



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 15)

- 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

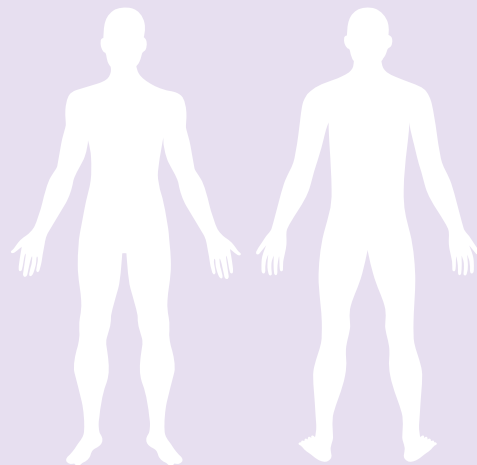
Good to know

- 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^a Are you aware of your symptoms?
 - Yes, my symptoms are:
 - No. I don't know my symptoms.

- 7^b 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^c Do you recognize your triggers?
 - Yes, my triggers are:
 - No, I don't recognize 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.

Individualized 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
- Preventive
- Multiple treatments
- 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.