

For:

Listed below are some of the symptoms that your child with HAE may experience during swelling attacks. Alongside each set of symptoms, you will also find the level of risk associated, and the treatment or care that is generally advised for these symptoms. Keep it somewhere you can refer to it easily. If your child develops any symptoms you think may be a sign of an attack, check them against the list below to see what course of action is recommended.

Your immunologist will help you to fill in the details in line with your child's emergency management plan. This information can be shown to medical staff, if needed. You may also have been given a letter to share with hospital emergency departments (ED letter) that provides information specifically about treatment of serious attacks.

There is also space at the end of this document to fill in the contact details of your local hospital emergency department (with whom your child's emergency management plan may have been discussed and agreed) and your child's immunology team.

Always seek emergency help if you think an attack could be serious

Remember to record and report all symptoms that may be related to HAE

All symptoms of HAE, however minor, **MUST** be recorded and reported to the paediatric immunology nurse/medical secretary.

Your immunologist may provide you with a symptoms tracker for this.

Details of medical condition:

Hereditary Angioedema (C1-esterase inhibitor deficiency)

- A rare blood disorder leading to episodic attacks of swelling.
- Episodes can be triggered by trauma, illness, hormones, stress and also for no determinable reason.
- Episodes can be life threatening and must be treated without delay.

Recognition and management of common symptoms of HAE for:

Assessing the risk level of common swellings:

Location of swelling	Accompanying symptoms	Risk level	Action required	Medical treatment?
FACE AND/OR THROAT	<ul style="list-style-type: none"> • Puffiness on the face or neck • Difficulty swallowing • Difficulty breathing • Panic • Pale pink rash similar to marble <p>IMPORTANT: Symptoms like these might be confused with an allergic reaction (anaphylaxis), which could delay appropriate treatment.</p>	HIGH	<p>This is a medical emergency that requires prompt treatment.</p> <p>Ambulance required to take child to nearest hospital emergency department (ED).</p> <p>Give hospital emergency department letter (ED letter) to medical staff.</p>	<p>..... to be administered.</p> <p>If treatment above not available, alternative treatment:</p> <p>.....</p>

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Location of swelling	Accompanying symptoms	Risk level	Action required	Medical treatment?
ABDOMEN	<ul style="list-style-type: none"> Dehydration – dizzy, headache, lightheaded, lethargic, confused, unable to urinate, dry mouth and eyes 	HIGH	Ambulance required to take child to (hospital) Give ED letter (if available) to medical staff. to be administered. If treatment above not available, alternative treatment: Intravenous fluids.
	<ul style="list-style-type: none"> Swollen tummy Abdominal pain Nausea/sickness Diarrhoea Pale pink rash similar to marble 	MEDIUM	Contact your child's immunology department for advice OR if your child is in distress, take to nearest hospital emergency department, and give ED letter to anyone treating your child. Any episode can lead to further swellings, so close supervision and medical attention is required.	Medical review required. Child may need administration of
HANDS, FEET, ARMS, LEGS, GENITALS	<ul style="list-style-type: none"> Soft tissue swellings Pale pink rash similar to marble Discomfort 	LOW	Any episode can lead to further swellings, so close supervision is required. If swelling/pain is severe take child to the nearest hospital emergency department.	Painkillers. Rest. Depending on severity of attack, may need administration of

This HAE paediatric treatment protocol for has been agreed with the hospital emergency department (ED) listed below:

Name of hospital	Telephone number	Address	Treatment located in

If possible, please telephone in advance of attendance and advise staff to prepare the medication.

If provided by your immunologist, always give the hospital emergency department letter (ED letter) to medical staff caring for

Contact details of immunology care team:

Name and job title	Mobile number	Work number	Email

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Reporting of side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at: www.mhra.gov.uk/yellowcard

By reporting side effects, you can help provide more information on the safety of this medicine.

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