

HAE BACK TO SCHOOL RESOURCES



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Every parent of a child with HAE has questions at the start of the school year, such as - 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 for you and your child's school. Taking the time to put the packet together ahead of time will help manage any anxieties while providing valuable education and insight for your school's staff.

We hope you will find the information below helpful as you meet your child's teacher and school nurse. The information provided is meant only as a guide – you will want to personalize your child's school packet to meet their own particular needs and situation.

Below, are a few items that might be helpful to include in the packet you present to your child's teacher.

1. Put together an attractive packet

Create a packet that includes your note to the teacher, your child's physician letter, and any printed resources from the HAEA website (www.haea.org) about HAE. Label the packet and place it in a large manila envelope or clear plastic portfolio.

2. Carefully choose what you will send in your packet

Sending too much information all at once may make it seem like an overwhelming task for your child's teacher. You can always offer to send additional resources later.

3. Understanding HAE Guide

This printed resource provides a brief overview of HAE for your child's teacher. To order a Guide from the US HAE Association, send your request to info@haea.org.

4. 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 specific things you want the teacher to know about your child and their HAE. Let the teacher know that you can provide more information if they have additional questions. (A sample letter is provided on the following pages.)

5. Follow up

If you don't hear back from the teacher, check back in a few days with a note or a phone call to make sure they received your packet and ask if they have any additional questions about the information presented. Repeat your offer to answer any questions and discuss further in person.



TIPS:

1. Create a focused and timely presentation. The start of a school year can be a hectic time for teachers. They may not have a lot of free time to read a large volume of material. A packet that looks manageable and well-thought out will be more effective. You may wish to allow more time for the teacher to review by delivering your HAE school packet in the weeks before school begins.
2. Make an effort to collaborate. In your note to the teacher, provide suggestions specific to your child's HAE health needs.
3. Keep your tone friendly. Remember, it's important to develop a positive relationship with your child's school. Make it clear that you are available to answer any questions, and that you would be happy to do what you can to ensure that the school has everything they need to help your child thrive despite their HAE.
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 outreach you made.

RESPONSIBILITIES:

Reinforce the importance of everyone (student, parent, and school) doing their part to help the child succeed in school.

STUDENT

Learn to communicate when something is wrong

Tell an adult at school when something is wrong or if you are experiencing swelling

Do your school work on time

Make the same amount of effort as someone without HAE

PARENT

Communicate about child's condition and needs

Help obtain makeup work

Help child have a positive attitude about school

Work with school staff and nurse to develop a care plan

SCHOOL

Monitor student achievement and notify parent of changes to performance or personality

Notify parent if student reports an HAE attack

Stress the importance of completing assignments

Respect privacy and confidentiality



SCHOOL NURSE SAMPLE LETTER

School name:

Date:

Dear School Nurse,

My child, _____, has been diagnosed with a rare and potentially life-threatening genetic disease called Hereditary Angioedema (HAE).

HAE symptoms include episodes of swelling (edema) in body parts, including the hands, feet, face, and throat. In addition, abdominal swelling can be accompanied by nausea and vomiting, and excruciating pain. Airway swelling is particularly dangerous and can lead to death by suffocation. HAE related swelling is not caused by an allergic reaction and, therefore, does not respond to antihistamines or corticosteroids. HAE attacks often occur spontaneously and can be triggered by many things – including stress, minor trauma, a cold, or flu.

It is important to call 911 immediately if my child reports any signs of swelling in the face, mouth, or throat. This requires emergency medical treatment to ensure that my child's airway is not compromised. In this situation, please also contact me as soon as possible.

Detailed information about HAE can be found at www.haea.org.

My child, _____, may recognize signs of HAE swelling and they may need to be excused from school. _____ is currently under the care of Dr. _____ who can be reached during office hours at _____. Attached is the current treatment plan for _____ that their doctor has developed. My child is treated with _____ for their HAE attacks. Please call me at _____ if you have any questions.

Signed _____ Relationship to Student _____

Attachments:

Prescribing physicians treatment letter

Medication informational brochure

HAE informational flyer

SAMPLE TEACHER LETTER

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 of year, but I would like to schedule a time for us to discuss _____'s medical condition. 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. He/she has a medical 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 which causes the release of fluids into surrounding tissue. This causes internal and external 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. Swelling in the throat (airway) 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. A throat swell may lead to changes in voice, the feeling of a lump in the throat, and strained breathing.

_____ '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 if days are missed.

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 life with this condition. I also recommend the HAE Association's website (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 - Parent of _____

Phone number _____



FREQUENTLY ASKED QUESTIONS

WHAT IS A 504 PLAN?

The "504" in "504 plan" refers to Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, which specifies that no one with a disability can be excluded from participating in federally funded programs or activities, including elementary, secondary, or postsecondary education. "Disability" in this context refers to a "physical or mental impairment which substantially limits one or more major life activities". This can include physical impairments; illnesses or injuries; communicable diseases; chronic conditions like HAE, asthma, allergies and diabetes; and learning disabilities.

A 504 plan spells out the modifications and accommodations that might be needed for a child with HAE if the condition is preventing them from the opportunity to perform at the same level as their peers. Accommodations might include such things as an extra set of textbooks, home instruction, or technology to support learning.

It's important to note that policies and procedures for 504 plans may vary by state, and even amongst individual school districts. Parents and/or caregivers of children who need a 504 plan should contact the

YOU, YOUR CHILD AND 504 PLANS (FAQ)

child's school district to find out who they should work with to get their 504 plan initiated. Determining eligibility for services under Section 504 is a team decision. Team members often include teachers, school administrators, school nurses, school psychologists, counselors, therapists, the parent and/or caregiver, and the child, if appropriate. You should insist that the child's physician has significant input into the team's decision-making process.

HOW DOES A 504 PLAN DIFFER FROM AN IEP?

It's important to know the difference between a 504 plan and an Individualized Education Plan (IEP). An IEP is a comprehensive document that (1) serves as a blueprint or roadmap for a child with special education needs, and (2) specifies **what** a child will be learning in school.

A 504 plan deals specifically with **how** a child will be learning within the school. A 504 plan is issued to students who are able to participate in a general education classroom but need unique accommodations.

ARE 504 PLANS REALLY NECESSARY?

The kind of accommodations and modifications offered by a 504 plan is often similar to what you may have worked out privately with your child's school or teacher in the past. Drafting an outline in a legal document may seem like too much trouble, but individual schools and their policies vary by district and state so it's always best to put your plan in writing. A new teacher, new principal, new superintendent, or a move to a new school or town can render all your handshake agreements invalid. Having a legally binding plan lets everyone know what's to be done and how to go about it while promoting consistency and accountability.





For students with Hereditary Angioedema who are entering college and possibly planning to move away from home, there are several important things to consider and plan ahead for to ensure a smooth transition.

PLAN AHEAD

Planning ahead for a major life transition will ensure that you are prepared to be independent in your HAE care and that you will be ready with a plan in the event of an HAE emergency.

Work with your HAE treating physician to develop a treatment plan and a care plan to ensure that you are prepared for an extended time away from home.

- ✓ Ask your physician to write a diagnosis confirmation letter and treatment protocol for you to keep on hand (keep one copy printed and one copy in digital form).
- ✓ Order an HAEA Member ID Card from www.haea.org to carry in your wallet. These FREE personalized cards have your emergency contact information, your physician's name and number, as well as your HAE medications.

HAE AND PREPARING FOR COLLEGE

- ✓ Get trained in self-administration of HAE medications.
- ✓ Ensure that your prescription doesn't expire while you are away at school.
- ✓ Make sure that you have enough supplies and medication to last while you are away from home.
- ✓ When returning home for visits, ensure that you schedule follow-up appointments with your HAE treating physician.

Coordinate medication shipments (if delivering to new address)

- ✓ Let your specialty pharmacy know of any address changes or new delivery schedules.
- ✓ Contact school mail service to determine the process for receiving packages at your school-Where are packages left? Who will sign for your package?

Find an HAE treating physician in the new city or town that you will be living in

- ✓ The HAEA can provide you with a physician referral to an HAE physician (contact an HAEA Health Advocate or request a physician referral by visiting haea.org).
- ✓ Contact the physician's office to confirm that they take your insurance.

Locate an Emergency Room (ER) facility that is close to your new residence/school

- ✓ Contact the local ER facility to see if they have HAE medications in the pharmacy that can be prescribed in the event of an emergency swell.
- ✓ Speak with someone in the ER to notify them that you have HAE and are moving to the area. Bring an HAEA ER Toolkit along with your treatment plan. To order a FREE Toolkit, visit www.haea.org.



Possible Insurance Changes

- ✓ Be aware of any changes to your insurance that may take effect if you are moving out of state. Determine if your current healthcare plan will cover you. If not, make sure you find an alternative prior to moving to ensure that your HAE medication is covered.
- ✓ Universities often offer a school-based insurance plan for emergency situations, look into this option as needed.

WORK WITH YOUR UNIVERSITY

Look into the services offered by the Student Disabled Services Office to see if you would benefit from developing a plan to ensure that accommodations are available to you if needed.

- ✓ It is helpful to have a plan in place to ensure that unexpected absences caused by HAE are not counted against you. Developing a plan with the Student Disabled Service Office will ensure that professors make accommodations when needed.
- ✓ Determine if you need any additional documentation to finalize a plan.

Communicate with your Professors

- ✓ Schedule an office visit with each of your professors in the beginning of the semester. Introduce yourself and tell them about your HAE. This way, they will be familiar with you and your HAE if it comes up later in the semester.

Contact School Clinic Staff

- ✓ Introduce yourself and explain your condition. Bring an HAEA ER Toolkit along with your treatment plan to ensure that clinic staff are educated about HAE and your needs.
- ✓ Order a FREE HAEA ER Toolkit
<https://www.haea.org/pages/p/ERkit>

COMMUNICATE WITH FRIENDS AND/OR ROOMMATES

- ✓ Have a conversation with new roommates or friends about your HAE and the fact that you may use needles to administer medication.
- ✓ Let your roommates/friends know what they can do to help you in the event of an HAE emergency.
- ✓ Invite your peers to ask questions about your condition to allow for open dialogue.



US Hereditary Angioedema Association

10560 Main Street
Suite PS40
Fairfax City, VA 22030

Toll Free: (866) 798-5598

Fax: (508) 437-0303

www.haea.org



@hereditaryangioedema



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