



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 your child's school. The information provided is meant only as a guide – you will want to personalize your child's school packet to meet his/her own particular needs and situation.

Preparing a School/Teacher Packet

1. **Include "What is HAE?"** in the materials you provide to your child's teacher(s). This brochure can be obtained from the US HAE Association. Send your request to info@haea.org
2. Provide "**Five Things Teachers Need to Know.**" A sample list is provided below for your reference, but please be sure to customize it to fit your child and his/her situation.
3. **Write a note to the teacher.** Your note does not need to be any more than a page long. Be positive about how much you are looking forward to working with the teacher this year.

Mention the specific things you want the teacher to know about your child or refer him/her to your “Five Things” list.

Let the teacher know that you can provide more information.

End by giving your phone number and e-mail address and indicating your eagerness to meet in person.

A sample note is included below for your reference below.

4. Put together an attractive package. Put your note to the teacher, “Five Things” and any printouts from the HAEA web site (www.haea.org) in a large manila envelope or clear plastic portfolio. The more seriously you take this material and your presentation of it, the more seriously the teacher will likely take it.

5. Carefully choose what you will send in your packet. Sending in too much information all at once may make it seem like an overwhelming chore for your child's teacher. You can always offer to send in additional resources later.

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 he/she 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 a lot of free time to read reams of material. A package that looks manageable and well-thoughtout 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 particular child and his/her 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 Teachers Need to Know

1. Due to my child's low levels of [non-functioning] C1 Inhibitor, a blood plasma protein, he/she can experience episodes of internal or external swelling – often without warning.

2. Swelling may result from trauma – please alert his/her gym teacher(s) - and

I ask for your assistance in monitoring for any trauma-related swelling.

3. My child is very aware of how HAE affects his/her body, but please do not

hesitate to contact me immediately if he/she is not asking for help and you

feel medical attention is needed.

4. Please call 911 immediately if my child reports a thickness in his/her throat or difficulty

breathing. Then please call my emergency contact phone number: ___ - ___ - ____

5. My child may or may not wish to share information about his/her HAE with classmates.

Please talk with my child and me to discern his/her wishes.

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 his/her 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 him/her.

_____ is a bright child, eager to learn and he/she enjoys the company of his/her peers. However, he/she has 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: 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 his/her HAE attacks are too severe to attend school. Please understand that days missed from school are not by _____ 's choice – he/she would rather be in class. I will be working with you

and the school guidance counselor 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 his/her 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 him/her. He/she may or may not wish to share information about HAE with classmates. Please talk with my child and me to clarify his/her 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 Association web site

(www.haea.org) – it contains a wealth of 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 will also be providing information regarding _____'s HAE to the school nurse.

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