

A patient's guide to living with hereditary angioedema

Immunology

Information for Patients and families

Produced: March 2024

Review: March 2027

Leaflet number: 1493 Version: 1

What is hereditary angioedema (HAE)?

Angioedema is a swelling underneath the skin. HAE affects between 1 in 20,000 and 1 in 50,000 people. There is a 50% chance that an affected parent will pass the gene onto their children. The gene that is affected controls the production of a blood protein, which controls swelling in the body.

There are no specific triggers for an attack.

Some patients can find warning symptoms such as;

- extreme tiredness,
- a rash or tingling over the affected site.

HAE cannot be cured, but medicines can help prevent and treat the swelling. Taking medication for allergies (anti-histamine) does not help symptoms.

Symptoms of HAE

- Sudden outbreak of swellings on various body parts, such the arms and legs and airways
- Repeated and unexplained tummy (abdominal) pain

You must call 999 if you have any of the following :

- Sudden or worsening breathing problems
- Feeling faint or dizzy
- Passing out or collapse

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

General reminders

- Every 6 months, you will have an appointment at the adult immunology (HAE) clinic at Leicester Royal Infirmary (LRI).
- Please attend your local Accident and Emergency department if you have airway swelling as you may need an infusion to stop the swelling. Please attend with your **emergency letter**.
- There is a dedicated HAE dental team in Leicester City. Please ask your dentist to refer you to: Dr M Patel, Westcotes Health Centre, The Community Dental Services, Leicester.
- Please call the Immunology team if you are planning to have an invasive medical or surgical procedure. You may need an infusion before this for your safety. This would be done on the Medical Day Case Unit (Ward 19) Leicester General Hospital (adult patients) or the Children's Day Care unit (paediatric patients) Leicester Royal Infirmary (LRI)

Injectable Medicine into the tissues just below the skin (sub-cutaneous): Icatibant

- Please keep your Icatibant nearby **at all times**. This is to be used as instructed.
- If you would benefit from Icatibant refresher training please ask to see the Immunology Specialist Nurse when seen by the medical immunology team in clinic.
- Please contact the home care company when you have **used the first 2 injections** of your Icatibant.

Please note further patient information can be found on the following HAE registered charity webpage: www.haeuk.org or by contacting support@haeuk.org

Contact details

Immunology Specialist Nurse (adult/paediatric)	0116 258 6711
Immunology Secretaries	0116 258 6702
Children's Day Care Unit LRI	0116 258 6317

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અસ્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk