



talking with your doctor

ABOUT PRIMARY HLH

A diagnosis of primary HLH can be overwhelming. You may wonder how you can cope during the journey ahead and have lots of questions.

THIS GUIDE CAN HELP YOU:

- Think about next steps
- Organize your thoughts and questions
- Get the most out of discussions with your doctor

HLH=hemophagocytic lymphohistiocytosis.

getting ready to **talk** with your doctor

It's normal to have lots of thoughts and questions running through your head right now. You may find it helpful to write them down as you think of them. This will make it easier to be sure you get the answers you need. You'll speak with your doctor a lot over the coming weeks and months.

HERE ARE 3 IMPORTANT TIMES YOU'LL HAVE A CONVERSATION WITH YOUR DOCTOR:



1

Shortly after
diagnosis

2

During
treatment

3

While getting ready
for a **transplant**

The next few pages have suggestions of what to ask your doctor at these times. There's also space for you to write down your own questions.

KEEP IN MIND

It's a good idea to have someone else there when you're going to have a discussion with your doctor. You'll have another set of ears to listen and help you take notes. This is especially important when you're feeling nervous or emotional.

questions you may have shortly after **diagnosis**

Use the spaces next to each question to take notes.

- How did I get primary HLH?
- Is there a cure for primary HLH?
- How did you find out I have primary HLH? How can you be sure?
- What did the different tests you performed tell you?
- Which signs and symptoms of primary HLH do I have?
- What other conditions did you rule out?
- Could other people in my family have primary HLH? Should they be tested?
- Is there a therapist or someone I can talk to about this?
- Is there a community support group you suggest I get in touch with?
- Now that I have a diagnosis, what are the next steps?
- Will I stay in the hospital for treatment?
- Can I bring some things from home to help me feel more comfortable at the hospital?
- What are visitation rules at the hospital?

questions you may have during **treatment**

Use the spaces next to each question to take notes.

- _____ • What are the possible side effects of treatment?
- _____ • How long does treatment for primary HLH usually take?
- _____ • How will we know if the treatment is working?
- _____ • What if this treatment doesn't work?
- _____ • Are there any other treatment options?
- _____ • Will I need to take medicine forever?

Add any other questions you have in the spaces below.

questions you may have about a **transplant**

Use the spaces next to each question to take notes.

- _____ • What is a bone marrow transplant?
- _____ • Does everyone who has primary HLH need a bone marrow transplant?
- _____ • When will you know if I need a bone marrow transplant?
- _____ • How will you know if I'm ready for a transplant?
- _____ • How do I find a donor? Does the donor need to be someone in my family?
- _____ • Will you perform the transplant or will another doctor?
- _____ • Will the transplant take place here or somewhere else?
- _____ • What will recovery be like?
- _____ • Where can I find more information about the transplant?
- _____ • Does a transplant always work?
- _____ • How soon after the transplant will I be able to go home?
- _____ • Is there anything special I need to do to recover?



your questions about primary HLH are important

Finding out you have primary HLH can be scary and confusing. But you are not alone. Your doctor is your partner in care and can answer any questions you may have. Don't hesitate to ask them.