



D[📍]SCOVER HAE

Frequently Asked Questions

Q: What is hereditary angioedema (HAE)?

A: HAE is a rare genetic disorder. It can cause attacks of painful, disabling swelling anywhere in the body, but characteristic locations include the face, hands, feet, genitals, abdomen and throat.

Most people with HAE don't have enough of a protein called C1 esterase inhibitor (C1-INH), or the protein their bodies produce does not work the way it should, which contributes to a cascade of events in the body. This cascade causes another protein called plasma kallikrein to trigger the increased production of a third protein called bradykinin. Having too much bradykinin causes the blood vessels to release fluid, resulting in localized swelling.

It's important to remember that an HAE attack that affects the throat is potentially life-threatening, because it puts you at risk of suffocation. Make sure you have a plan in place for this type of attack and seek emergency care as soon as possible.

Q: How common is HAE?

A: HAE is a rare genetic disorder. In fact, it's thought that only 1 in 10,000 to 1 in 50,000 people in the entire world have HAE.

Q: Can it be difficult to get an HAE diagnosis?

A: Yes. Because HAE is rare, getting an accurate diagnosis can be challenging. In fact, 1 survey of 313 patients showed that up to 65% of people with HAE have been misdiagnosed with another condition prior to receiving their HAE diagnosis.

Q: How do you get HAE?

A: Seventy-five percent of HAE cases are passed down through families. The other 25% develop HAE because of a spontaneous change in their genetic code, so family history can't always help with diagnosis.

Q: How can I find out if I have HAE?

A: Because HAE is rare, few people know about it, including many doctors. If you think there is a chance you have HAE, fill out the Doctor Discussion Guide on DiscoverHAE.com and take it with you to your doctor. It can help you and your doctor determine whether you should be tested for HAE.

Go to DiscoverHAE.com/Doctor-Discussions

Q: How long does it take for HAE to go away?

A: HAE is a lifelong, chronic condition. While there is no cure for HAE, you can talk to a doctor about how to manage your condition.

When untreated, the swelling, or angioedema, in an HAE attack usually increases over a 24-hour period and then gradually subsides during the next 48-72 hours. An HAE attack can also start in one location and then spread to another before getting better.

Q: Where can I find a doctor who is experienced in helping people with HAE?

A: Finding a doctor who has experience diagnosing and helping patients manage HAE can be challenging. The US Hereditary Angioedema Association (HAEA) provides an online tool that can help you find a doctor who treats HAE.

Visit [HAEA.org](https://www.haea.org) to get started.

Q: If I have HAE, will I pass it on to my child?

A: HAE is a genetic disorder that can be passed on from parent to child. If you have HAE, there is a 50% chance you will pass it on to your child.

Q: What are the symptoms of an HAE attack?

A: HAE can cause attacks of painful, disabling swelling anywhere in the body, but characteristic locations include the face, hands, feet, genitals, abdomen and throat.

Usually, swelling in the skin occurs without hives or itchiness. An attack in the abdomen can cause mild to severe pain and be accompanied by vomiting and/or diarrhea.

Swelling in the throat, or a laryngeal attack, happens less frequently than skin or abdominal attacks but is the most serious. Swelling in the throat can become life-threatening, because it can lead to suffocation. If you have a throat attack, you should seek emergency care right away.

HAE symptoms vary greatly from person to person. That means one HAE patient's symptoms could be very different from those of someone else who has HAE. HAE symptoms can also change within the same person. For instance, the frequency of attacks might increase as a patient enters adolescence.

Q: What triggers an HAE attack?

A: Although triggers can be different for everyone with HAE, some common triggers include:

- Emotional stress
- Minor trauma, surgery or dental procedure
- Infection
- Hormonal influences, like menstruation or using a contraceptive containing estrogen
- Mechanical pressure from physical activities, like mowing the lawn or using scissors

HAE attacks can also happen without warning or an obvious trigger. That can make it difficult to predict when an attack is coming, so it's always important to have a plan in place in case of an emergency.

Q: How can you tell if you're about to have an attack?

A: Before an attack, some patients experience early warning signs, also called prodromes, such as tingling, rash, fatigue, or nausea. Please keep in mind that an HAE attack can also happen without warning, so you should always be prepared in case of an emergency. If you haven't done so already, consider asking your doctor about on-demand treatment.

Q: Does HAE affect men and women equally?

A: HAE affects both men and women in equal numbers, but their experiences may be very different. For instance, women seem to be affected more severely by HAE than men. Fluctuations in the female sex hormones (including estrogen) can have an influence on HAE symptoms. As a result, many women experience changes in the severity and frequency of their HAE attacks during various life stages, such as childhood, puberty, pregnancy and menopause.

Q: Is there a way to prevent and treat HAE attacks?

A: Although there is currently no cure for HAE, there are treatment options available that can help prevent or reduce the frequency and severity of HAE attacks.

Preventive therapy involves taking medication for HAE attacks on a regular basis. The goal of this therapy is to reduce the likelihood of an attack occurring and decrease the severity and number of attacks.

Learn more about a preventive treatment at ssshare.it/wSkA

On-demand therapy is treatment you take when you are having an HAE attack to treat the symptoms. HAE treatment guidelines recommend that everyone with HAE should have access to on-demand therapy, so if you haven't already discussed it with your doctor, bring it up at your next appointment.

Learn more about a on-demand treatment at ssshare.it/WDOO

Q: Where can I meet other people who have HAE?

A: When you live with a rare disease, it can be difficult to meet other people who know what you're going through from firsthand experience. Fortunately, there are several ways you can get involved in the HAE community.

Get started by joining the conversation on Facebook.com/DiscoverHAE

Q: Where can I find more resources for living with HAE?

A: There are several organizations and advocacy groups that offer a range of resources for people living with rare diseases, including HAE. Discover tools you can start using now at DiscoverHAE.com/Hereditary-Angioedema-Resources and check out the US Hereditary Angioedema Association (HAEA) at HAEA.org.

The HAEA is a nonprofit patient advocacy organization dedicated to serving people with HAE. They provide patients and their families with a support network and a wide range of services.

The mission of the US HAEA is to increase awareness of HAE by providing patients and physicians with reliable and readily accessible information about the disease. They are committed to advancing and conducting clinical research designed to improve the lives of HAE patients and, ultimately, find a cure.

The HAEA wants to lead a nationwide advocacy movement that focuses on increasing HAE awareness and education, empowering patient access to suitable therapy/treatment, and fostering groundbreaking research that includes searching for a cure.

Q: How can I help other people with HAE?

A: If you have HAE or you care for someone who has been diagnosed, consider sharing your story with other patients and caregivers. Hearing about your personal experience could help someone else navigate his or her own HAE journey. You can learn more at SendUsYourStory.com.

You can also get involved in the activities surrounding hae day :-), which happens every year on May 16. It's the day when the HAE community comes together to raise awareness of HAE among the general public and medical community.

Learn more about hae day :-) at DiscoverHAE.com/HAEDay