

Last month,
I thought this was
an allergic reaction

Last week,
I thought this was
a bug bite



Now I know it's all
HAE

The symptoms of **hereditary angioedema (HAE)**, like swelling and pain, are often mistaken for other, more common, conditions. If you or a family member has experienced unexplained swells, use this guide to learn more about HAE and how it's diagnosed.

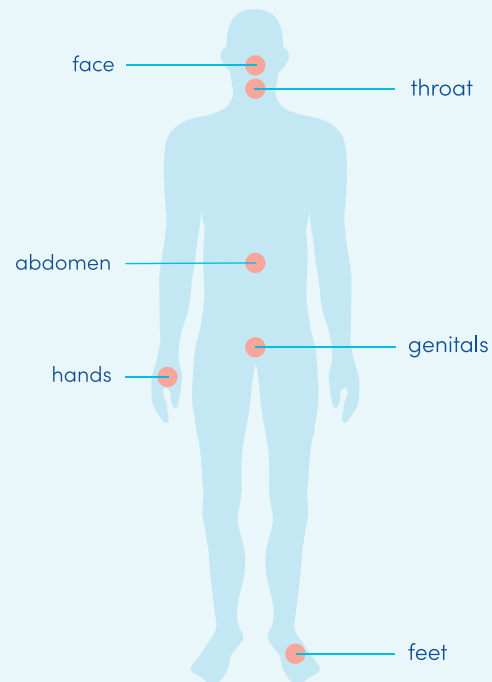
knowHAE
awareness, answers, action

know the disease

signs and symptoms of hereditary angioedema (HAE)

The main symptom of HAE is sudden, sometimes painful, swelling in almost any part of the body. These HAE swelling “attacks” can happen without warning and last for days. They can also be disabling and make it difficult to perform everyday tasks.

common attack locations



- **Swelling in the throat can become life-threatening** because it can lead to suffocation
 - If you feel like your throat is affected, seek emergency care right away
- **Abdominal attacks** can be extremely painful, and may cause vomiting and diarrhoea
 - It's possible to have an abdominal attack without any visible swelling

anyone can have HAE

Male or female, young or old, and any ethnicity. Other family members will often have the disease, since it is usually inherited.





HAE attacks are unpredictable

An attack can start in one part of the body and spread to another.

HAE can appear in many ways

HAE symptoms may look very different from person to person—and even within the same person. For instance, someone with HAE may get attacks more often during puberty. Or someone who usually experiences abdominal swelling may still have an attack in the throat or elsewhere.

Some people experience a tingling sensation before an attack. They may also notice a nonraised, non-itchy rash before the swelling begins.

HAE attacks may last for days if not treated. The swelling usually gets worse over a 24-hour period and then slowly goes away during the next 48-72 hours.

potential attack triggers

HAE attacks are sometimes set off by a trigger. HAE can vary a lot from person to person, so your triggers might be very different from someone else's. For some people, physical trauma like falling off a bike might cause an attack. For others, an attack could be set off by something as simple as the repetitive motion of using a pair of scissors.

Some common triggers are:



Emotional stress



Minor injury, surgery, or dental procedure



Infection



Hormonal influences, like menstruation or taking certain types of birth control

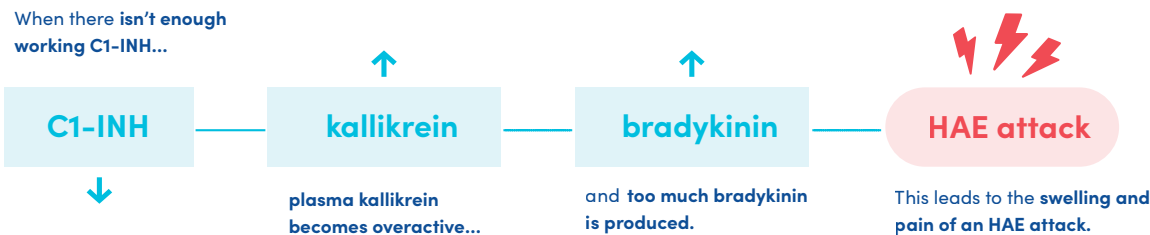


Physical activities like mowing the lawn

know the cause

HAE is caused by genetic mutation

There are more than 450 known genetic mutations associated with HAE, but it only takes 1 to cause the disease. Most of these mutations affect a key protein in the body called C1 esterase inhibitor (C1-INH). This protein is responsible for controlling swelling in the body.



there is more than 1 type of HAE

Type 1 is the most common, accounting for about 85% of people with HAE. People with Type 1 HAE do not produce enough C1-INH.

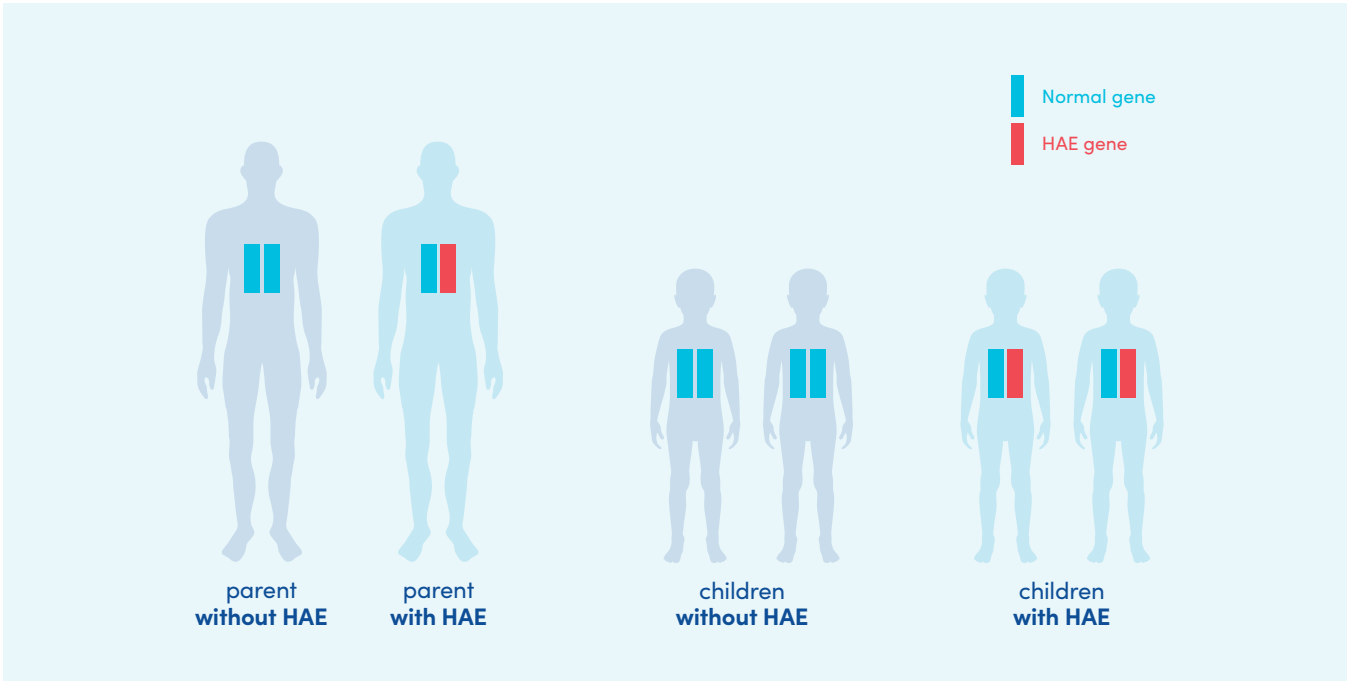
Type 2 occurs in about 15% of people with HAE. People with Type 2 HAE have enough C1-INH, but it does not work the way it should.

Other types: In a very small number of people, C1-INH is normal. This used to be called Type 3 HAE, but there are a number of mutations that can cause HAE with normal C1-INH so it is no longer grouped together under a single name.

HAE usually runs in families, which is why it's called "hereditary"

If one parent has HAE, each child has a 50% risk of inheriting the condition. If a child does not inherit the disease, he or she will not pass it on to future generations.

If you get diagnosed, make sure you encourage your family members to talk to their doctors about getting tested.



learn more about HAE and families at www.HAE.ee

know how to get diagnosed

it starts by talking with your doctor

If you have unexplained, repeated episodes of swelling or pain, your doctor will likely ask for more information about your symptoms and when you first noticed them. Your doctor may also ask if anyone in your family has swelling episodes or has been diagnosed with HAE.

You could still have HAE even if no one else in your family has it. One in four people do not inherit the condition, but develop it from a genetic mutation.

If your doctor thinks that you might have HAE, a blood test will likely be used to confirm the diagnosis. This will help determine if you have HAE, and if it's Type 1 or 2.



misdiagnosis is common

Because HAE is rare, few people have heard of it, including many doctors. In fact, many doctors will never see a patient with HAE—so getting an accurate diagnosis can be challenging. Some people with HAE can take years to figure out the cause of their attacks.

It's thought that only 1 in 50,000 people in the entire world have HAE

HAE symptoms can look very similar to the symptoms of other, more common, conditions. Most frequently, skin attacks are mistaken for allergic reactions. Abdominal attacks are often confused with appendicitis or irritable bowel syndrome.

In a survey of 313 people with HAE, nearly 65% of responders had been misdiagnosed with another condition prior to receiving their HAE diagnosis

what your doctor needs to know

prepare for your doctor's appointment

Whether or not you've already been diagnosed, it may be helpful to keep a journal of how you feel. This will help your doctor better understand your symptoms, make a diagnosis, and manage your condition. You can record things like:

- ☒ The location and severity of your attack(s)
- ☒ How you were feeling before your attack(s)
- ☒ What you were doing before your attack(s)
- ☒ If any family members have similar symptoms
- ☒ How your swells impact you—for instance, missing school or work, or avoiding travel and social engagements

working with your doctor

Because HAE can affect people so differently, it's important to work closely with your doctor to create a treatment plan that's right for you.





there's always more to know about HAE

diagnosis is just the first step

If you know it's HAE, remember that you're not alone. Even though HAE is rare, there are support groups and other resources that can help.

It's also likely that someone else in your family has HAE. In about 75% of cases, people inherit HAE. Help empower your family members to discuss the condition with their doctors and encourage them to get tested.

go to www.HAE.ee for
more information



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