



Hereditary Angioedema (HAE) Canada
Angioedème Héréditaire (AOH) Canada

HAE: You and Your Child's School

Every parent of a child with HAE has questions at the start of the school year. How will the school respond if my child misses too many days of school? How will my child make up missed assignments?

An HAE school packet can be a great resource in this regard. We hope you will find the information below helpful as you meet your child's teacher and work with their school. The information provided is meant only as a guide – please feel free to personalize your child's school packet to meet their own needs and situation.

Preparing a School/Teacher Packet

1. Include HAE Canada's "Infographic" in the materials you provide to your child's teacher(s). This PDF document can be downloaded from the HAE Canada website, found under Resources.
2. Provide "Five Things for Teachers to Know." A sample list is provided below for your reference, but you may want to customize it to fit your child's situation.
3. Write a note to the teacher. Your note does not need to be any more than a page long. You can mention how much you are looking forward to working with the teacher this year, and specific things you want the teacher to know about your child. Let the teacher know that you can provide more information, if necessary. End by giving your phone number and e-mail address and let them know you are happy to meet in person if required. A sample letter is included below for your reference.
4. You can also include a letter from your child's HAE physician for the school's administration. This letter can include your child's HAE treatments and the physician's contact information. A sample letter for your physician to fill out is included in this package.
5. Carefully choose what you will send in your packet. Sending in too much information at once may make it seem like an overwhelming task for your child's teacher. You can always offer to send in additional resources later. You can find printouts on HAE Canada's Resources page. (haecanada.org/resources/)
6. Follow up. If you don't hear anything from the teacher, check back in a few days with a note or a phone call to make sure they received your package and is reviewing it, and to repeat your offer to discuss it further in person.





Tips:

1. Remember, the start of school is a hectic time for teachers. They may not have enough time to read a lot of information. A package that looks manageable and well-thought out will be more effective. You may wish to allow more time by delivering your HAE school packet in the week before school begins.
2. In your teacher note, provide suggestions specific to your child's HAE health needs rather than insisting on rights and obligations.
3. Keep your tone friendly. You are writing as an expert on your child and their HAE, not as a pleading or pushy parent.
4. Make a copy of all correspondence for your records. Keep a log of when and what you sent to the teacher, and what follow-up you made.

Five Things for Teachers to Know

1. Due to my child's low levels of [non-functioning] C1 Inhibitor, a blood plasma protein, they can experience episodes of internal or external swelling – often without warning.
2. Swelling may result from trauma. Please alert their gym teacher(s) and can you please monitor for any trauma-related swelling.
3. My child is aware of how HAE affects their body, but please do not hesitate to contact me immediately if they are not asking for help and you feel medical attention is needed.
4. Please call 911 immediately if my child reports a thickness in their throat or difficulty breathing. Then please call my emergency contact phone number: ___-___-____
5. My child may or may not wish to share information about their HAE with classmates. Please ask my child what they are comfortable sharing.



Sample: Teacher Note

Dear

I hope we will be able to meet in person soon, so that we can get to know one another better. I am excited that _____ will have you for their teacher this year. I know the beginning of school is always a very busy time, but I would very much appreciate time to sit down and talk about _____. In the meantime, here is some information to help you get to know them.

_____ is a bright child, eager to learn and they enjoy the company of their peers. However, they have a condition of which you should be aware. _____ has been diagnosed with Hereditary Angioedema or HAE. HAE is a very rare and potentially life-threatening genetic condition that occurs in about 1 in 10,000 to 1 in 50,000 people. HAE patients have a defect in the gene that controls a blood protein called C1 Inhibitor. Because defective C1-Inhibitor does not adequately perform its regulatory function, an imbalance can occur that causes the release of fluids into surrounding tissue. This causes swelling. HAE symptoms include episodes of swelling in various body parts including the hands, feet, abdomen, face and/or throat.

Kids like _____ with HAE may have bouts of excruciating abdominal pain, nausea and vomiting, caused by swelling in the intestinal wall. Throat (airway) swelling is a medical emergency and must be taken seriously. Throat swelling can lead to death by suffocation. **Important Note:** At the slightest hint of throat swelling, please call 911 for immediate medical treatment to ensure that my child's airway is not compromised.

_____’s HAE is as well-controlled as possible, but there may be times when their HAE attacks are too severe to attend school. Please understand that days missed from school are not by _____’s choice – they would rather be in class. I can work with you and the school administration to make arrangements for makeup work so that _____ will not fall behind.

We will always make the best effort to make sure _____ has the same school experience as any of their classmates – to arrive on time, to have a terrific attendance record, to do the best work possible, to participate in all activities, to be a kid. _____ may be sensitive about how others perceive them. They may or may not wish to share information about HAE with classmates. Please talk with my child and me to clarify their wishes.

Please take the time to read the HAE materials I have provided. They will help you to understand not only HAE, but also my child's life with this disease. I also recommend the HAE Canada website (haecanada.org) – it contains information and HAE resources. If you have any questions at all before school begins, please do not hesitate to call me.

I appreciate your attention to _____’s particular needs. I look forward to meeting with you once the school year begins. Or if you have time to meet before school begins, please let me know.

Sincerely,

Name

Phone number

email address

Sample: Letter from your physician to the school administration

Physician's name & contact information

Date

Dear _____, *(school official's name)*

This letter is to inform you that _____ has been diagnosed with Hereditary Angioedema (HAE), a rare, but potentially life-threatening, genetic medical condition.

About HAE

HAE is a rare disease that can cause considerable swelling in various body parts including the hands, feet, face and airway. Extreme pain and nausea can occur during an intestinal wall swelling. 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.

During an HAE attack, the symptoms may appear to be an allergic reaction; 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 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.

Treatment for Attacks

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

Contact Information

If you have questions about HAE, I am available for a consultation and can be reached at the following number(s):

Office _____

In emergencies, please call _____

Thank you for your interest in HAE and our shared commitment to the student's health and well-being.

Sincerely,