



# Your HAE Discussion Guide

## Why this guide?

This tool has been designed as a help to guide you through your conversation with your HAE specialist. Answer the questions below and bring the results to the next check-up with your medical advisor. Be prepared and have a well-informed conversation about your condition and your treatment options. This can be your first step on a path for contributing to a good quality of life.

### Your patient profile

**1 Have you been diagnosed with HAE?**

- Yes (proceed to question 2)
- No (go to question 16)

**2 What HAE type have you been diagnosed with?**

- Type I
- Type II
- With Normal C1-INH
- I don't know

**3 At what age were you diagnosed?**

- 0-5 years old
- 5-10 years old
- 10-20 years old
- 20-30 years old
- 30-40 years old
- 40-50 years old
- >50 years old

**4 How often and how many attacks do you experience?**

- attacks
- Week
- Month
- Year
- I don't know

### Good to know

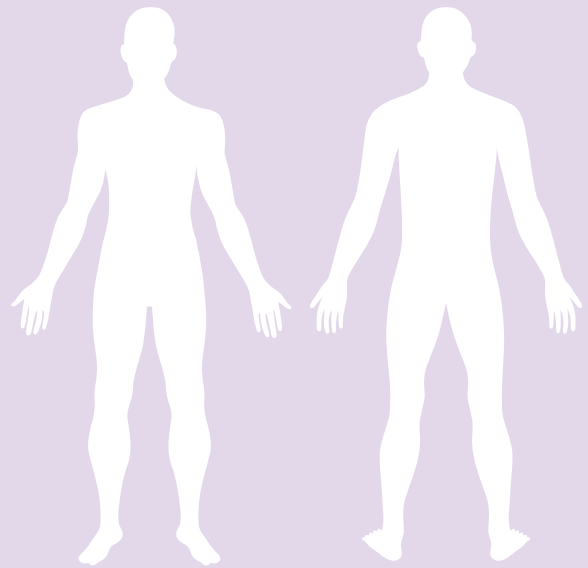
- Treat at the earliest signs of an HAE attack. Some attacks can be life threatening
- Fatigue or stress, hormonal fluctuations and small surgical procedures, amongst others can be a trigger

### Attacks and symptoms

**5 Do you treat all of your attacks?**

- Yes
- No

**6 Where do you suffer from most attacks?**



**7<sup>a</sup> Are you aware of your symptoms?**

- Yes, my symptoms are:
- No. I don't know my symptoms.

**7<sup>b</sup> When do you treat your attacks?**

- I treat my attack at the earliest symptoms
- I treat my attacks when the physical swelling is emerging

**7<sup>c</sup> Do you recognize your triggers?**

- Yes, my triggers are:
- No, I don't recognise my triggers

## Quality of life

**8** During the past month, how many times have you changed your plans because of your symptoms?

Your number:

**9** How does your condition make you feel?

Same as normal

Sad

Afraid/frightened

Anxious/nervous

Not sure

Other:

**10** Are there any events or activities you prefer not to attend because of how you feel?

Yes. For example:

No

### Good to know

- Don't let your quality of life be compromised, work closely with your HAE specialist to get the best out of your treatment
- Even if you are on a preventive treatment, it's always important to have an emergency plan in case of an acute attack



**Individualised Treatment Plan**  
means talking to your doctor to come up with a treatment plan specifically designed for you.

## About your treatment

**11** What treatment are you on at the moment?

On demand

Multiple treatments

Preventive

Not sure about it

**12** How do you feel about your treatment?

I don't have any concerns – my treatment is fine

I would like to know what other treatments are available to me

I only want to feel better, so I will do whatever it takes

Why am I on this treatment rather than another one?

My treatment is not really working for me right now

Other:

**13** What is important for you when it comes to your treatment?

Rapid relief of symptoms

Ease of use, convenient

Safe and effective treatment

Possibility to treat at home

No/few side effects

Other:

**14** Do you have an emergency plan in case of a severe acute attack?

Yes

No

**15** Do you receive any help from a family member or caregiver for your treatment?

Yes

No

**Answer these questions if you have not been diagnosed with HAE**

**16** Were you tested for HAE?

Yes

No

**17** Do you have any family members diagnosed with HAE?

Yes. Who?

No

### Good to know

- HAE is a genetic disorder. Family members should be screened for the condition