

SHARED DECISION-MAKING IN HAE MANAGEMENT



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Introduction

For the past 10 years, we have had approved treatments to treat HAE attacks, and several treatments to prevent attacks. In treating medical conditions, it is good to have options, because not every medication is appropriate for every person with the condition. Having HAE treatment options means that you and your specialist can discuss which treatment is best for you. This is called **shared decision-making**.

Shared decision-making is a model of care in which the patient and the doctor together decide on a management plan that is specific to the patient, taking into account the patient's values, preferences, and goals.

Your doctor can tell you about the available medications to treat attacks as well as to prevent attacks, how the medication is given, how often, possible side effects, and how long to try the medication before deciding if it works.

To make informed decisions, it is just as important for your doctor to know about your treatment goals, preferences, and medical history.

Examine your own treatment goals, preferences, and medical history

Before your appointment, think about how you would answer the following questions:

- Do you want to participate in certain activities, such as sports, without worrying about an HAE attack?
- How does HAE limit your work, school, and/or social activities?
- What are your travel goals?
- Are you planning a family?
- Do you have a support system?
- Do you prefer a particular way to administer your medication?
- Are you willing and able to self-administer your medication?
- Would you like to reduce the impact that your treatment is having on your life?
- Do you have any concerns about side effects?

During your appointment, your doctor may ask you the following questions:

- How frequently do you have attacks?
- Where are your attacks occurring?
- How severe are your attacks?
- How does HAE impact your quality of life and well-being between attacks?

This information is very important to share with your doctor as part of the shared decision-making process to help in the discussions and decisions about your treatment plan.

There is no "correct answer" for an HAE treatment plan and the plan is not carved in stone. Our life circumstances frequently change. Current and future options for HAE treatment allow for HAE treatment to be adjusted to patients' lives, rather than patients' lives revolving around treatment for HAE.



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