



Hereditary Angioedema (HAE)

Shared decision aid

To help you prepare for discussions with your doctor or nurse about treatment options

This shared decision aid has been developed and funded by Takeda Pharmaceutical Company Limited.



Shared decision making

What is shared decision making?

Shared decision making is a process whereby healthcare professionals work together with patients (and caregivers) to make decisions about their health and care based on clinical evidence and patient preference.

Shared decision making helps you understand your diagnosis and the treatment and management options available to you as well as the known risks, benefits and effectiveness of those options.

Reaching a shared decision with your doctor or nurse means you are more likely to stay on track with your treatment and have improved results.

Shared decision making is part of the NHS Long Term Plan to make sure that personalised care is available to everyone.

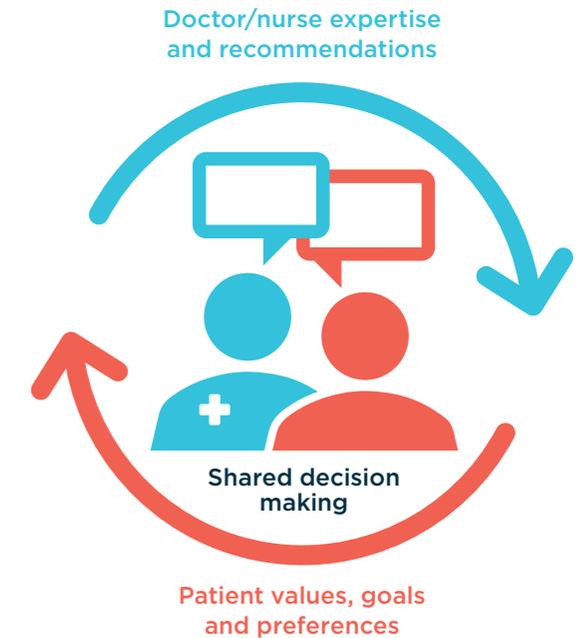
How to use this shared decision aid?

You can use this Shared Decision Aid to help you prepare for your conversation with your doctor or nurse about your HAE treatment and management options.

Being prepared for your appointment can put you in control and help ensure the care you receive is the best possible for your HAE and your lifestyle.

We hope this guide equips you to ensure the best possible consultation with outcomes that are truly tailored to you.

Because HAE can affect people so differently, it is important to work closely with your healthcare team to create a treatment plan that is right for you.



In order to determine how your HAE could be managed and treated, think about the following questions

1 Describe your attacks

How often do they happen? Where on your body do you commonly get them? How severe are they?



2 What impact does your HAE have on your quality of life?

Please select:



3 Would you say your HAE is well controlled?

Please select:

Yes No Don't know



4 Describe how HAE affects your daily life

Does it affect your work/school? Does it have an impact on your family or social life?



5 What impact does HAE have on your life in between attacks?

Consider your physical and mental health.



6 What are your biggest concerns about the care and treatment you receive for your HAE?



Now that you have looked at your individual needs, what are the treatment options available to you?

	What is the treatment used for?	How do I take the treatment?	What is the dosing regimen?	Can I self-administer the treatment?
Prophylactic treatments 	To prevent HAE attacks	<ul style="list-style-type: none"> Orally (taken by mouth and swallowed) Subcutaneous injection (injection just under the skin) Intravenous injection (injection into a vein) 	From daily to once every 2 weeks	Yes
Non-prophylactic treatments 	To treat HAE attacks as they happen (also known as acute or on-demand treatment)	<ul style="list-style-type: none"> Intravenous injection (injection just under the skin) Subcutaneous injection (injection into a vein) 	As soon as an attack happens	Yes

REPORTING 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 that comes with your medicine.

You can report side effects directly via the Yellow Card Scheme at: www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store.

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



NOTE

Not all treatments may be available due to local protocols or national guidelines.



Points for you to consider

Route of administration	Advantages	Disadvantages
Oral medication (taken by mouth and swallowed) 	<ul style="list-style-type: none"> Easy to take No training needed 	<ul style="list-style-type: none"> Food and other medication can affect how much of, and how fast, the medicine is absorbed into the bloodstream You may be unable to swallow tablets or capsules
Subcutaneous injection (injection just under the skin) 	<ul style="list-style-type: none"> Can be injected by you or your caregiver Low risk of infection that spreads throughout the body (systemic infection) Different injection sites can be used 	<ul style="list-style-type: none"> You may have a fear of needles Injection can be painful You will need to be trained how to self-inject May need a number of injections over time to reach a working level in the bloodstream
Intravenous injection (injection into a vein) 	<ul style="list-style-type: none"> Exact dose given gets straight into the bloodstream, which means it starts to work quickly The speed of injection can be controlled 	<ul style="list-style-type: none"> You may have a fear of needles Injection can be painful You will need to be trained how to self-inject Injecting into a vein can be tricky Risk of infection that spreads throughout the body (systemic infection) Risk of blood clot formation in the vein (thrombosis) Can be time-consuming

Dosing schedule

Oral medication



- Frequent dosing
 - Oral HAE medications often need to be taken every day and sometimes more than once daily

Subcutaneous and intravenous injection



- Less frequent dosing
 - Some of these HAE treatments need to be given every 3 to 4 days and others are given every 2 weeks
 - Having to dose less frequently could mean you have more time day-to-day

What kind of treatment would work best for you?

Think about what aspects of treatment are important to you and rank the following in order of importance ('1' being the most important and '5' being the least important):

How effective the treatment is in treating or preventing your HAE

How the treatment is administered (oral, subcutaneous injection or intravenous injection)

How often you administer your treatment dose

The possible reactions you may have

Any other aspects of treatment you feel are important to you (please describe below)

You can use the ranked list above when having an open discussion about treatment options with your doctor or nurse.

What are your ideas, concerns and expectations of HAE management?

Please describe below.

What would ideal control look like?

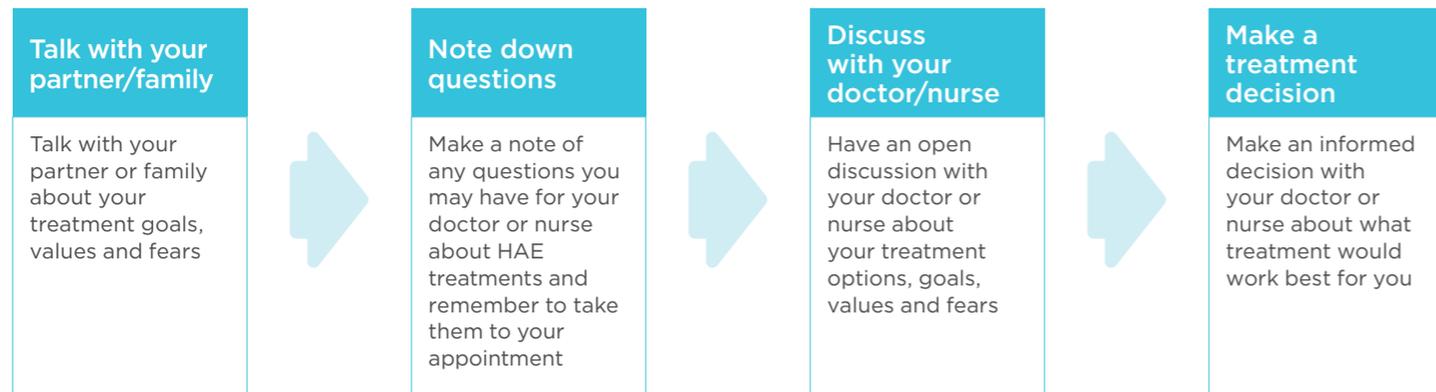
Please describe what ideal control of HAE would look like to you.

What would having ideal control of your HAE mean to you?

Think about your social life, relationships, work/school, holidays or any other aspects of your life your HAE may affect.

Next steps

Once you have read and completed this decision aid and thought about what is important to you about HAE treatment, follow the steps below.



Note down questions for your doctor or nurse here

For example, questions about managing your treatment when travelling or at work/school, dosing and administration, treatment benefits, or side effects of treatment.

Where to find more information

HAE UK is a Patient Association focusing on the needs of people with HAE and their families.

Contact details for HAE UK:

E-mail: support@haeuk.org

Telephone: 07975 611787

Website: www.haeuk.org



KnowHAE.co.uk is an online educational resource for everyone in the HAE community.



Notes

A large, empty rectangular box with a thin teal border, intended for taking notes.



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