

Communicating your daily reality with HAE to friends & family



HAE reality

Life with hereditary angioedema (HAE) can feel isolating, especially when friends and family don't seem to fully realize or understand its impact on your day-to-day. There can be confusion over what HAE really is, awkward silence when others don't know what to say, or moments where others may inadvertently minimize your experience. All of this can make talking about HAE stressful, but there may be strategies that can help.

Helping others understand

While there's no "right" way to have difficult conversations, these strategies from the American Psychological Association and experts in rare disease may help make connecting with others a little easier.

➤ Plan ahead

Let the other person know ahead of time what you'd like to talk about so they're not caught off guard. Choose a time and place that works for both of you, ideally when you feel relaxed and have ample time to talk. Allow yourself the chance to gather your thoughts. Consider writing down, or using a digital tool, to capture what you'd like to say so you don't forget key points.

➤ Use real examples from your daily life

Sharing specific examples can help others empathize with your reality. Do you worry about how mild attacks might disrupt your day? Does the unpredictable nature of HAE create fear or anxiety? Do you avoid certain activities or adjust your plans to avoid triggering an attack? Are you missing out on experiences?

➤ Be direct

It's natural to want to protect loved ones from uncomfortable conversations, but being direct and open can help others better understand how HAE affects you. This can make it easier for them to be more empathetic, offer emotional support, and help you navigate the day-to-day. Having an honest conversation with a friend or loved one can also help you feel less stressed.

➤ Be clear about how others can help

Your loved ones can provide more support if you are direct about your needs. Remember that you are your best advocate. Family and friends want to feel useful, so don't be ashamed to ask for help or favors, and let them know the questions that are most important to ask you.



➤ **Practice active listening**

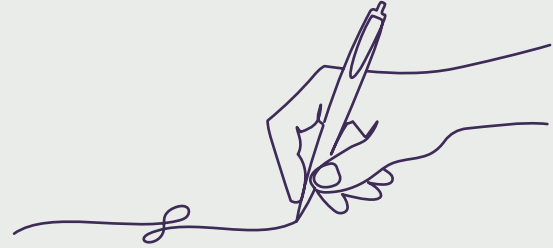
Use active listening to help understand how your loved one might be feeling about what you're sharing. It includes nodding, smiling, asking questions, empathizing with their perspective, and paraphrasing what you hear back to them.

➤ **Make a plan to talk again**

Set up a time and place to reconnect after a set period of time to see how things are going.

Taking action

Still not sure where to start? These questions can be helpful to answer.



*What is my goal with this conversation?
What do I want the person to understand?*

*Who do I want to share this information with?
Who will offer support and strength?*

What response am I looking for?

*When and where is the best time
for this conversation?*