

Hope

There is now hope after a HAE diagnosis. The Australian & New Zealand HAE landscape has improved substantially in the past few years. Treatment options are increasing, more physicians are now aware of HAE and there is a support network for patients & carers.

Advocacy

You need to be an advocate for your HAE family members. Help them if a HAE attack is preventing them from doing their daily activities. Be a trusted supporter if they encounter a medical professional who is unfamiliar with HAE. Be a voice for future HAE sufferers to help get treatments subsidised.

Education

Educate yourself about HAE. Find out if you or your children have the condition. Even if you aren't diagnosed with HAE, familiarise yourself with the condition: what the symptoms are, how they can impact day to day life, what the triggers might be, what treatments your family member uses and who to contact for information and support.



This resource is proudly produced by HAE Australasia, a not-for profit organisation dedicated to improving the quality of life for those that live with Hereditary Angioedema. If you would like any additional educational HAE resources, would like to know where to locate a HAE specialist or if you have any other questions or queries in regards to HAE or HAE Australasia, please do not hesitate to contact us.

Website: www.haeaustralasia.org.au
Support & Questions: info@haeaustralasia.org.au
Like us on Facebook: [@HAEAustralasia](https://www.facebook.com.au/HAEAustralasia)
Follow us on Twitter: [@HAEAustralasia](https://twitter.com/HAEAustralasia)
Postal Address: PO Box 285 Webb Street
NARRE WARREN VIC AUSTRALIA 3805

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Someone in my family has been diagnosed with Hereditary Angioedema (HAE).



Information for:

Family members of those that have HAE

The information contained within this brochure is of a general nature and not intended to be substituted for professional medical advice, diagnosis or treatment. Please see a Hereditary Angioedema specialist for further information.

What is Hereditary Angioedema (HAE)?

HAE is a rare disease that can cause attacks of swelling in body tissues due to “leaky” blood vessels. Attacks of HAE can occur anywhere around the body and can move from one part to another. Separate attacks can affect different parts of the body. The most common sites for these swelling are:

- Extremities (hands, feet, arms, legs)
- Face
- Intestines (abdomen)
- Larynx (voice box)
- Genitals

People with HAE say that attacks of the hands, feet, and abdomen occur most often. One of the most serious types of attacks is an attack around the voice box, or larynx, as swelling in this area can cut off the air supply to the lungs. **This is a life threatening situation and a medical emergency.**

What causes HAE?

HAE is caused by a problem in a person's genetic code for a single protein, known as C1 Inhibitor (C1-INH). An abnormal code can lead to a lack of C1-INH (HAE Type I) or a normal level but a non-functioning C1-INH (HAE Type II). Whether you are told you have HAE Type I or Type II, the symptoms and treatment are exactly the same. Parents with HAE have one healthy gene and one unhealthy gene that encodes for HAE so each child born to a person with HAE has a 50/50 chance of having the condition. It is also possible for people to have HAE without their parents having it. This is because there is a spontaneous occurrence of the abnormal gene.

People with HAE have the disease for life, because it's part of their genetic makeup. However, depending on the severity of the illness, some people will have many swelling attacks each month, while others can go months - or even years - without an attack. Others may not even be aware they have the condition.

Triggers of HAE Attacks

- Emotional or psychological stress
- Physical stress (for example: injuries, surgery, repetitive or manual work)
- Viral or bacterial infections
- ACE inhibitors (for high blood pressure) or oral contraceptives (the Pill)

For people with frequent attacks of HAE swellings preventive therapy can be administered on a short-term or long-term basis.

My doctor thinks it's something else....

Other medical problems, such as swelling due to an allergic reaction, can closely resemble a HAE attack. Allergies are much more common than HAE so sometimes many people with HAE are at first mistakenly diagnosed with an allergy. Even when HAE is not mistaken for an allergic reaction, it may be thought to be caused by another medical problem. Depending on the site of the swelling, the condition is sometimes misdiagnosed as appendicitis, intestinal blockage, a sprain, or even a psychological problem.

Warnings Signs & Symptoms

- Fatigue
- Tingling
- Nausea
- General gut discomfort
- Noisy gut
- Bowel movement changes
- Non-itchy lacy rash
- Flu-like feelings



Call your local emergency number

if you notice:

- Lump in throat, difficulty swallowing
- Change in voice
- Whistling or wheezing when breathing
- Shortness of breath
- Swollen tongue
- Lip or facial swelling that is progressing

These can be the first signs of a life-threatening attack

Have you & your children been tested?

It's just a simple blood test.

As HAE is a genetic condition, there is a possibility that other family members, in addition to the one that's already been diagnosed, have HAE. Some HAE patients have no noticeable symptoms throughout their entire life, yet their own children may eventually suffer terribly from fortnightly or weekly attacks. HAE attacks may occur suddenly and without warning. Without a diagnosis and a clear medical plan, sudden attacks could be very scary.

The test used to make the diagnosis of HAE include testing for levels of C4 and C1 inhibitor proteins in the blood. Occasionally the test will have to be done more than once to be certain of the diagnosis