



HAE and You: Finding Support for Emotional Wellbeing

This leaflet is for adults living with hereditary angioedema (HAE).

It's designed to help you feel supported and give you clear, useful information about looking after your emotional wellbeing. Inside, you'll find practical tips, ideas for coping, and details on where to find extra support if you need it. Remember, HAE is only one part of your life - it doesn't define who you are. You can still enjoy the things you love, make plans for the future, and aim high, with adjustments where needed.

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HAE Affects More Than Your Body – It Can Affect Your Mind Too

Living with HAE and Psychological Challenges

Whether you've been managing your HAE for a number of years or are newly diagnosed, managing your emotional wellbeing is just as important as managing your physical health. As you may already know, HAE is a rare genetic condition that causes unpredictable episodes of swelling in areas like the face, hands, feet, abdomen, and sometimes the airways. These attacks can range from mild to life threatening, especially if breathing is affected.

This unpredictability doesn't just impact your body – it can affect how you feel too. If you are experiencing psychological issues, you are not alone. People with HAE often find that difficult feelings can arise not only from managing their own symptoms but also from seeing family members affected by the condition. Many people with HAE experience emotional challenges such as:

- **Anxiety** – worry about when the next attack will happen or fear of airway swelling. In addition, there's also concern about the impact of your condition on your family
- **Stress** – managing treatment, work, and daily life while coping with uncertainty
- **Isolation** – avoiding social activities due to visible swelling or fear of attacks, which can impact mood

While the majority of people with HAE cope well day-to-day, studies show that up to 40% of adults with HAE report moderate to severe anxiety, about half experience depression, and most feel some stress linked to the unpredictability of attacks. These feelings are common and valid, and you don't have to face them alone – help and support are available.

How Emotions and HAE Affect Each Other

By understanding how stress and anxiety influence HAE, you can take steps to reduce their impact. Stress and anxiety don't just happen after an attack – they can sometimes trigger one. Emotional stress can activate processes in the body that raise **bradykinin**, the chemical that causes swelling in HAE. When bradykinin levels rise, blood vessels become leakier, leading to fluid build up and swelling. This creates a vicious cycle:



Living with HAE can understandably cause ongoing worry and fear, which may affect your work, social life, and overall quality of life. Recognising this is the first step towards feeling more prepared and confident in managing both your emotional wellbeing and your HAE, especially as psychological stress and anxiety are recognised triggers for attacks. Learning strategies to reduce anxiety can therefore play an important role in lowering attack frequency and improve overall disease control. Research during the COVID-19 pandemic showed that patients who felt less stressed and anxious experienced fewer attacks.



Your Emotional Health Matters – Here's How to Take Care of Yourself

Support for Stress and Anxiety

Managing stress and anxiety can feel challenging, but small steps can make a big difference. Here are some strategies that can help to reduce stress and anxiety:

- **Recognise your feelings:** It's normal to feel worried about future attacks or frustrated by the unpredictability of HAE
- **Talk it out:** Share your concerns with someone you trust – family, friends, or your healthcare team. Having someone listen to you and show they care can help in itself
- **Try breathing exercises:** Breathing exercises can help you feel calmer and more in control. They only take a few minutes and can be done anywhere. One simple technique is *box breathing*: breathe in for 4 seconds, hold for 4 seconds, breathe out for 4 seconds, and hold again for 4 seconds before repeating
- **Keep a diary:** Writing things down can help you feel more in control. Note what happens when you feel anxious or stressed about an attack – this can help you spot triggers or early warning signs
- **Professional help:** If anxiety or low mood feel overwhelming, ask your GP about talking therapies. Clinical guidelines recommend psychosocial support as part of HAE care

Mindfulness and Relaxation Techniques

Mindfulness can help calm racing thoughts and reduce stress.

Try these techniques and find out what works for you:

- **Grounding technique:** Focus on 5 things you can see, 4 you can touch, 3 you can hear, 2 you can smell, and 1 you can taste
- **Mindfulness meditation:** Sit quietly and pay attention to your breath or body sensations, bringing your focus back when your mind wanders
- **Yoga or Tai Chi:** Combine movement and breathing for relaxation

For more tips and guided practices, see the "Your Support Network at Your Fingertips" section at the end of this leaflet.

Self-Care and Building Your Resilience

Self-care isn't selfish – it's essential. It doesn't have to involve big changes or cost a lot – simple, consistent routines often make the biggest difference. Below are some ideas on self-care and building resilience:

- **Balanced diet:** Eating regularly and keeping blood sugar stable can improve mood and energy. Include fruits, vegetables, whole grains, and lean protein
- **Exercise:** Gentle activity like walking, yoga, or stretching can boost mood and reduce stress hormones. Aim for short sessions several times a week
- **Sleep:** Good sleep helps your body and mind recover. Try to keep a regular bedtime, avoid screens before bed, and create a calm sleep environment
- **Celebrate small wins:** Every time you manage a situation successfully, take a moment to acknowledge it. Noticing these positives – even small ones – can boost your confidence and resilience over time



Confidence Starts with Knowledge and Support

Living with HAE often means adapting to new situations, whether at work, with friends, or in daily life. Feeling confident helps you stay engaged in the things you enjoy and reduces the stress that uncertainty can bring. Confidence isn't about ignoring challenges; it's about having the tools and support to handle them.

Tips for Social Situations

- **Be prepared:** Take some emergency medication with you and know your treatment plan before attending events. Every person living with HAE should carry on-demand medication at all times, and consistently have sufficient treatment for at least 2 attacks, even if you're taking prophylaxis. You should also carry your medical ID card to ensure quick recognition and appropriate care in an emergency
- **Choose comfort:** Many patients report embarrassment and anxiety if swelling occurs unexpectedly. To help, choose familiar venues where you've been before and where you'll feel relaxed, or try visiting new venues with the people you feel most comfortable with
- **Wear comfortable clothing:** Loose-fitting clothes can help you feel more at ease if swelling occurs and reduce discomfort during an attack
- **Don't let HAE define you:** You are more than your condition – keep doing activities you enjoy and aspire to, with adjustments if needed

Navigating HAE at Work

Living with HAE while managing a career can present unique challenges, but with preparation and open communication, you can create a work environment that supports your success.

Know your rights

HAE is a recognised medical condition. You are entitled to request reasonable adjustments under workplace health policies. These may include flexible scheduling, remote work options, or time off for medical appointments.

Communicating clearly and confidently

Hiding what you're going through can be exhausting and may lead to misunderstandings. If you choose to share information about HAE:

- **Stay focused and prepared:** Clearly and concisely explain how HAE may impact your work. Before speaking with your manager or human resources (HR), decide what you need, what you're willing to accept, and how you'll respond to questions
- **Provide specific examples:** Mention considerations such as needing occasional sick days, flexibility for appointments, or limits on travel
- **Offer ideas:** Suggest practical solutions like job sharing, working from home, or adjusting deadlines to help address anticipated barriers
- **Work to your strengths:** Highlight your skills or the tasks you can perform with greater ease or flexibility that benefit your team
- **Share resources:** Provide your employer with information about HAE (e.g., the HAE UK leaflet) to help them understand your condition and support you effectively

Emergency readiness

Keep your medication accessible at work and let a colleague you trust know what to do if you have an attack. This ensures quick action and peace of mind.

Managing stress and triggers

Stress can increase the risk of attacks. If your role is high pressure:

- Discuss ways to manage workload or take short breaks to reduce stress
- Set realistic goals by breaking large tasks into smaller, manageable steps to maintain control and reduce pressure
- Use techniques from the "Support for Stress and Anxiety" section above to help lower your baseline stress

Confidentiality matters

You can decide who knows about your HAE and how much detail you want to share. HR and your manager should understand your needs without oversharing personal details.

Communicating with Family and Friends

Living with HAE can sometimes feel isolating – especially when those closest to you don't fully understand its impact. Sharing information about HAE can help others understand what you're going through, reduce misconceptions, and make it easier for them to support you. Misunderstandings, awkward silences, or comments that minimise your experience can make conversations stressful. The good news? There are ways to make these discussions easier and more meaningful.

Choose the right moment:

Choose a time and place where you feel relaxed and have enough time to talk. Let the person know in advance what you'd like to discuss so they're prepared

Share real examples:

Help others understand by describing how HAE affects your daily life.

For example:

- Do mild attacks disrupt your routine?
- Does unpredictability cause fear or anxiety?
- Have you had to avoid certain activities or miss out on experiences?



Specific examples make your reality easier to relate to.

- **Be direct and honest:** It's natural to want to protect loved ones from uncomfortable conversations, but openness helps them understand your needs. Honest discussions can reduce stress and make it easier for others to offer support. Only share as much as feels right for you – you can always open up more gradually, at your own pace
- **Explain how they can help:** Family and friends often want to support you but may not know how. Be clear about what you need, whether it's help during an attack, flexibility with plans, or simply someone to listen
- **Plan to reconnect:** Set a time to check in again. Ongoing conversations help strengthen relationships and ensure your needs continue to be met
- **Practise a quick response for acquaintances:** If there are people you don't want to share full details with, prepare a simple phrase that redirects the conversation, such as: *"I have a long-term medical condition, but let's not go into it right now."* This helps maintain your privacy while keeping the interaction comfortable



Planning Ahead Brings Confidence and Calm

Feeling prepared can make a big difference to your emotional wellbeing. When you know what to do and have everything ready, it reduces fear and gives you confidence to manage your HAE – even in stressful situations. Planning isn't just practical, it's a powerful way to feel in control.

Emergency Preparedness Checklist

- ✓ **Know your medication**
 - Depending on the severity and frequency of your attacks, treatments could be:
 - **On-demand** or **rescue treatment** – which is only taken once you 'feel' an attack happening or has happened
 - **Prophylaxis** – medication that is taken daily, weekly or sometimes monthly to prevent attacks happening
- ✓ **Always be ready**
 - **Carry at least two doses of your on-demand medication** at all times
 - Check **expiry dates** regularly and store medicines as instructed
 - Pack medication for **travel or work** (consider temperature requirements)
- ✓ **Have a written action plan**
 - Keep a clear, written emergency plan:
 - Share copies with family, friends, caregivers, and your employer
 - Carry a printed or digital emergency card or letter from your consultant if you are travelling in case of needing to attend A&E
 - Include:
 - When to treat (early in the attack)
 - When to repeat treatment
 - What to do if medication is unavailable
- ✓ **Practise and review**
 - Practise self-injection or infusion techniques with your healthcare professional until confident
 - Review your plan regularly and update it if your situation changes
- ✓ **Stay informed**
 - Know the signs of an attack and act quickly
 - Keep emergency contact numbers handy

Quick Checklist for Peace of Mind

- ✓ Do I have my on-demand medication with me?
- ✓ Do I know my nearest hospital and emergency contacts?
- ✓ Do my family/friends know what to do?
- ✓ Do I have my emergency card with me?

Stay safe when travelling abroad

- **Pack enough medication in carry-on baggage** – include extra doses to cover any delays or surprises
- **Bring your emergency card and translated info** – hard copy or digital, to show to healthcare providers and security abroad
- **Record destination HAE-aware care options** – look up doctors or hospitals familiar with HAE in the countries you'll visit
- **Prepare a "what-if" travel plan** – consider scenarios like lost luggage or delayed flights, and make contingency plans to reduce stress



You're Not Alone – Help is Always Available

At times, HAE can make it hard to feel connected – but support is always within reach. Your emotional wellbeing matters as much as your physical health. If you're struggling, don't wait – reach out early. Mention how you're managing emotionally during appointments, even if the focus is on physical symptoms. Preparing a few notes on triggers, symptoms, and any questions you may have can make these conversations easier.

Getting the Most Out of Your Appointments

A little preparation can make things easier and ensure you cover what matters most.

Before your appointment:

- **Choose what feels right for you:** If possible, ask for a healthcare professional you're comfortable with, for example, someone who understands HAE or speaks your first language
- **Bring support if you want to:** A friend or family member can help you feel more at ease and help you to remember things that were discussed
- **Make a quick list:** Note down your symptoms, how often they happen, any triggers you've noticed, and how HAE affects your daily life

- **Write down questions, for example:**
 - What treatment options are available for me?
 - How can I manage attacks better?
 - Are there lifestyle changes that could help?

During your appointment:

- **Be open and honest:** Your healthcare team is there to help, and they're used to hearing personal details
- **Share what matters to you:** If you think something might help, say so
- **Ask questions:** Don't hesitate to ask for clarification or for things to be repeated
- **Take notes:** Write down key points or ask for written information. Make sure you understand the next steps before you leave

Connecting with Peers and HAE Communities

Being part of a community of others with HAE can offer comfort, practical advice, and emotional support beyond what healthcare professionals provide.

HAE UK: UK's National HAE Patient Charity

HAE UK offers comprehensive support tailored specifically to people living with HAE in the UK:

- **One-to-one support:** Dedicated telephone and email support
- **Annual patient days:** Face-to-face events featuring expert talks and peer interaction
- **Online community:** Facebook support groups and regular postings on Instagram and X channels to connect and share
- **Practical resources:**
 - Downloadable patient booklets, attack diaries, post-attack questionnaires, emergency cards and video content to provide further support
 - HAEi TrackR app for logging attacks and treatments

How to Get Involved:

- **Visit haeuk.org** to download resources, check upcoming patient days, and access their social media platforms
- **Join the Facebook group** for peer conversation and support
- **Attend patient days or virtual events** to connect directly with other patients, caregivers, and specialists
- **Reach out by phone or email** on support@haeuk.org or [07975 611787](tel:07975611787) for one-to-one advice
- **Ask your HAE clinic or specialist nurse** for introductions to local peer networks



Your Support Network at Your Fingertips

Managing HAE isn't just about medication – it's about feeling supported and informed. Whether you need emotional help, practical advice, or a community that understands, these resources can make life easier. Explore these trusted options for guidance, connection, and peace of mind.

The apps and websites listed below are third-party resources. BioCryst UK is not responsible for the content of external sites. If accessing this leaflet digitally, clicking these links will take you away from the BioCryst material.

Wellbeing Apps

Apps can help you manage stress and practise mindfulness anywhere:

- **Calm:** Guided meditation and breathing exercises for relaxation
- **Headspace:** Mindfulness tools to reduce anxiety and improve focus
- **Evergreen Life:** Track your health and wellbeing in one place
- **Bearable:** Track symptoms, mood, and triggers to understand patterns and improve wellbeing
- **Sleepio:** A NICE-recommended online sleep improvement programme
- **Flaredown:** Track symptoms, triggers, and treatments for better control

Websites & Helplines

- **NHS mindfulness**
Website: www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness/
- **How to meditate for beginners**
Website: www.nhs.uk/every-mind-matters/mental-wellbeing-tips/how-to-meditate-for-beginners
- **Breathing exercises:**
Website: www.nhs.uk/mental-health/self-help/guides-tools-and-activities/breathing-exercises-for-stress/
- **Short videos with tools and techniques to reduce stress:**
Website: www.england.nhs.uk/supporting-our-nhs-people/support-now/wellbeing-apps/bright-sky/calm-amongst-chaos/
- **HAE UK:** UK's national patient charity
Website: www.haeuk.org | Email: support@haeuk.org | Telephone: 07975 611787
- **Genetic Alliance UK:** National alliance advocating for people affected by rare, genetic conditions in the UK
Website: www.geneticalliance.org.uk | Email: contactus@geneticalliance.org.uk
- **Every Mind Matters:** NHS tips for mental wellbeing
Website: www.nhs.uk/every-mind-matters/

Regional Mental Health Support

If you need additional help, speak to your GP about what local mental health services are available. They can guide you to resources in your area and help with referrals if needed.

England

- **Talking therapies:** Free, confidential support for adults experiencing anxiety, depression, or related mental health issues. Services include cognitive behavioural therapy (CBT) and other evidence-based treatments. Self-referral is available online
Website: www.england.nhs.uk/mental-health/adults/nhs-talking-therapies/
- **Mind:** A leading mental health charity offering advice, information, and support for anyone experiencing mental health problems. Provides resources, helplines, and local services across England

Website: www.mind.org.uk | Email: info@mind.org.uk
Telephone: Support line: 0300 102 1234 | Information line: 0300 123 3393

Wales

- **Mind:** The Welsh branch of Mind, providing tailored mental health support, advocacy, and information for people living in Wales. Works with local services to improve mental health care

Website: www.mind.org.uk/about-us/mind-cymru-mind-in-wales/
Email: info@mind.org.uk
Telephone: Support line: 0300 102 1234 | Information line: 0300 123 3393

Scotland

- **Scottish Association for Mental Health:** Scotland's national mental health charity. Offers a helpline and information service to support anyone experiencing mental health issues or seeking guidance

Website: www.samh.org.uk/ | Email: info@samh.org.uk
Telephone: 0344 800 0550

Northern Ireland

- **Lifeline:** Free, confidential crisis helpline available 24/7 for anyone in Northern Ireland experiencing distress or concerned about someone else

Website: www.lifelinehelpline.info | Telephone: 0808 808 8000

