

NAVIGATING HIDRADENITIS SUPPURATIVA (HS) AND MOTHERHOOD

Information for Women of Childbearing Age living with HS

This resource was funded by UCB. It has been prepared by the authors and reviewed by an HS WoCBA Patient-HCP Expert Council: Angela Gibbons, Brindley Brooks, Catherine Nelson-Piercy, Chevonne Smellie, Cydney Cartner, Farida Benhadou, Ginette Okoye, Gloriel Veillard, Jennifer Hsiao, John Ingram, Lauren Lam, Stephanie Goldberg, Valeri Liebig

HS = hidradenitis suppurativa

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GUIDE OVERVIEW

Being informed is the first step to feeling confident and in control when managing hidradenitis suppurativa (HS) during pregnancy and motherhood.

This guide answers common questions about living with HS as a woman of childbearing age. The information was developed with input from medical experts and people living with HS* based on their own experiences.

You can also access a video series featuring experts discussing these topics by scanning the QR code:



Introduction

This resource is split into four topics, selected by experts:

-  **Family planning**
-  **Mental and sexual health, intimacy, and HS**
-  **Lactation, breastfeeding, and postpartum**
-  **Treatment effects and safety**

Information is provided as a starting point for discussion with healthcare providers, family members, or support groups.

Healthcare providers remain the first point of contact for any concerns or questions around the management of HS, but being informed can support you to advocate for yourself during these discussions.



*Experts who featured in the panel discussion:

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Lauren Lam, Dermatologist and Vice President of the Canadian HS Foundation
Stephanie Goldberg, General Surgeon, US
Valeri Liebig, Therapist and person living with HS, US



FAMILY PLANNING

When should I discuss pregnancy with my doctor?

- Try to plan ahead and talk to your healthcare team before trying to get pregnant, although this may not always be possible
- If a pregnancy is unplanned, it is important to let your healthcare team know as soon as possible so that they can guide you on next steps
- You may need to work with a team of specialists such as dermatologists and obstetricians (OB-GYN) to manage your care during pregnancy

Will I need to change my HS treatment before or during pregnancy?

- Some treatments may need to be adjusted before or during pregnancy. Your doctor will help you decide what is safest for you and your baby
- There may be a need to adjust treatment during pregnancy in line with HS symptoms, but this should be under the supervision of your healthcare team
- Hormonal changes during pregnancy may impact HS symptoms – some women may notice improvement, while others experience flares
- HS symptoms during pregnancy and postpartum can differ between individuals, and can also differ between pregnancies

Does HS impact fertility?

- There is no evidence to suggest that HS directly impacts fertility, but some women with HS may face fertility challenges similar to women in the general population
- Some women with HS may also have polycystic ovary syndrome (PCOS) which can affect fertility
- Fertility treatments (such as IVF) may be available for some women with HS. It is important to talk to your doctor early if you are considering these options and to determine whether this might be an option in your country

“I think it is really important as a patient advocate to make sure that our patients know that you can have a fully healthy pregnancy and be a healthy mother and have a healthy child, even though you have HS”

Patient Advocate



FAMILY PLANNING

Can tracking my cycle help me manage HS symptoms?

- Tracking your menstrual cycle and hormonal changes may help you to identify patterns in your HS symptoms
- There are apps and tools championed by patient advocates that are useful for women living with HS who want to track their cycle and symptoms. Consider asking your doctor or support groups for suggestions

Could HS be passed on to my children?

- HS has a genetic link, meaning it can run in families, but predicting whether or not it will be passed on is complicated
- There is an increasing amount of research being conducted into the genetic link of HS
- Studies suggest that multiple genes may play a role, and many people with HS have a family history of the condition
- Deciding to have children is a personal choice, and your healthcare team can support you to make the decision that is right for you

Does birth control impact HS?

- HS symptoms and flares are often linked to changes in hormone levels
- Hormonal birth control can reduce HS symptoms for some women. It is not considered a treatment, but talk to your doctor about your options
- It is important to consult your doctor before starting a new birth control

Does HS management impact birth control?

- There is no evidence to suggest that HS itself impacts the effectiveness of birth control
- Certain antibiotics used to treat HS can make some types of birth control less effective. Always check with your doctor or pharmacist if you are not sure

“There’s no genetic test for HS...there’s no universal gene mutations that have been identified for HS. So that’s kind of a challenge for us in the research community, to try and figure it out”

Dermatologist



MENTAL AND SEXUAL HEALTH, INTIMACY, AND HS

How might HS impact my mental health during pregnancy?

- It is normal to experience emotional changes during pregnancy
- Women with HS may face additional challenges, such as stigma or difficulty making decisions about medication and breastfeeding
- People with HS are at higher risk for anxiety and depression, so it's important to seek support if you are struggling
- Postpartum depression may be experienced by women with or without HS in the first year after birth, and it is unclear whether the risk of postpartum depression is increased in those with HS

Where can I find support for mental health during pregnancy and motherhood?

- It is important to take care of your mental health throughout pregnancy and motherhood, and seek support as needed
- Your healthcare provider may be able to connect you with mental health support and resources
- Many women find support groups and patient advocacy organizations helpful for connecting with others who share similar experiences
- Patient advocacy groups may provide useful resources on mental health and family planning for women living with HS

“ Many people with HS, they don’t want to feel like a burden, and so they just carry the weight of the disease on their own, and especially during this time, during pregnancy, this is a time where you can absolutely depend on your friends and your family...it’s important that we communicate, and it’s so good if you have a supportive partner ”

Patient Advocate



MENTAL AND SEXUAL HEALTH, INTIMACY, AND HS

How may HS impact intimacy and sexual health?

- HS is not sexually transmitted and cannot be passed on through contact by any means
- HS can be misdiagnosed as herpes simplex virus (often known as herpes), which can add to stigma and impact intimacy
- Lesions in areas like the thighs, groin, or breasts can cause discomfort which may impact intimacy
- Feelings of shame can lead some women to avoid intimacy, and fatigue and pain may decrease desire for sexual activity

Where can I find support around sexual health and intimacy?

- Maintaining open communication with your partner is crucial for a healthy relationship
- Some women may find speaking to a therapist or counsellor helpful in supporting them to have healthy intimate relationships
- Others may find discussing sexual health and intimacy with their patient advocacy group or support community helpful

“First of all, I explain the disease, just to make them feel not guilty, because a lot of patients say, I’m guilty, what did I do wrong? So, I try to reassure them and tell them it’s not a sexual disease, it’s due to a problem with the hair follicle...it is important for them to hear that from a physician”

Dermatologist



LACTATION, BREASTFEEDING, AND POSTPARTUM WITH HS

What should I consider when making the decision to breast- or bottle-feed?

- Breastfeeding is a personal decision, and women with or without HS should feel supported no matter what they choose
- Lesions on the breasts or near the nipples may make breastfeeding difficult for some women with HS
- Your decision may depend on the type of medication you are taking. Talk to your doctor about the risks and benefits of breastfeeding on your current treatment plan
- The decision on breastfeeding is not fixed and might change if HS symptoms flare up. You may need to revisit the decision with your healthcare team through the postpartum period

What should I expect in the postpartum period from HS?

- HS symptoms may change after giving birth. Some women experience flares, although this is difficult to predict and differs between women and pregnancies
- Talk to your healthcare team prior to giving birth about how to plan for the postpartum period and for support on managing symptoms if they do flare up

Is there anything I can do to prepare for the postpartum period?

- Consider scheduling a follow-up appointment with your healthcare team after delivery to discuss how to manage changes in your symptoms, if possible
- Talk to your healthcare team about how you can be prepared for physical recovery after delivery
- Adapting to motherhood can be challenging for all women and you should prioritize your health and wellbeing during this time
- It is important that you seek support where necessary; HS support groups can be great resource during this time as you adapt to motherhood

“There’s definitely support groups for new moms, pregnant moms that they can turn to, and then, of course, HS support groups will be super helpful. You’ll certainly encounter other women who have already been through this and can walk you through it and provide that guidance, support, and encouragement during this time”

Patient Advocate



HS TREATMENT EFFECTS AND SAFETY

What is known about treating HS during pregnancy and motherhood?

- Treatment guidelines written by experts provide evidence-based recommendations for managing HS during pregnancy. These include guidelines by the European Academy of Dermatology and Venereology (EADV)¹ and the American Academy of Dermatology²
- Often guidelines exist for specific countries depending on which treatments are locally available, and are updated when new evidence becomes available
- Guidelines are used by healthcare professionals to guide treatment decisions
- Some women find it helpful to be aware of guidelines to support them to have informed discussions
- If you are pregnant, considering trying to become pregnant, or breastfeeding, you should always speak to your healthcare team when making treatment decisions
- While there are no supplements or vitamins specifically recommended for HS during pregnancy, there are vitamins recommended in general for pregnancy
- Speak to your doctor about which options may be appropriate for both your health and that of your child

“We often encourage people with HS to be their own advocate. And that just means when you are aware of information like the guidelines, you are better equipped to go into your appointment and have a discussion about your treatment instead of just being told what you should do. So definitely make yourself aware of what’s being advised in maybe other countries or just in your country, just so you can have a better conversation with your doctor”

Patient Advocate

1. Ghanshani R, Lee K, Crew AB, et al. A Guide to the Management of Hidradenitis Suppurativa in Pregnancy and Lactation. Am J Clin Dermatol. 2025;26(3):345-60. 2. Alhusayen R, Dienes S, Lam M, et al. North American clinical practice guidelines for the medical management of hidradenitis suppurativa in special patient populations. J Am Acad Dermatol. 2025;92(4):825-52.
HS = hidradenitis suppurativa



HS TREATMENT EFFECTS AND SAFETY

Why might treatments not be recommended in guidelines?

- Historically there has been a lack of research, and therefore data, on use of treatments in pregnant and breastfeeding women across many diseases
- When data is lacking it makes it difficult to make informed treatment recommendations in guidelines
- Pregnancy and lactation databases or registries are important to learn more about the use of treatments during these periods, and will improve future treatment approaches
- Ask your healthcare team about how you can get involved in future research

Can I take pain relief during pregnancy?

- Pain relief medications should follow guidelines based on the stage of pregnancy as some may not be recommended for use
- Always talk to your healthcare team before taking any supplementary medications
- Non-medical options, such as warm towels or salt baths, can help to manage pain associated with HS. Check with your healthcare team to confirm which options are safe for you during pregnancy

“I think there’s gaps in guidelines, in terms of they have to be evidence-based where they can be. And so, where there’s uncertainty, we rely on expert consensus. But, you know, it may be that there just isn’t enough consensus to then, find a single recommendation”

Dermatologist

This guide is designed to help you feel informed and empowered as you navigate pregnancy and motherhood with HS.

For more detailed information, scan the QR code to watch expert discussion on these topics.



This resource is funded by:



Inspired by **patients**.
Driven by **science**.

And is supported by the following organizations, who have additional resources at their respective websites:



HS Connect

