – may affect the way you feel. Recording how you feel during specific day-to-day experiences can help you understand how you react to certain situations. It can also be helpful to have a written record if you want to discuss certain issues with your doctor, nurse or pharmacist. It's important to express how you feel: sometimes, writing things down is enough to help you feel better, and can even help you put things into perspective.

Use the space below to jot down some unwanted thoughts or feelings you experienced, and the situations or incidents that triggered them.

Situation/Incident	How it made me feel

COPING WITH STRESS

Everyone deals with stress differently, but there are simple steps you can take to help reduce your stress:

Focus on your breathing. Taking deep breaths really works to calm you down – take a deep breath in (make sure to expand your rib cage and abdomen, and keep your shoulders down) and slowly let it out. Do this ten times.

Relax your body from head to toe. Focus on relaxing your body one part at a time, starting with your fingers and toes: move on to your hands and feet, arms and legs, hips and torso, and neck and face.

Eat a healthy diet. Eating well and regularly keeps your body strong, which helps when dealing with stress.

Keep routine and healthy sleeping habits. Going to bed at the same time every night and getting enough rest will help you face day-to-day challenges.

Be kind to yourself. Often times, we experience stress because our expectations are different from what life brings our way. We feel stressed because we didn't remember to pick up some milk, or we slept through our alarm. When this happens, give yourself a break, and remember that nobody's perfect. And getting stressed doesn't solve the situation at hand.

Treat yourself every now and then. We are used to being thoughtful toward others – why not give yourself the same treatment for a change? If life has got you down, give yourself a boost by treating yourself to something special – for example, buy a new book, or maybe indulge in your favourite food. Or give yourself permission to take an evening off and just lounge in your living room.

WORKING WITH YOUR HEALTH CARE TEAM

Actively manage HS

Managing any medical condition is a team effort – it needs input from you and your health care team. You can try and take responsibility for HS by being involved in the decisions related to your disease.

See page 12 for more tips and tricks to help you with symptoms in day-to-day life.

Be open and honest

Working well with your health care team is a really important aspect of managing HS.

Sharing how you're feeling and how HS is affecting you is the best way to help your health care team understand the impact of HS on your life. Consider keeping a symptom diary, such as the one provided in the following pages and share it with your dermatology health care professional. Use it to record how you're feeling and any changes in symptoms.

Make the most of appointments

Notes for my medical appointments

Before and during your appointment with your dermatologist, fill in this page with concerns you want to raise and follow-up points you want to remember. Writing these things down may trigger some additional questions that you can also run by your dermatologist.

Questions for my dermatologist:

To be completed before the appointment

Points discussed with my dermatologist:

To be completed during the appointment

Actions I need to take before my next appointment:

To be completed during the appointment

Points to follow up on at my next appointment:

To be completed during or after the appointment

SYMPTOM SELF-ASSESSMENT QUESTIONNAIRE

Complete this questionnaire before your next appointment with your dermatologist. At your next appointment, show your answers to your doctor to give him or her a clearer understanding of how your condition is progressing.

Date: / /

1. In the last 6 months, have you had 2 or more HS flares? ☐ Yes ☐ No

Describe your symptoms during flares if your disease isn't constant. You can also take pictures of your lesions during your flares to show your dermatologist.

2. Approximately how many inflammatory lesions (nodules and abscesses) do you have in the following areas?

_____ On, around or under the breasts

_____ In the armpits

_____ Between the buttocks

_____ In the groin/genital area

_____ Other location(s)

SYMPTOM SELF-ASSESSMENT QUESTIONNAIRE (CONT'D)

3. For the areas listed below, describe what a typical skin lesion looks and feels like in terms of redness and pain, and describe whether abscesses are leaking or not. Circle the appropriate response.

On, around or under the breasts

☐ No lesions

Redness	None	Pink	Red	Very red
Pain	None	Mild	Moderate	Severe
Leaking abscesses	None	Mild	Moderate	Severe

In the armpits

☐ No lesions

Redness	None	Pink	Red	Very red
Pain	None	Mild	Moderate	Severe
Leaking abscesses	None	Mild	Moderate	Severe

Between the buttocks

☐ No lesions

Redness	None	Pink	Red	Very red
Pain	None	Mild	Moderate	Severe
Leaking abscesses	None	Mild	Moderate	Severe

In the groin/genital area

☐ No lesions

Redness	None	Pink	Red	Very red
Pain	None	Mild	Moderate	Severe
Leaking abscesses	None	Mild	Moderate	Severe

Other location (please specify)

☐ No lesions

Redness	None	Pink	Red	Very red
Pain	None	Mild	Moderate	Severe
Leaking abscesses	None	Mild	Moderate	Severe

Other location (please specify)

☐ No lesions

Redness	None	Pink	Red	Very red
Pain	None	Mild	Moderate	Severe
Leaking abscesses	None	Mild	Moderate	Severe

Other location (please specify)

☐ No lesions

Redness	None	Pink	Red	Very red
Pain	None	Mild	Moderate	Severe
Leaking abscesses	None	Mild	Moderate	Severe

SYMPTOM SELF-ASSESSMENT QUESTIONNAIRE (CONT'D)

4. Overall, do your lesions cause you pain? ☐ Yes ☐ No

If yes, please specify:

The frequency of pain (daily, approximately once a week, etc.)

If the severity of pain:

☐ is constant throughout the day

☐ is more severe (at night, in the morning, during specific activities, in specific situations, etc. Describe all that apply.)

5. How have you been feeling, overall, in the last six months?

Not well **1 2 3 4 5 6 7 8 9 10** Very well

USEFUL ONLINE RESOURCES

Canadian Web sites*

Canadian Skin Patient Alliance
skinpatientalliance.ca

Canadian Dermatology Association
dermatology.ca

International Web sites*

Hidradenitis Suppurativa Foundation (USA)
hs-foundation.org

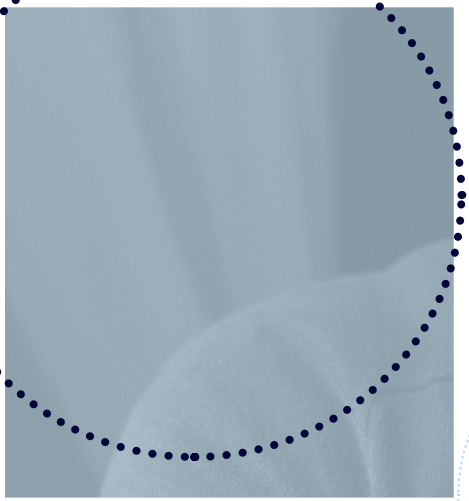
American Academy of Dermatology
aad.org

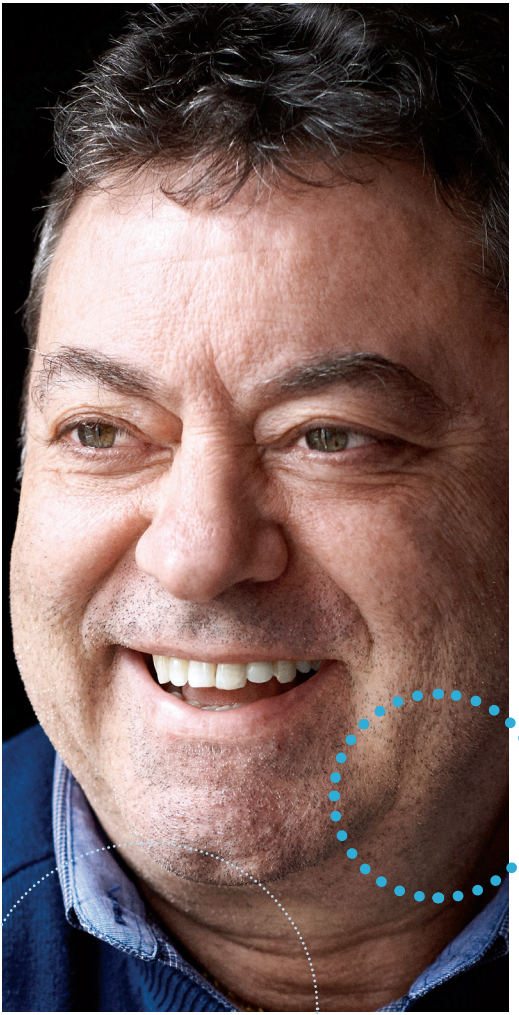
The Hidradenitis Suppurativa Trust (UK)
hstrust.org

Mayo Clinic
mayoclinic.org/diseases-conditions/hidradenitis-suppurativa/basics/definition/con-20027334

MedlinePlus
nlm.nih.gov/medlineplus/hidradenitissuppurativa.html

* The Web sites suggested in this brochure do not imply an endorsement of, or association with third-party organizations/Web sites, and are provided for information purposes only.





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