

Dear Emergency Medical Professional,

My patient, _____, has asked me to tell you about his/her diagnosis of a rare, but potentially life-threatening, genetic medical condition called hereditary angioedema (HAE).

About HAE

HAE is a rare inherited disease that can cause considerable swelling in various body tissues. People with HAE are missing a blood protein called C1 esterase inhibitor (C1-INH). When the body's need for C1-INH overwhelms its ability to keep up with demand, a sudden attack can occur.

Not an Allergic Response

During an attack, the edema may appear to be allergic in nature; however, HAE is **not** an allergic condition, and the patient typically will not respond to antihistamines or corticosteroids.

Life-threatening Symptoms

Please note that if an HAE patient experiences a swelling attack in the face or in the mouth, throat, or airway, this can be a serious and potentially life-threatening condition requiring immediate emergency care.

Potentially life-threatening symptoms in HAE attacks:

- Extreme dizziness or fainting
- Hoarse voice or laryngitis
- Significant lip or facial swelling
- Shortness of breath
- Swollen tongue
- Throat swelling
- Whistling or wheezing when breathing

Some patients may experience symptoms in advance of an attack, such as fatigue, nausea and flu-like feelings, bowel movement changes, urticaria, non-itchy rash, and tingling. Individual patients often are aware of specific symptoms that herald the onset of their attacks.

Treatment for Attacks

My patient is being treated with _____ for HAE. Here is some important information you should know about it: _____

Contact Information

Like many healthcare professionals, you may have questions about HAE or the patient's needs. I am available for a consultation and can be reached at the following number(s):

Office _____

In emergencies, please call _____

If you'd like to learn more about HAE, please visit: www.allaboutHAE.ca.

Thank you for your interest in HAE and our shared commitment to the patient's healthcare.

Sincerely,

LETTER TO SCHOOL NURSE:

Dear _____ ,

My patient, _____ , has asked me to tell you about his/her diagnosis of a rare but potentially life-threatening medical condition. This genetic condition is called hereditary angioedema (HAE).

About HAE

HAE is a rare disease that can cause considerable swelling in various body parts. During an HAE attack, the symptoms may appear to be allergic in nature; however, HAE is **not** an allergic condition and the patient typically will not respond to antihistamines or corticosteroids.

Please note that if my patient experiences a swelling attack in the face or in the mouth, throat, or airway, this can be a serious and potentially life-threatening condition requiring immediate emergency care.

Specific Triggers and Symptoms of an Attack

HAE attacks often occur spontaneously without a known cause. Other times, specific triggers, such as anxiety, emotional or physical stress, hormonal changes, minor trauma, surgery, and common illnesses such as colds and flu can elicit attacks.

Some patients experience symptoms in advance of an HAE attack. These symptoms may include any of the following: fatigue, nausea, flu-like feelings, diarrhea, non-itchy rash, or tingling.

Individual patients often are aware of specific symptoms that **occur before** the onset of their attacks and, when possible, will avoid known triggers. On occasion, my patient will be aware of symptoms in advance of an attack and may need to be excused from school for treatment purposes.

If you'd like to learn more about HAE, please visit: www.allaboutHAE.ca .

Treatment for Attacks

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Sincerely,

LETTER TO PRIMARY CARE PHYSICIAN

Dear _____ ,

Our mutual patient, _____ , has asked me to tell you about his/her diagnosis of a rare, but potentially life-threatening, genetic medical condition called hereditary angioedema (HAE).

About HAE

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Not an Allergic Response

During an attack, the edema may appear to be allergic in nature; however, HAE is **not** an allergic condition, and the patient typically will not respond to antihistamines or corticosteroids.

Please note that if an HAE patient experiences a swelling attack in the face or in the mouth, throat, or airway, this can be a serious and potentially life-threatening condition requiring immediate emergency care.

Some patients experience symptoms in advance of an HAE attack. These symptoms may include any of the following: fatigue, nausea, flu-like feelings, bowel movement changes, urticaria-like skin eruptions, non-itchy rash, or tingling. Individual patients often are aware of specific symptoms that herald the onset of their attacks.

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Sincerely,

LETTER TO GENERAL SURGEON/DENTIST

Dear _____,

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About HAE

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Not an Allergic Response

During an attack, the edema may appear to be allergic in nature; however, HAE is **not** an allergic condition, and the patient typically will not respond to antihistamines or corticosteroids.

Specific Triggers and Symptoms of an Attack

HAE attacks can be triggered by emotional or physical stress, including dental and surgical procedures.

HAE attacks occur more frequently **after** such procedures; however, because some patients experience stress in advance of dental or surgical events, they may experience an HAE attack **before** or even **during** the procedure.

Check Your Patient for Symptoms Prior to the Procedure

Prior to the start of a dental or surgical procedure, please verify with the patient that he/she is not currently experiencing prodromal symptoms. These might include fatigue, nausea and flu-like feelings, bowel movement change, urticaria-like skin eruptions, non-itchy rash, and tingling. Patients often are aware of their specific triggers and symptoms, and know how to avoid them. On occasion, my patient may be aware of symptoms well in advance of an attack and may be able to alert you to an oncoming attack.

Please note that if my patient experiences a swelling attack on the face or in the mouth, throat, or airway, this can be a serious and potentially life-threatening condition requiring immediate emergency care.

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