



# Taking Control: Managing HAE and Your Mind

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**This leaflet is for young people 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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## Your Feelings Matter as Much as Your Health

### What Does HAE Mean for You as a Young Adult?

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. HAE is a rare genetic condition that causes episodes of swelling in different parts of the body, such as the face, hands, feet, stomach, and sometimes the airways. These attacks can range from mild to life threatening, especially if swelling affects your breathing.

Managing HAE while navigating education, work, and your social life can feel overwhelming, especially as you move from paediatric to adult care. Attacks often happen without warning and that unpredictability can bring emotional challenges. If you are going through these kinds of challenges, you are not alone.

It is common to experience some or all of the following issues:

- **Anxiety** – worrying about when the next attack will happen, fear of airway swelling, or feeling nervous about taking full responsibility for your treatment plan
- **Stress** – managing treatment, deadlines, and social life while coping with uncertainty; explaining HAE to new doctors, teachers, employers or friends
- **Isolation** – avoiding socialising or activities you enjoy because of visible swelling or fear of an attack in public; feeling different from friends who do not have health concerns

These feelings are completely understandable, and many young adults with HAE experience them. While the majority of people with HAE cope well day-to-day, studies show that it's common for people with HAE to experience significant emotional challenges: around 40% report moderate to severe anxiety, about half report moderate to severe depression, and most experience moderate stress, often linked to the unpredictability of attacks.

### 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 do not just happen after an attack – they can sometimes trigger one. When you are stressed, your body releases chemicals that can make blood vessels leakier. For people with HAE, this can raise bradykinin – the chemical that causes swelling – making an attack more likely. This creates a vicious cycle:



Because HAE can affect many aspects of life, finding ways to support your emotional wellbeing can help you feel more in control and confident every day. That is why looking after your emotional health is just as important as managing your physical symptoms.

**The good news:** Research shows that reducing stress and anxiety can help lower attack frequency and improve overall wellbeing.

**You are not alone. Living with HAE can bring unique emotional challenges – sometimes more than others face. It is normal to feel ups and downs, and support is here for you.**



## Calm Mind, Strong Body

Uncertainty about attacks can make life stressful, but there are steps you can take to manage anxiety, boost your confidence, and feel more in control every day.

### Coping with Uncertainty and Peer Pressure

It is normal to feel anxious about missing classes, social events, or work because of HAE. You might also feel pressure to “fit in” with friends who do not have health concerns. Here are some tips you could try to ease anxiety and/or uncertainty:

- **Be prepared:** Keep your medication and emergency contacts handy so you feel confident wherever you go. Having essentials close by can reduce anxiety and help you feel more in control
- **Talk openly:** Share what HAE means with close friends or a trusted teacher/employer. Most people want to help once they understand. Just by having someone listen to you and show they care can help in itself. Only share as much as feels right for you – you can always open up more gradually, at your own pace
- **Set boundaries:** It is okay to say no to activities that feel risky for your health; doing so helps you stay safe and in control
- **Boost your confidence:** Recognise what makes you unique – your skills, hobbies, and achievements. Celebrate the wins, big or small. When you feel good about yourself, you are less likely to rely on others for approval

## Mindfulness and Relaxation Techniques

Stress can make life harder – and sometimes even trigger an attack. Learning to calm your mind can help you feel more in control. Try these techniques and find out what works for you:

- **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
- **Grounding technique:** Focus on 5 things you can see, 4 you can touch, 3 you can hear, 2 you can smell, 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.

Managing stress is not about being perfect – it is about finding small ways to feel more in control every day.



## You Are More Than Your Condition

Growing up with HAE can sometimes make you feel different – but it does not define who you are. Confidence comes from understanding your condition and finding ways to live life on your terms.

### Navigating School, University, Work, and Social Life

Starting college or university, or stepping into your first job? These changes can feel exciting and stressful, even without HAE. Below are a few ways to help you prepare for and navigate these changes.

#### Moving away for university

- **Start by taking responsibility for your healthcare early.** Practise remembering to take your medication (set alarms), reordering prescriptions on time, and keeping track of deliveries. Setting reminders or using a checklist can help

- **Practise talking about your condition.** Rehearse how you would tell new friends about your HAE, or how you would explain your condition to a healthcare professional in case of an emergency for example:  
*“I have hereditary angioedema. It is a rare condition that causes swelling attacks. If I have an attack, I need [treatment name] as soon as possible.”*
- **Get a treatment letter** from your consultant early so you can register with your GP and share it if needed (e.g., with your university health centre). Keep a digital copy on your phone so you can access it quickly if needed
- **Arrange prescriptions and deliveries.** Make sure your medications arrive on time and are stored properly
- **Identify your support network.** Universities have disability, mental health, and wellbeing services ready to help, even before you start
- **Order a medical ID card** with emergency contacts and treatment info to keep in your wallet or phone for quick access in an emergency
  - An example of a medical ID card can be found on the HAE International website: <https://haei.org/emergency-cards/>
- **Identify a local HAE specialist in your university city or town.** Your consultant or HAE centre can help you find the right contact where you’ll be living, and charities such as HAE UK can also offer guidance. They can also help you check which A&E departments or pharmacies nearby stock HAE treatments

#### University support services

- **Disability or wellbeing services** can help if an attack affects your attendance or your ability to take an exam, for example by arranging short-notice adjustments or support plans. Contact them early and outline what you may need
- **Personal or course tutors** can help when HAE affects your schedule – reach out early for support
- **Disabled Students’ Allowance (DSA)** provides funding for equipment, travel, or note-takers

#### Social life

- **Stay ready:** Before social events, check your treatment plan and make sure you have what you need, including emergency medicine for peace of mind
- **Plan social events thoughtfully:** Choose accessible venues where you can step away if needed
- **Wear comfortable clothing:** Loose-fitting clothes can help you feel more at ease if swelling occurs, and reduce discomfort during an attack
- **Do not let HAE define you:** You are more than your condition – think about what you can do and become as you enter adult life. Keep doing activities you enjoy, and make adjustments if needed

## First job or new workplace

HAE is considered a long-term health condition. You can request **reasonable adjustments** at work – like flexible hours, remote working, or time off for appointments – and employers must consider these.

## Communicating clearly and confidently

- **Stay focused and prepared:** Explain how HAE may impact your work clearly and concisely. Before speaking with your manager or human resources (HR), decide what you need, what you are willing to accept, and how you'll respond to questions
- **Give examples:** "I may need occasional sick days, flexible working hours, or fewer business trips."
- **Suggest solutions:** Offer realistic options like working from home during recovery, or flexible deadlines
- **Highlight strengths:** Showcase your skills and how you can contribute even during a flare-up

## Talking About HAE With Friends and Partners

Living with HAE can sometimes feel isolating – especially when people do not fully understand what you are going through. Misunderstandings or comments that minimise your experience can make conversations stressful. There are ways to make these discussions easier and more meaningful without making them heavy:

- **Start simple:** "I have a rare condition that causes swelling. It is not contagious, but sometimes I need treatment." You can always build up the information gradually as you feel more confident
- **Share what helps:** Let people know what to do if you have an attack
- **Choose your circle:** You do not have to tell everyone if you do not want to, just those you trust
- **Keep it light:** You can explain the basics without going into every detail. Most people appreciate honesty and want to help once they understand



**With early planning, openness, and support, you can confidently handle school, work, and your social life. HAE is a part of your story – but it does not define your potential.**



## Your Health, Your Voice

As you take on more responsibility for managing your HAE – whether you are starting or already in adult care – it might feel daunting at first. But it is also your chance to take control and feel confident about your health.

## Understanding Your Treatment Plan

Knowing your treatment options helps you make informed decisions. Depending on the severity and frequency of your attacks, treatments could be:

- **On-demand or rescue therapy** – which is only taken once you 'feel' an attack happening or has happened
- **Prophylactic therapy** – medication that is taken daily, weekly or sometimes monthly depending on attack frequency to prevent attacks from happening

## Advocating for Yourself in Adult Clinics

You are the expert on your own body – and your voice matters. Here's how to make sure you are heard:

- **Know your rights:** You have the right to privacy and to be involved in decisions about your treatment. If something is not clear, ask for an explanation
- **Prepare questions:** Write them down before your appointment so you do not forget anything
- **Share your experiences:** Tell your doctor how HAE affects your daily life, both physically and emotionally – not just your symptoms
- **Ask questions:**
  - What are my options?
  - What are the pros and cons of each option for me?
  - How can I get support to make the decision that's right for me?
- **Practise how to start the conversation:** Sometimes it is hard to know what to say. Try phrases like:
  - "I've noticed more swelling since starting Uni – can we revisit my prevention plan?"
  - "Sometimes I find it hard to manage medication during shifts – do you have suggestions?"

These examples can help you feel more confident and make sure your doctor understands what matters most to you. Remember, you don't have to lead every discussion right away – confidence builds over time as you practise managing your own healthcare. And if it helps, you can bring someone with you to support you and help remember important information.

Want more tips on becoming independent in your healthcare?  
Check out the NHS Ready Steady Go transition programme:  
[www.readysteadygo.net/rsg.html](http://www.readysteadygo.net/rsg.html)

### Emergency Preparedness: Be Ready, Stay Confident

Taking control also means planning ahead for independence and emergencies:

- 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, school, university, work or social events** (consider temperature requirements)
- Have a **written action plan** and share copies with family, friends, and your school/university or employer. Include:
  - When to treat (early in the attack)
  - When to repeat treatment
  - What to do if medication is unavailable
- Carry a **printed or digital emergency card** or letter from your consultant if you are travelling in case of needing to attend A&E
- **Practise self-injection or infusion techniques** with your healthcare team until confident
- Know your **nearest hospital and emergency contacts** wherever you are

### Quick Checklist for Peace of Mind

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

Independence does not mean doing it alone – your healthcare team and support networks are here to help.



## You Are Not Alone – Support is Out There

At times, HAE can make it hard to feel connected, but you do not have to manage it alone. Support networks can make a big difference – emotionally and practically.

### Connect With The HAE Community

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, and emergency cards
  - HAEi TrackR app for logging attacks and treatments

### How to Get Involved

- **Visit [haeuk.org](http://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](mailto:support@haeuk.org) or 07975 611787 for one-to-one advice
- **Ask your HAE clinic or specialist nurse** for introductions to local peer networks



## Your Toolkit for Support

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/](http://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](http://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/](http://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/](http://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](http://www.haeuk.org) | Email: [support@haeuk.org](mailto: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](http://www.geneticalliance.org.uk) | Email: [contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)
- **Every Mind Matters:** NHS tips for mental wellbeing  
Website: [www.nhs.uk/every-mind-matters/](http://www.nhs.uk/every-mind-matters/)

- **NHS Ready Steady Go:** A UK transition programme to help build your skills and independence before you leave paediatric services  
Website: [www.readysteadygo.net/rsg](http://www.readysteadygo.net/rsg)
- **Great Ormond Street Hospital for Children** – Healthcare transition: Helps guide young people towards adult care, starting from age 12  
Website: [www.gosh.nhs.uk/patients-and-families/your-hospital-visit/teen-space](http://www.gosh.nhs.uk/patients-and-families/your-hospital-visit/teen-space)

### Regional Mental Health Support

#### 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/](http://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](http://www.mind.org.uk) | Email: [info@mind.org.uk](mailto: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/](http://www.mind.org.uk/about-us/mind-cymru-mind-in-wales/)  
Email: [info@mind.org.uk](mailto: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/](http://www.samh.org.uk/) | Email: [info@samh.org.uk](mailto: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](http://www.lifelinehelpline.info) | Telephone: 0808 808 8000

**Save these links and numbers – you never know when you might need them. Support is just a click or call away.**

