

Advocating for your needs at work



HAE reality

Navigating a career while living with hereditary angioedema (HAE) can pose unique challenges and specific considerations that can be difficult for others to accept. Though HAE may sometimes get in the way, it doesn't mean you can't ask for a solution that works for you. An open conversation about how you'd like to succeed in your job despite HAE may make work less stressful, improve your relationship with your supervisor, and be an important step in your self-care.

Below are strategies from experts in rare disease that can help make asking for what you need a little easier.

Know your rights [↗](#)

Did you know you aren't required to disclose your condition to your supervisor? If you'd like to explore specific accommodations, you can start with your human resources (HR) department. HR can work as a go-between, helping you figure out what may be most helpful and how to best relay this to your supervisor.

Preparing for conversations

Hiding what you're going through can be exhausting and may lead colleagues to form false assumptions about you. If you choose to share information about the impact of HAE on your reality, here are some tips that can help:

➤ Stay focused

Don't feel the need to provide a lot of detail about your personal experiences. Rather, talk about how HAE may impact your work and any special accommodations you need.

➤ Provide specific examples

Acknowledge that you have certain considerations that may be difficult for others to accept, such as needing to take more sick days than your coworkers, needing to work remotely, or being unable to travel.

➤ Offer ideas

Share suggestions to help address anticipated barriers, such as job sharing, working from home, or having a flexible work schedule.

➤ Work to your strengths

Do you have skills that you don't use in your day-to-day work that could be helpful to your supervisor or coworkers? There may be ways that you can contribute at work with greater ease or flexibility that you might not have considered.



➤ **Prepare ahead of time**

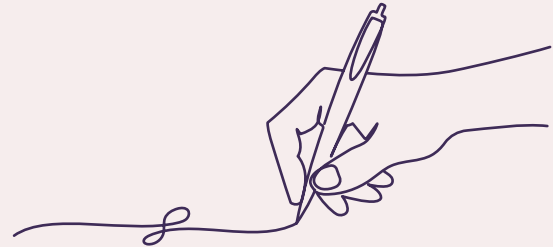
Before starting the conversation, know exactly what you want to ask for, including what you are willing to accept and what you are not. Consider how you might respond to questions or concerns.

➤ **Get support**

Consider confiding in your work friends if you haven't already. It can help to have someone at work who supports you. Some organizations offer workplace peer-support programs to help match people who may have a similar experience.

Taking action

If you're struggling to know where to start, use the below to spark ideas.



What brings you joy at work?

How would you describe your ideal workday or work situation?

What do other people seem to rely on you for? Do you enjoy that role or not?

What will allow you to prioritize your health and well-being at work?