

Hidradenitis Suppurativa (HS)

What causes HS?

We know that HS is not an infection. HS is an inflammatory skin condition, because it is caused by the immune cells that normally protect us from infection. The immune cells make chemicals in the skin that cause the redness, pain, swelling, itch, and drainage. The hair follicle seems to be a place that HS spots happen, but we don't know yet why HS happens more in the folds of the body. HS may be worsened by bacteria, but bacteria are not the main cause of HS. This is why antibiotics can help some people with HS, but they are often not a cure.

Things to remember:

- HS is not a sexually transmitted disease.
- HS is not caused by poor hygiene.
- HS is not contagious.

Stages of HS: This describes how bad the HS is at each body site. Today, my stage is _____/not active.

- **Stage I:** usually means single or multiple bumps/boils without tracts between the bumps, and no scarring.
- **Stage II:** usually means you have more than a few bumps/boils, there are scars, and tracts between the bumps.
- **Stage III:** usually means you many bumps/boils and tracks with scars.

Nutrition: There is a lot of interest in nutrition and HS, but there isn't a lot of research showing what works. There is some research to show that weight loss, such as 10 pounds or more, and the 'Mediterranean Diet' may help us have better health, so it can be something to consider. Tips to try the Mediterranean diet:

- Eat more fruits and vegetables. Aim for 7 to 10 servings a day of fruit and vegetables.
- Opt for whole grains. Switch to whole-grain bread, cereal and pasta.
- Use healthy fats. Try olive oil as a replacement for butter when cooking. Instead of putting butter or margarine on bread, try dipping it in flavored olive oil.
- Try to avoid or eliminate processed foods: Sugar-sweetened beverages, added sugars, processed meat, refined grains, refined oils and other highly processed foods.
- Reduce red meat. Substitute fish, poultry or beans for meat. If you eat meat, make sure it's lean (less fat) and keep portions small.

Another option is the FODMAP diet, which can be helpful for people with Irritable Bowel Syndrome and more information can be found here: <https://my.clevelandclinic.org/health/treatments/22466-low-fodmap-diet>

Mental well-being: HS can be an emotionally challenging condition to have. It is common for people with HS to feel anxious, alone, and depressed. It can be helpful to talk to someone about how HS is affecting your everyday life. Your provider can give you a list of counselors in your area. There are also patient support groups which can be very beneficial to talk to other people who are experiencing the same feelings as you. People may have thoughts about suicide. If this happens, then it's important to get help. You can visit the emergency room or call the National Suicide Prevention Lifeline at 1-800-273-TALK (8255). It is available 24 hours a day, 7 days a week.

HS Communities for Support & Resources

- The **HS Foundation** is a non-profit dedicated to improving the lives of people affected by HS through research, education, and advocacy. The HS Foundation website has many educational resources: www.hs-foundation.org
- **Hope for HS** Hope for HS is a support group meeting for people with HS that is run by people with HS and doctors. The meeting is free and open to people with HS and their friends and family. www.hopeforhs.org
- **HS Connect** is an organization providing resources, support and solutions to the HS community. Passionate about helping others navigate HS, they personally know the toll this

disease takes physically, mentally, emotionally, and financially. Their goal is to change the narrative and eradicate the stigmas surrounding HS. www.HSconnect.org

Manage Your Whole Health:

- The inflammation that causes HS can cause problems with other parts of your body, such as your joints. People with HS are also more likely to have high blood pressure, higher weight, and diabetes. We think it's important for you to have a primary care provider.
- Sometimes smoking also makes HS worse - plus it injures the lungs and causes heart disease.

Actions needed:

HS MANAGEMENT

HS often acts like a rollercoaster, with periods of worsening (flares). There are multiple approaches to treatment and we tailor the plan to match the HS activity and your preferences. There is a website available to help people think through the options: informed-decisions.org/hidradenitispda.php. We encourage you to discuss your preferences with your provider.

MAINTENANCE TREATMENT *(Things you do to reduce the symptoms and get ahead of flares)*

Medicines (used singly or in combinations):

Procedures (Laser, deroofting, excision):

FLARE TREATMENT *(Periods of new or worsening HS with pain, itch, or drainage)*

Topicals: Topical clindamycin Ichthammol Resorcinol 15% Other:

Pills: Antibiotic:

Steroid (often prednisone 50 once a day for 3-7 days):

Steroid Shot

If you develop SEVERE worsening of HS with pain, itch, drainage: Contact the office as we may need to change your treatment for the flare (717-531-6820). If you are feeling really sick, then it may be best to be seen at your primary care doctor's office, urgent care, or emergency room.

TO TREAT PAIN:

- Nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen 600 or 800mg 3 times a day can ease pain and inflammation associated with HS. Consider switching between this and acetaminophen (Tylenol) since the medicines get broken down by different parts of the body.
- Topical creams may also help with the pain. Look for the brand or store-brand equivalent of: Preparation HS Rapid Relief with Lidocaine or Boil Ease (benzocaine).
- A warm compress can help to reduce the swelling and inflammation of an HS lesion when applied.
- Medical Marijuana: A Pennsylvania Medical Marijuana card can be obtained using the steps on this website: pa.gov/guides/Pennsylvania-medical-marijuana-program

WOUND CARE: Wound care can help decrease pain and odor, while protecting the wounds and clothing.

- Some insurance companies cover wound care supplies. Typically, alginate dressings with silicone adhesive are used for HS. These can be purchased, but can be expensive.
- Other materials that absorb fluids and protect the wounds include panitliners, maxipads, sterile gauze, and disposable hand towels (such as Kleenex Hand Towels).
- HidraWear is specialized clothing with slots for gauze. It is sometimes available through insurance or can be purchased out-of-pocket at hidrawear.com.