

# WHAT PARENTS AND CAREGIVERS NEED TO KNOW ABOUT A CHILD WITH HAE



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Published August 2024

## Introduction

Discovering that your child has been diagnosed with hereditary angioedema (HAE) can be overwhelming and emotional. As a parent or caregiver, it's understandable to have concerns about the testing process, explaining the disease to the child, managing anxiety, informing schools and friends, and helping the child adjust to living with HAE. This article will provide easy-to-understand explanations of these important aspects of caring for a child with HAE.

## Testing

HAE is a genetic condition that can be passed down from a parent to their child with a 50% chance. To diagnose HAE, your child's medical history will be carefully reviewed and a blood test for C1 inhibitor and complement C4 will be conducted. This test will need to be performed twice, at least one month apart, to confirm the diagnosis. However, the C1 inhibitor test may not be accurate for children under the age of one, so your doctor may wait to perform the test. Genetic testing may also be done to identify specific gene mutation associated with HAE. This test can be performed at any age but is costly and not always covered by provincial health plans.



## How to Explain HAE to a Child

Explaining HAE to a child can be challenging. When it comes to discussing HAE with your child, honesty and age-appropriate explanations are key. It's essential to help them understand their condition without causing unnecessary fear or anxiety. Describe HAE in simple terms. Explain that it's a rare condition that makes certain parts of their body swell unexpectedly, like their stomach, face, hands, or throat. Make sure the child knows that HAE is not their fault, and they didn't do anything to cause it. Emphasize that they are not alone and that you, along with their healthcare team, are there to help them manage the condition. Reassure them that there are ways to manage HAE, such as taking medication that can prevent attacks as well as treating attacks as they occur.



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NPRMCDA/CA/1518

## Parental/Caregiver Anxiety

Parents and caregivers often experience anxiety when managing a child's chronic condition like HAE. The unpredictability of swelling episodes can lead to anxiety and stress. Knowledge about HAE can help alleviate some anxiety. Learn about the condition, treatment options, and emergency plans. The more informed you are, the more empowered you'll feel. Connect with other parents or caregivers of children with HAE. Sharing experiences and tips can provide emotional support and reduce anxiety.

## Child Anxiety and Mental Health

Children with HAE might experience anxiety due to the uncertainty of when swelling episodes will occur and the pain associated with the swelling. Encourage your child to talk about their feelings. Let them know it's okay to be worried or scared sometimes. It's important to address their emotional well-being and provide tools to manage anxiety. Professional therapy might also be beneficial for both the child and the family.

## Informing Schools, Sports Teams, and Parents of Friends

It's important to inform your child's school, sports teams, and the parents of their friends about their HAE. Meet with school staff to discuss your child's needs, including potential triggers and emergency plans. Collaborate with school staff to create an action plan that outlines necessary steps, such as when to administer medication, and make sure everyone involved is aware of it. If your child is involved in sports, inform their coaches and teammates about HAE. Discuss any necessary accommodations or precautions. Injury from contact sports can trigger an attack. It's a good idea to have a conversation with the parents of your child's close friends. This helps them understand the condition and what to do in case of an emergency.

## Transitioning

As children grow, they'll need to take on more responsibility for managing their HAE. Encourage your child to gradually become more involved in their care, such as learning about triggers for attacks, how to recognize early signs of an attack, and how to administer medication. We suggest they wear a medical alert bracelet, have a health app on their smartphone, and/or carry a card with emergency contact information.



## Conclusion

Caring for a child with HAE can be challenging, but with the right information and support, you can both effectively manage the condition. Remember to seek emotional support, use simple language when talking about HAE with a child and educate others about their condition. By working together, you can help your child live a healthy and fulfilling life.

