

Your HAE Treatment Experience Log

This questionnaire is intended to support you in your ongoing treatment of Hereditary Angioedema (HAE) by recording your experiences using your prescribed medication(s). You may find it helpful to complete this questionnaire and share your answers with your healthcare provider at your next appointment. The information you provide may help them better understand any specific issues you may be experiencing with HAE and enable them to give more guidance to help you manage your HAE attacks.

HAE Patient Experience Questionnaire:

1 On average how often do you experience an HAE attack?

Useful tips: If your attacks are regular and frequent, you could say how many you get every week, month, or every two months, for example. However, if your attacks are not regular, then saying how many you get in a typical year might be better.

If you are taking prophylactic medicine to prevent attacks, please write down how often you get 'breakthrough' attacks.

2 Where in your body do your attacks occur?

Useful tips: List all the places on your body where attacks have occurred, but if you get attacks more often on particular parts of your body compared to the rest, please mention these.



3 **At what point do you treat the attack – do you wait until you see swelling, or feel pain, or do you treat as soon as you ‘sense’ that an attack is coming?**

Useful tips: Some people can ‘sense’ an attack is coming before the swelling can be seen (such as an attack on the face or hands), or before they feel pain (such as an attack in the tummy). This ‘sense’ that an attack is coming may be felt as a faint tingling sensation, pressure or tightness in skin, feeling tired or just a feeling that something is not right. Also make a note of the feeling you get when you sense an attack is coming.

4 **Does your on-demand treatment ever fail, so that you need to give yourself a second dose? If ‘yes’, how often do you need to do this, in general? How does this affect your daily life?**

Useful tips: If you ever need to take a second dose of your on-demand HAE medicine, it is because your first dose has failed to work properly which can of course be very worrying for you.

Think about how often you have needed to take a second dose and write down in whatever way you find easiest:

- The number of times per month or per year – or you could say one in every five attacks, for example.
- If you are on prophylactic treatment to prevent attacks, note how often you have needed on-demand medication when you get a ‘breakthrough’ attack and if you need to administer more than one dose at a time.

Also make a note of the feeling you get when you sense an attack is coming.



5 Do you always use the same on-demand treatment for the second dose as you did for the first dose? If 'no', please make a note here of the second medicine you have used.

Useful tips: some people always re-dose with the same medicine as their first dose, in the hope that the second dose will ease their swelling or pain. Other people may use a different HAE medicine for the second dose, when their first dose has failed to ease symptoms.

If you are taking prophylactic medication to prevent attacks, note what medication you use for your first dose when you get a 'breakthrough' attack, and what medication you use for any second 're-doses' if the first dose fails to ease your symptoms.

6 When you have to give yourself a second dose, does it always work?

Useful tips: Think about whether you have had any attacks where two doses of your on-demand HAE medication were still not enough to ease your swelling or pain, and you had to take a third dose and/or seek medical attention.
